

Experiences, needs and expectations of people with diabetes mellitus

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Abstract

This study aims to identify the experiences, needs and expectations of subjects with diabetes, for self-reliance for health promotion. It is a descriptive/exploratory, qualitative, in the program Estratégia Saúde da Família (Family Health Strategy) in the state of Rio Grande do Norte, Brazil. They participated in three rounds of conversation with 44 people. The data were submitted to thematic content analysis and generated the following categories: recognizing the rights and responsibilities; the capacity to decide responsibly; and protagonism of subjects. Experiences are described, needs and expectations of individuals with diabetes on autonomy, self-care and quality of life, to carry out a survey, together with subjects with diabetes, on aspects that serve to build proposals for health promotion actions. In conclusion, it is necessary to analyze the health promotion for self-reliance, considering the respect for choices of people with diabetes.

Keywords: Health promotion. Personal autonomy. Diabetes *mellitus*.

Resumo

Experiências, necessidades e expectativas de pessoas com diabetes mellitus

Este estudo tem como objetivo identificar as experiências, necessidades e expectativas dos sujeitos com diabetes, a partir da perspectiva da autonomia para a promoção da saúde. Trata-se de estudo exploratório-descritivo, qualitativo, aplicado na Estratégia Saúde da Família no Rio Grande do Norte. Participaram de três rodas de conversa 44 pessoas. Os dados foram submetidos à análise temática de conteúdo e geraram as categorias: “reconhecer os direitos e as responsabilidades”; “ser capaz de decidir com responsabilidade”; e “protagonismo dos sujeitos”. São descritas experiências, necessidades e expectativas dos sujeitos com diabetes sobre autonomia, autocuidado e qualidade de vida, para fazer levantamento, junto com os entrevistados, sobre aspectos que propiciem construir propostas de ação para promover a saúde. Conclui-se que é necessário analisar a promoção da saúde na perspectiva da autonomia, considerando o respeito pelas escolhas das pessoas com diabetes.

Palavras-chave: Promoção da saúde. Autonomia pessoal. Diabetes *mellitus*.

Resumen

Experiencias, necesidades y expectativas de las personas con diabetes mellitus

Este estudio tiene como objetivo identificar las experiencias, necesidades y expectativas de las personas con diabetes, a partir de la perspectiva de la autonomía personal para la promoción de la salud. Se trata de un estudio exploratorio/descriptivo, cualitativo, aplicado en la Estratégia Saúde da Família en Rio Grande do Norte, Brasil. Participaron 44 personas en tres rondas de conversación. Los datos se sometieron a análisis de contenido temático y se generaron las categorías: reconocer los derechos y responsabilidades; ser capaz de decidir de manera responsable; y el protagonismo de los sujetos. Se describen las experiencias, necesidades y expectativas de las personas con diabetes sobre la autonomía, el autocuidado y la calidad de vida, para llevar a cabo una encuesta, junto con los sujetos con diabetes, sobre los aspectos que sirven para construir propuestas de acciones de promoción de la salud. Llegamos a la conclusión de que es necesario analizar la promoción de la salud de la autosuficiencia, teniendo en cuenta el respeto a las decisiones de las personas con diabetes.

Palabras clave: Promoción de la salud. Autonomía personal. Diabetes *mellitus*.

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Declararam não haver conflito de interesse.

Diabetes *mellitus* is the most frequent chronic syndrome in world population –one in every ten adults has diabetes –and it is direct responsible for 3.5% of deaths¹. The disease usually has predisposing factors and conditioners, such as obesity, unhealthy eating habits, sedentary lifestyle, stress and heredity. Except for the latter, all other factors can be prevented or controlled by health promotion actions.

People who are already affected are suddenly challenged to radically change their lifestyle, especially the aptitude to autonomy, from adequate control of glycemic levels, acquiring healthy life habits, such as balanced diet, taking up physical exercise regularly and adhering to medicine treatment, whenever required. Thus, it is crucial that individuals have their personal autonomy, so that they can adhere to treatment among possible options.

Therefore, working autonomy in chronic diseases is challenging and it requires acknowledging the right of those people to express opinions and make reasonable and responsible choices. As it is pointed out by Beauchamp and Childress, *in this conception, the respect for autonomy implies to treat people in order to qualify them to act in an autonomous way*². Understanding autonomy *unconditionally depend on life context where the individuals are inserted, real routine*³, such as social-economical, environmental and cultural variables. The complexity that involves autonomy makes it unlikely the existence of a single meaning to the term.

It is common that diabetes patients become dependent on health services, whenever they are not properly instructed to autonomy. They often have a low quality of life, either due to feeling of dependency of relatives and health services or for not being able to avoid complications of the disease. Different factors favor such dependency, but especially the lack of knowledge about *diabetes* and the fact of having to follow “rules” which are not always understood, accepted and incorporated by them. After all, the capacity to set out and follow their own rules, with reasonableness and responsibility determines the empowerment of subjects.

This reality creates the necessity of analyzing health promotion within the perspective of autonomy, considering the respect for people’s choices, even in limiting situations. This study intends to identify experiences, necessities and expectations of subjects with diabetes, with the purpose of identifying mechanisms and processes that can contribute to health promotion.

Method

This article is part of a greater research called “Promoting health: Strategies to autonomy and quality of life of subject with diabetes”, which was approved by Ethics Committee of University Hospital Onofre Lopes. This investigation had the objective of proposing strategies within health promotion in Family Health Strategy, which contribute to more autonomy and quality of life of people with diabetes *mellitus*.

The research occurred in the state of Rio Grande do Norte, Northeastern Brazil. The study field has seven health micro areas, including family health and oral health team. This group is responsible for coordination of care of 2.758 people, 1.303 of them are male and 1.455 female.

In qualitative approach, it is described experiences, necessities and expectations of subjects who live with diabetes when it comes to self care, personal autonomy and quality of life, picked up in three focal groups (conversations) to make a survey with those individuals with diabetes about aspects that are theoretical presuppositions to health promotion actions, focused on autonomy. From total 44 participants included in the research, 67.69% participated in the process.

The conversation script was prepared grounded on research objectives. The meeting was coordinated by responsible researcher, and the speeches were recorded, transcribed and handled according to steps made explicit by thematic content analysis⁴. In this regard, the content analysis was spread in three stages: Pre analysis, exploration of empirical material and handling results; interference; and interpretations.

The first of them corresponded to period of intuitions, having the objective of systematizing the initial basic ideas, making them operational and conducting to an accurate scheme of development of successive operations in an analysis plan.

The second stage explored the empirical material, essentially consisting in codification and decomposition operations. It was defined analysis categories and registration units (RU). Thus, the *corpus* of those conversations have 77 RU, which enabled to build up three categories grounded on necessities observed by participants to health promotion actions: 1) to acknowledge the rights and responsibilities; 2) to be capable of deciding with responsibility; and 3) protagonism of subjects.

The third and last stage of content analysis was handling the results. In this regard, it was made summaries, inferences, interpretations and articulations between obtained information and theoretical contribution of research. The names of subjects were replaced by pseudonyms of cities of Ancient Greece, as the words “diabetes” and “autonomy” have greek etymology.

Results

Acknowledging rights and responsibilities

This category has 11 registration units (14.28%) and it is related to understanding rights and responsibilities to carry out citizenship. The participants considered, as a proposal to create health promotion actions, the incentive to carry out citizenship and, therefore, they mentioned the understanding of those aspects.

Whenever informed about some rights of patients with diabetes, such as access to required medicines to treat the condition and required materials to application, as well as monitoring the capillary glycemia, the participants did not have knowledge, as it can be observed in the speeches below:

“When there is no medicine, I buy it. I did not know it was a right of mine” (Abae);

“Make people know the rights [proposal]. I did not know I had right to medication” (Athens).

Not being aware of the right to have access to medications is a situation which even hinders the continuation of treatment, because if the person needs a medicine and does not buy it or did not have free access, the process is interrupted and it can even harm his/her health even more: *“The doctor of my health insurance told me I needed a better insuline, lantus (...) But when I checked the price, my Goodness! My father could not afford it. Then, I used the common one”* (Phara).

It must be emphasized that Phara has type 1 diabetes, is 15 years old and was diagnosed with diabetes in his second year of life. He needs different applications of regular insuline and Neutral Protamine Hagedorn (NPH) to control hyperglycemia. The lantus insulin (insulin glargine) would be the most adequate to his case, as it is a basal insulin of long duration, which requires daily applications and provides a better quality of life to the sick person.

When it is approached the importance of acknowledging the responsibility of State towards health, but also individual and collective responsibilities to control the disease, as well as the role that health promotion has in this process, it is observed that the latter is understood as a strategy that potentializes the autonomy of subjects, so that they are protagonists of their own well-being. It can be observed in the speeches below:

“The person has to take care of himself/herself also at home. There is no use to go to the doctor every day and eat half a watermelon upon arriving home” (Delphi);

“I do not take medicines every day, I will not lie. I know I have to take them, but sometimes I forget, I let it go”. (Eretria);

“But the person has to understand, right? Otherwise, it is not possible to do it” (Edessa).

Nevertheless, *only after acknowledging rights and responsibilities it is possible to decide, grounded on his ideal of life in the collective*⁵. Thus, there is another category, the necessity of being capable of deciding with responsibility.

Being capable of deciding with responsibility

This category has 12 RU (15.59%) and it crosses matters related to the individual will of subject, available options and possibilities to decide. To the person takes responsible decisions, it is required to develop a set of skills that, presupposed by experience, have three dimensions: Want, have options to and decide.

When it comes to diabetes, the “want” dimension is clearly identified in speeches, as eating habits, engaging in physical activity, medicines with strict times and *limitations imposed by the disease cause a conflict between want and can do*⁵. Nevertheless, it is observed that, when subjects do not have choice options that balance both aspects, some people with diabetes simply do not observe the prescribed norms, as they were not negotiated, as it can be observed in reports of some of them:

“Sometimes I wish to eat something different, but my son says: ‘Mon, you cannot eat it’ (...). I am always hungry, they do not let me eat anything. Then, I hide and eat” (Pellana);

“Can banana be eaten or not? The nutritionist told me I could not eat it. If I want to eat it, I do it” (Chaeronea).

The dissatisfaction about lack of information to decide with responsibility and with available options to treatment and adherence was also mentioned:

"About this history of jogging I started thinking. It is actually it, huh? Sometimes I want to take up water aerobics, but I think: 'If I go jogging for 30 minutes, take up water aerobics, I get really tired'. I even wanted it, but I stick to jogging (...) It was only a wish" (Athens);

"If I knew that another treatment would also be good, as I only take that small medicine. I feel ill afterwards, but I do not say it to the doctor, as the appointment is so fast" (Ephyra).

The health promotion actions focused on autonomy have an important role to ground sensible decisions from spreading the biggest amount of options possible. It is not enough to only show the options to assure the decision power, as the context that crosses the lives of subjects requires lots of intersectorial articulation to broaden this power, such as adequate social-economic conditions. Thus, it is expected that health promotion actions reinforce the decision capacity and protagonism of subjects.

Protagonism of subjects

Such category includes 54 RU (70.13%) that show situations that need to be transformed, such as no critic participation to active participation, indicating the requirement of emancipation power and, specifically to long-term care in diabetes. The no critic acceptance by some participants can be observed in some speeches:

"If I speak something, people think it is bullshit" (Megara);

"I went to the nutritionist and she told me to eat so many weird things that I almost said: 'Hey! Where do we buy it?' There is no such thing in Brazil" (Ephyra);

"I am used to attend the lectures. Sometimes they say things I have no idea about and I merely nod" (Toroni).

It must be highlighted that those reports also bring reflections about joint participation of health professionals to strengthen autonomy, encouraging to overcome the no critic acceptance. Therefore, it is crucial to know the social-cultural reality of the subject.

On the other hand, the active participation is observed when, for instance, Sardis claims: *"If*

a medicine does not work, I notice it". More than simply speaking, to actively participate requires acting in the situation: "When I show up, I say: 'Look, you can change this medicine because I do not take the other one anyway'" (Sardis). However, other reports show that active participation encourages a relational process that can also involve other aspects, such as sharing and being solidary with the other one. After all, everyone has unique experiences in their biographies, which can contribute to build up the experience of other people:

"It is good because we share our necessities" (Dime); "[Share] ideas too, right? Everyone knows something" (Olympia).

It was also mentioned two types of self-care in speeches of participants: There is alienated self-care, where patients act mechanically, only to observe certain prescribed rules. The super valuation of monitoring glucose is an example, especially when it is observed it is carried out without a defined objective to the subject, making it mechanical:

"I make that exam, no matter how much the finger aches. Then, in the ambulatory the girl says the value and does not even say if it is normal or not" (Mystras);

"I am not even afraid, I follow a diet, go jogging, I am obedient, pierce my finger every day with that little monitor I have" (Vasiliki).

The second type of self-care usually occurs when the patient has the required information about the disease and treatment, which is disclosed in criticism about the therapeutics adopted in his dependency network. Upon being the protagonist of decisions, the patient fosters the critic and sensible self-care, as it can be observed in some reports. It is highlighted in this process the importance of information that contributes to the patient knows the symptoms of disease and knows how to identify the signals in his body:

"When my urine has [a strong smell] I know the diabetes is high" (Delphi);

"In that day you went to my house and asked if I felt a strong smell in the urine and mouth, did not say (...) But now I will say that I feel it and a lot" (Athens).

From the analysis of results it is possible to observe that the subjects of sample understand the intrinsic relationship between the balance of health-disease process of diabetes and the requirement of

autonomy for them to have a better quality of life. Consequently, it is concluded that the discussion about autonomy has to focus on indispensable encouragement to full performance of actions towards health promotion.

Discussion

The health promotion actions are crucial to consolidate the principles of Single System of Health (SUS), provided since its creation, not only being limited to National Policy of Health Promotion. The Reorganization Plan of Attention to High Blood Pressure and Diabetes Mellitus⁶ reinforces the importance of promoting health when it deals with the required autonomy to *self-care to assure quality of life and also upon considering education as ground of health promotion practices*⁷. As it is highlighted by Sperandio and others, *health promotion plays a crucial role in the development and application of integrated and transversal healthy public policies seeking the production of health and it enables the interaction of different areas of knowledge*⁸.

Within the first category –to acknowledge rights and responsibilities – it is observed that, to have autonomy, it is indispensable that health promotion actions strengthen the understanding about fundamental rights. After all, health is right of everyone and duty of State⁹ and it includes having access to universal attention, equal, grounded on health promotion, including free access to required medicines to treat and recover health¹⁰. But the duty of State does not exclude the duty of people, family, companies and society⁹. Thus, it is also belongs to other social actors the responsibility with the right to health. Therefore, it is important to be aware of individual, collective and State responsibilities to control the disease.

In this perspective, there are different proposals in the first category to set out health promotion actions, grounded on the necessity of the own subjects to acknowledge rights and responsibilities. However, people can only be questioned when they are consciously able to act and it necessarily means to identify both aspects in society. It enables the emancipation and consequent autonomy, which is the way through which the subjects carry out their real citizenship and can transform the reality and themselves.

The *Ottawa Charter* must be remembered, which is a result of First International Conference on Health Promotion. It conceptualizes health

promotion as *qualification process of community to work to improve their quality of life and health, including a greater participation to control this process*¹¹. In this regard, it is important that health professionals discuss with the society the notions of fundamental rights, so that *it is possible to construct together the perception of rights and responsibilities to conduct the disease in the long term*¹².

When it comes to empowerment related to self-critic care, it is further considered that society and services, especially health ones, have to be attentive and do not neglect the affection and meaning of life of population, effectively encouraging full care with health¹³. It is important to point out that treatment options of diabetes are not limited, there are different types of diet, physical activities, medicines, etc. To acknowledge their rights in all those dimensions enables patients to responsibly decide, a subject that is part of the second category.

It is clear the importance of developing health promotion actions intending to modify the determinants and conditioners of disease process and negative perception of quality of life of people¹³. But such process reflects the hegemony of scientific knowledge, which is disclosed in the fact that professionals always prescribe the same rules to all patients, not considering their specificity, which decharacterizes the required equity in such situations. This wrongful perception excessively affects the autonomy of subjects. In health promotion actions focused on autonomy, it is indispensable that everyone know the existing options and each one can choose, among available possibilities, the one that most adjusts to their life context.

The willingness, decision and possibility of deciding with responsibility require, in addition to knowing the available options, to be sensible and have critic sense to adjust the options to values, preferences, wishes and personal possibilities. Therefore, the subjects need to be qualified to become protagonists. The study demonstrated that vertically prescribed rules, in other words, that have not considered the decision power of patient or his context of life were ineffective to encourage self-care.

Self-care can be classified as action developed in concrete situations of life that the individual directs to himself activities in his own benefit¹⁴. This capacity is essential to have independence to deal with deciding and acting, determining the way of living of each one¹⁵. The autonomy takes into consideration the respect for choices of people, even

in limiting situations, as *acting – even in difference – is what makes the individual an ethical being and enables him to organize and hierarchize life*¹⁶. Thus, medical action towards the well-being of sick person becomes jointly considered with informed and free will of sick people¹⁷.

The interviewees show preoccupation with self-care. However, as the own nomenclature indicates, to be effective it is indispensable the action of each individual, considering his health and well-being. The results of study made it clearer that primary healthcare services cannot handle such necessity in isolation, as it is something related to daily life, either to eat, take a bath, cut the nails, etc. Any of those situations can be rather complex for those who do not empower themselves, therefore the importance of autonomy for people with diabetes.

It is required to foster conscious self-care, qualifying the patient to be protagonist and autonomous, enabling him to identify the situation, making a conscious choice and only then act. To have health promotion actions, considering autonomy, it is crucial to deeply understand the current situation of subjects, to know their history of life and identify their potentialities and fragilities: *The capacity of subjects of facing their reality with responsibility implies their autonomy and quality of life*¹⁸.

In health field, to acknowledge autonomy of people so that they determine their own course of life means to assure they know all diagnostic and therapeutic alternatives, making explicit the risks and benefits of each one and attesting that all information was clearly understood and then it must be respected their final¹⁹, free and informed decision. Moreover, the adherence to treatment depends on autonomy level, which has as pre requisite the idea that available choices cannot repress or deny the integrity and value of the own person²⁰.

The possibilities of choice must be meaningful to subjects and it means to consider their beliefs and basic values. In this regard, health promotion actions, when grounded on strengthening and encouraging autonomy, assure a greater adherence to treatment and, consequently, effective control of the disease.

Final considerations

It was observed in this study that the own subjects with diabetes identify the necessity of understanding rights, responsibilities and available options and then making their choices in a free and informed way. It was also identified that health promotion strategies must be set out to strengthen autonomy, emphasizing the participation of health professionals in this process.

It was also observed that the quality of life of people with diabetes is a daily challenge that divides their routines in *before* and *after* diagnostics, requiring changes in life habits, which are not always negotiated. The diagnostics and coping with the disease seem to be processes of difficult adjustment and familiarity, especially related to proper diet and physical activity, considered by the patients as main faced challenges.

The protagonism of subjects is related to carry out autonomy, experienced in different situations by patients and associated with self-control, freedom, self-government and capacity to act in a sensible and responsible way. It is only through autonomy that subjects become real citizens, considering the meanings of context of life and individual and collective values.

To respond to situations identified in the study, it is required to encourage health promotion actions that qualify people to be active participants of society, with critic awareness of reality and available options to safe and responsible decisions.

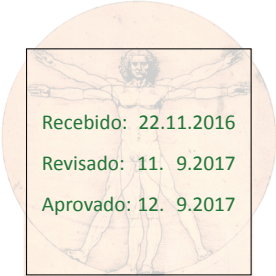
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Participation of the authors

José Adailton da Silva and Karla Patrícia Cardoso Amorim participated in the conception, preparation, analysis and interpretation of results, writing and approval of the version to be published. Cecília Nogueira Valença made the interpretation of data, writing and critical review. Elizabeth Cristina Fagundes de Souza cooperated in the final review.



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