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FINDING YOURSELF A CARRIER OF A CHRONIC DISEASE: RESULTS OF AN ACTION RESEARCH

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ABSTRACT
The objective of this study was describing the activities of personal care of chronic patients developed before and after educational activities of the nurse. This is an action research, carried out in a Basic Health Unit in a municipality in the metropolitan region of Curitiba-Paraná, with 13 users suffering from hypertension and / or diabetes mellitus of both genders, aged between 18 and 60. The data were obtained through a semi-structured interview and group meetings, which were subjected to content analysis theme. The categories derived from this analysis were: "The diagnosis as a starting point" and "Change of life: care adopted". The results showed that users could identify the discovery of the disease as the starting point for performing personal care. The change of lifestyle and pharmacologic treatment were the most commonly type of care mentioned. However, it was demonstrated a certain independence to carry out personal care and have adapted the directions given by healthcare professionals and their knowledge stated needing determination to perform personal care.

Keywords: Chronic disease. Health education. Nursing. Adult health. Professional practice.

INTRODUCTION

The chronic disease is classified by the World Health Organization[1] as communicable diseases, non-communicable diseases, disabilities and mental disorders. The increase of these diseases is the result of economic transformations, policies, social and cultural rights produced by human societies over time[2].

The developing countries are responsible for 80% of chronic disease deaths by confirming the expressiveness of long-term diseases[1,3]. It is estimated that by 2020 the chronic conditions are the leading cause of disability in the world, and therefore, the most expensive treatment for health systems, causing serious social and economic problems[1,3].

Thus, chronic diseases constitute a global challenge, since changes in the lifestyles of individuals directly reflect in patterns of illness and require measures of health systems to deal with this problem[2].

In Brazil, four decades ago, cardiovascular diseases were considered the first cause of mortality, the incidence of diabetes mellitus, which typically occurs associated with hypertension and these are the main risk factors for Chronic Non-communicable Diseases (NCD)[1,3]. Thus, it is necessary the implementation of sectorial and intersectoral strategies, through integral care which presupposes joint promotion, surveillance, prevention and health assistance[1].

It is considered as the main strategy for health promotion and / or prevention of NCD risk factors is health education, because its historical aspect is closely connected to the Brazilian health care system. However, the focus in the treatment and diagnosis of acute diseases still remain preponderant in our country, which contradicts with the treatment of long-term health problems, such as the case of chronic diseases[4].

In this context, education beyond informative must promote "disalienation, transformation and emancipation" of the individuals involved in the prospect that the behavior change happens by reflection of health as a social right[4:235].

So, after developing educational activities from an extension project for four years, wondered: "What care actions are developed by people with chronic disease before and after participation in educational activities?" Front of

[1]Manuscript extracted from the Master´s dissertation of the Graduation in Nursing at Federal University of Paraná (UFPR): "Effects of educational assistance of the nurse in chronic patient care".

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the exposed, the goal is to describe the activities of personal care of chronic patients developed before and after educational performance of nurses.

METHODOLOGY

This is an action-research with qualitative approach, developed in the period from March 2009 to June 2010, being a part of the results of a university extension project entitled "Systematization of assistance to patients with Arterial hypertension", and which also derived from a master thesis.

Action research[5] enables the extension projects with conventional research on social knowledge elaboration with the participation of different subjects. Because, besides the participation, it is assumed a form of planned action of social, educational, technical character or another.

For the application of the method followed by the stages proposed by the author [5] as follows, those do not have a rigid structure with predefined steps and were in every situation reset with all users. In the exploratory phase, the discovery of the lookup field, stakeholders and their expectations, and establishes an initial diagnosis of the situation with the problems and possible solutions[5]. This recognition, in this survey was previously conducted by researchers since the deployment of the extension project in the year from 2006 until 2008.

The subject of the research, which is the second phase, is the designation of the practical problem and of the knowledge area to be covered[5], and in this research were the chronic diseases and their forms of care on the part of users. This theme was requested by the responsible health unit at the time of insertion of the extension project in the year of 2006, since users do not attend the meetings of the Program of Hypertensive and Diabetic (HIPERDIA).

The Placement phase of problems those are characterized by the establishment of the issues that will trigger an investigation. It must "define a problem in which the theme chosen acquire sense"[5:57], within certain theoretical and practical field. To fulfill this step, all involved were interviewed individually and invited to group meetings, which were reported the difficulties that emerged from the analysis of the contents of the interviews, which were: complications, comorbidities, eating habits and chronicity of pathologies. However, to achieve the objectives of this research there were suggested, in addition to the topics they listed, discussions about care performed before the diagnosis, the current moment with the pathology installed and the care that can be carried out after the meetings. They all accepted and agreed with the proposed subjects.

The Place of the theory is the phase when the research-action is "articulated within a problematic with a theoretical reference framework"[5:60], to guide and support the interpretations. However, this theoretical knowledge must be compatible and appropriate with the understanding of the participants of not discouraging them[5]. In this way, this phase consisted in the appropriation of the theme on the part of the researchers for the dialogue with the participants.

On the stage at which bases are set, the researcher assumes regarding possible solutions of problem of research, that direct information and techniques necessary for the resolution of a problem[5]. Thus, to find an answer to the research question - "What actions of care are carried out for people with chronic disease, before and after participation in educational activities?" – sought, through group meetings, discuss collectively aspects relating to personal care and treatment.

The Seminars are meetings to direct the actions of the research since the search for the theme until the analysis of solutions found[5]. This phase corresponded to the discussions between guides and guided in the monitoring and evaluation of actions, which were exposed to the group in the meetings.

The phase Field of survey, sampling and qualitative representativeness is the delimitation of the field of action[5]. In this research, the site was a Basic Health Unit (BHU) with Community Health Agent Program (PACS), in the metropolitan region of Curitiba-Paraná, seat of the extension project.

At the BHU selected, the target population was composed by 282 users, divided into 201 hypertensive, 71diabetic and hypertensive, and 10 diabetics registered in the HIPERDIA, and to

constitute the sample we used qualitative representativity, established with inclusion criteria. There were included users with Hypertension and/or Diabetes Mellitus, aged between 18 and 60 years old, registered and active in HIPERDIA, which corresponded to 26 users who have agreed to participate and signed the Free Savvy Consent Form. These 26 were interviewed and the analysis of these interviews made it possible to meet the educational needs in the placing of problems cited.

The data collection was controlled by the seminar, and its main form of empirical information is capture of collective nature, by techniques such as seminars, press conferences, discussion meetings, among others. However, are not discarded the other conventional scientific research techniques[5]. In this research, the data were collected in two stages: the first was used the semi-structured interview, recorded at the domicile of the users who enabled us to identify the needs and problems to be discussed subsequently in five meetings in group, these being the second stage of the collection.

The meetings had an approximate duration of 1:30 each, arranged as follows: first meeting - adequacy of the subjects to be discussed; second - complications, comorbidities, chronicity and eating habits; third – care performed before diagnosis; fourth - care performed currently; and fifth - care that can be incorporated. All 26 respondents were invited through telephone contact and / or home visit, and of this total, 13 attended at least one of the five group meetings.

The Learning phase occurs throughout the process for the exchange of knowledge between researchers and participants to investigate and discuss the possible actions, the results of which offer teachings[5]. The stage Know formal / informal is established for communication between the scientific and popular knowledge, i.e. knowledge interface that integrates a shared decision-making process[5]. These last two phases occurred throughout the realization of the research, mainly in group meetings.

The action plan must meet the objective, which may be the resolution of the problem, awareness or knowledge production, through a planned action that will constitute the "object of analysis, deliberation and assessment"[5:75]. In this study corresponded to the awareness about the personal care those users performed and who need to perform in order to obtain a better quality of life.

The last phase external Disclosure of results provides the information to the participants involved and to the interested sectors[5], and in each encounter, in the end, there were synthesized the subjects discussed and exposed to the participants, and at the last meeting was held a summary of all the discussions and the results achieved. We also return the results to the interested sectors, Municipal Health and Basic health Unit in the year 2011 and for the community in general for the publication of scientific articles.

From the transcript in its entirety of the data from the interviews and group meetings, the material was treated by the method of Analysis of Thematic Content, used for all phases of the research and which resulted in the following categories: "Understanding of the disease", "Ways to handle", "Diagnosis as a starting point", "Life-changing: care adopted" and "Autonomy of personal care". However, in this article, we will discuss only the categories **"The diagnosis as the starting point", "Life-changing: care adopted**".

As regards the ethical aspects, the research project was approved by the Ethics Committee of the Health Sciences Sector Federal of the University of Paraná (CEP/SD Record: 578.115.08.07). In respect to the anonymous users were identified with the letter U followed by numeric digits, according to the order of speech at meetings.

RESULTS AND DISCUSSIONS

The average age of the 13 users who participated in the study was 51 years old, with variation between 37 to 58, and predominance of aged between 51 to 60 years old with 9 participants. All participants were female, being 10 married or who resided with the companion, 2 widows and 1 separated/divorced. With regard to schooling, 11 had incomplete elementary school and two were not literate, and as for the profession/occupation, 9 were from home, 3 had paid activity, and 1 was unattended, but at a time wasn't working.

The thematic analysis of the data enabled the construction of two categories, the first-"**The diagnosis as a starting point**"-emerged from the lines of users when they were questioned about how they handled before they find out the arterial hypertension and diabetes mellitus. The thematic analysis of the data enabled the construction of two categories, the first-"the diagnosis as a starting point"-emerged from the lines of users when they were questioned about how they handled before they find out the arterial hypertension and diabetes *mellitus*.

The starting point for change was recognized by some participants as the moment of diagnosis and felt the need to report how they discovered the disease. The search for health service and subsequent diagnosis of hypertension and diabetes *mellitus*, for some users it occurred by the perception of signs and symptoms as the lines below:

> My blood pressure was very high, and that's why I had these blackouts [...]. Fainting, weakness in the vendor face felt, burning, that backside, when attacking felt covering the ear, and eyes burning and scratching [...]then when he got very nervous [...] they had two, three blackouts that was pressure. (U4)

> [...] I was like a month just in the House, I just wanted to sleep, didn't want to eat, I was with the heavy body and have been getting bad, getting bad, there was [...] the emergency room [...] did the blood test and urine and hence I was discovered with 600 of diabetes, not dead even because it's time [...] I did because I didn't know [...]. (U11)

The symptoms and/or signs suggesting referenced by users above are the main responsible for the demand for health services, it is worth mentioning that hypertension promotes the appearance of complications, as it is an asymptomatic disease and insidious, Silent Assassin featured as, because their carriers are considered only patients in the event of complications and/or unable to perform their daily activities[6,7].

The suspicion of the diagnosis of diabetes *mellitus*, unlike hypertension that is asymptomatic, can occur by signs and symptoms mentioned by user U11 as polyuria, polydipsia, polyphagia, weight loss, fatigue, weakness and lethargy,[8] however, there are a significant proportion of asymptomatic diabetics.

Another survey conducted with patients with hypertension and diabetes confirms the words of users of this study, when referencing the following signs and symptoms as responsible for the discovery of chronic pathologies: headache, pain in the back of the head and stomach, dizziness, weight loss, dry mouth, thirst, polyuria and loss of vision[9].

The discovery by chance mentioned in another study[9] was also quoted by users in this research, as the lines of U5 and U8 below, who have had the diagnosis after seeking the health service by other pathologies and/or by triage performed by other health professionals.

> There are 5 years ago I went into the gym and when measured the pressure I was told was high, hence I went to health clinic [...].(U5)

> I was 26 [...] went on health clinic and my blood pressure was high [...].(U8)

Hypertension as a disease of multifactorial etiology should be constantly monitored, as well as the "genetic predisposition and environmental factors tend to contribute to an aggregation of cardiovascular risk factors in families with unhealthy lifestyle"[10:09].

The initial diagnosis during the gestational period was also referenced by some users as U7, U10 and since the disturbances during the gravid period antihypertensive are common and evidenced in another study[11].

> The problem was the youngest kid (during their last pregnancy) that started the high blood pressure, began taking the medicines [...]. (U10)

Hypertension in pregnancy is a worrying factor in its two forms: pre-existing (chronic) present before pregnancy or diagnosed until the 20th week, and induced by pregnancy (preeclampsia/eclampsia) that occurs in most cases after the 20th week with proteinuria[10].

Note that users associate the onset of the disease to stress situations are the signs and symptoms, pregnancy, trip to the doctor by chance and/or the counter of a traumatic accident, as in the speech of U9:

> [...] I started that way (refers to arterial hypertension) because of subject of accident, I lost an11 years old girl on the road. (U9)

It is known that when experiencing a traumatic event, as occurred with U9 raises the

risk of developing a stress disorder, major depression, panic and anxiety and substance abuse, as well as somatic symptoms and/or physical illnesses such as hypertension, asthma and chronic pain[12]. However, the relationship between stress and pathophysiology of hypertension is still contradictory, but it is known that the neuroendocrine pathways, which trigger the agents are the same stressors that cause hypertension[13].

The diagnosis of chronic pathologies allowed users to start adhering to treatment, which consequently caused in breach of their ways of life. The reports concerning the care they have incorporated in their lives after the educational activities were grouped and composed the second category – "**Life-changing: care adopted**". The concern to join healthy eating habits was more care mentioned, which can be elucidated by the lines of U9 and U10:

> I ate a lot of pork fat, for me the food had to show the fat to put flour on to be fabulous, [...] but now have to eat just meat dry, whenever I go to the market have to buy meat with less fat, [...]. (U9)

Adhere to a healthy lifestyle is crucial in the treatment of pathologies in question, and the main environmental factors modifiable to be tackled are inappropriate eating habits, physical inactivity, obesity, smoking and excessive consumption of alcohol[8,10]. The ingestion of certain foods can induce undesirable response in blood pressure control and risk foods rich in sodium and saturated fats[10].

In this way, a proper diet is necessary for the control of hypertension and diabetes *mellitus*, however, sometimes users find limitations in conducting the food control, even having knowledge of its importance. In speaking of U5 is possible to notice that the working condition was obstacle to accomplish healthy eating and was forced to find a solution.

> I already had the problem of high blood pressure, at that time I worked in family home, then rolled of everything you could imagine, you had to eat everything and was this big. And that regime was good nobody did, because only the bosses were already 200, 300 pounds each [...] I had to separate food for me.(U5)

The financial situation was also considered a limitation, as reports U5 U7 and because foods like fruits, vegetables, legumes and whole grains have high cost which makes its acquisition by the low-income population.

> Thing I can't get enough back home is a fruit [...] but when we eat.(U5)

> Has time we purchase, sometimes do not buy, when it's very expensive. (U7)

Besides eating healthy, users recognize the importance of reducing body weight, since this relate to the drop in serum insulin, reduced sensitivity to sodium and a decrease in the sympathetic nervous system activity[10]. The reduction in body mass was an evident concern in the speeches of users as U3 and U5:

> Do not lose weight even more than I do my walks, gymnastics, and who says I leanness? (U3)

> Then my life has improved as well, my blood pressure after I came to my house and I had my baby [...] in my house no, I used lard and I started using the oil [...] and very slimming also, I was fine, with 80 pounds when he leaves. (U5)

The decrease in body weight is recommended for all people who are overweight and obese and people who also have a diagnosis of hypertension and / or Diabetes *mellitus*. To achieve this loss, it is targeting the modification of lifestyle, including reduced caloric intake along with increased physical activity, because often this occurs by increased body weight and energy imbalance in which small losses bring significant metabolic benefits[8].

Physical activity is recommended for users with hypertension and diabetes mellitus not only in order to reduce body weight, but to improve metabolic control and realize their hypotensive effect. Thus, reducing the need for hypoglycemic and antihypertensive decreasing cardiovascular risk and increasing the quality of life[8,10]. The concern in performing the exercise was mentioned by users as the lines U3 and U6:

> Today I do walk, do gymnastics once a week, changed everything, at the [...] thanks to God my blood pressure has improved a lot. (U3)

> I'll go out to walk with him, but not every day I do because he is lazy (refers to the husband). (U6)

The use of medication and control of stress and nervousness were also referenced by the participants as a result of felt personal care and/or imposed by diseases need, according to the statements below:

> I took over was little medicine home [...]
>
> I only drank tea, then took my blood pressure to rise, reached the point of swelling mouth, bending his mouth all know [...] my medicine gives the straight-laced month even without symptom I take straight [...] I take care straight diabetes know, I do not direct examination, because I do not like [...] it has a vegetable garden at home [...] I like to tinker, for I am very nervous and there are days when I'm attacked, stressed, then I run my hand with a hoe. (U8)

Pharmacological treatment and emotional control contribute to the reduction of blood pressure and glucose levels and to make drug treatment and try to control stress, some users were able to maintain blood pressure and blood sugar levels checked, but the emotional aspects are not easy to control the latter being mostly to blame for high blood pressure, a fact confirmed in the report of U8. Stress, positive or negative[13], causes reactions in humans such as increased heart rate, increased blood pressure, sweating, dry mouth, muscle tension and feeling of warning, however by definition this cannot be avoided.

In this study, adherence to treatment may have been influenced by the educational activities throughout the development of research, and all users reported the continued use of prescribed medication, which is consistent with the results obtained in another study[14] that described the effect of home care nursing in patients with hypertension and obtained membership and improve blood pressure levels through the development of educational activities. The changes in the personal care were perceived by users, especially for those who participated in the group meetings, all results of educational activities in these four years of the extension project, which can be elucidated by the following reports:

> But the problem is pressure every month I consult and be at the meeting, the pressure is good. (U4)
>
> We changed a lot through you here, you helping, teaching, prompting what could and could not been what we improved. [...] (Before) We came only in consultation and took the medicine and went one to its own home. (U6)

It is perceived by lines U4 and U6 that educational activities based on reflection, dialogue and exchange of experiences enabled mutual learning between user and professional through an empowerment process. Thus, this practice socialization allows you to search, expose, challenge, live, experience, create, contribute, rescue, conquer their place in society[15].

However, the participants of this study for four years were co-participants in an outreach program in which they were encouraged, while conducting educational activities, to think and cope with their problems, whereas today it emphasizes the use of health-promoting practices consider the autonomy of individuals, as well as its political and cultural context. Because it believes that teachers and students have complementary knowledge and mutual dialogue aimed at better living conditions[4, 16].

FINAL CONSIDERATIONS

In describing the personal care provided by patients with chronic users was realized that they knew and cared pathologies, and group activities could have passed as reinforcement in changing lifestyle habits. Personal care reported by users demonstrated some independence, but they respect the guidelines offered by health professionals.

Users to adhere to treatment, post educational activity reinforces the assertion that the nurse can assist in adherence to treatment, although it is known that this is just one of the strategies that assist in the care of chronic disease.

DESCOBRINDO-SE PORTADOR DE DOENÇA CRÔNICA: REPERCUSSÃO DE UMA PESQUISA-AÇÃO

RESUMO

O objetivo do estudo foi descrever as atividades de cuidado pessoal de doentes crônicos desenvolvidas antes e após atuação educativa do enfermeiro. Trata-se de uma pesquisa-ação, realizada em uma Unidade Básica de Saúde da região metropolitana de Curitiba-Pr, junto a 13 usuários com hipertensão arterial e/ou diabetes *mellitus* de ambos os sexos, na faixa etária de 18 a 60 anos. Os dados foram obtidos mediante entrevista semiestruturada e encontros em grupo, os quais foram submetidos à análise de conteúdo temático. As

categorias oriundas desta análise foram: “O diagnóstico como ponto de partida” e “Mudança de vida: cuidados adotados”. Os resultados mostraram que os usuários identificaram a descoberta da doença como o ponto de partida para a realização de cuidados pessoais. A mudança de hábitos de vida e o tratamento farmacológico foram os cuidados mais mencionados. Contudo, demonstraram certa independência para realizarem o cuidado pessoal e adequaram as orientações dadas por profissionais de saúde aos seus conhecimentos e afirmaram necessitar de determinação para realizar o cuidado pessoal.

Palavras-chave: Doença crônica; Educação em saúde; Enfermagem; Saúde do adulto; Prática profissional.

DESCUBRIENDO SE COMO PORTADOR DE ENFERMEDADES CRÓNICAS: IMPACTO DE UNA INVESTIGACIÓN-ACCIÓN

RESUMEN

El objetivo del estudio fue describir las actividades de cuidado personal de los enfermos crónicos desarrolladas antes y después de la actuación educativa del enfermero. Se trata de una investigación-acción, llevada a cabo en una Unidad Básica de Salud de la región metropolitana de Curitiba-Paraná, con 13 usuarios con hipertensión arterial y/o diabetes *mellitus* de ambos los sexos, en la franja de edad de 18 a 60 años. Los datos fueron recolectados a través de entrevista semiestructurada y reuniones de grupo, los cuales fueron sometidos al análisis de contenido temático. Las categorías oriundas de este análisis fueron: "El diagnóstico como punto de partida" y "Cambio de vida: cuidados adoptados". Los resultados mostraron que los usuarios han identificado el descubrimiento de la enfermedad como punto de partida para la realización de cuidados personales. El cambio de hábitos de vida y el tratamiento farmacológico fueron los cuidados más mencionados. Sin embargo, demostraron una pequeña independencia para realizar el cuidado personal y adaptaron las orientaciones dadas por los profesionales de salud a sus conocimientos y afirmaron necesitar de determinación para realizar el cuidado personal.

Palabras clave: Enfermedad crónica; Educación en salud; Enfermería; Salud del adulto; Práctica profesional.

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