

## HEALTH CARE NETWORK IN THE PERSPECTIVE OF USERS WITH DIABETES

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## ABSTRACT

**Objective:** To understand the perspectives of SUS users with Diabetes Mellitus Type 2(DM2) about their care in the Health Care Network (RAS). **Method:** This is a qualitative study of descriptive nature, developed through digital individually recorded interviews, later transcribed and applied to the technique of content analysis, thematic modality. **Results:** Twelve people with DM2 were interviewed, predominantly women, with complete elementary education, with a mean time diagnosis of six years. These characteristics reinforced the use of different points of RAS. Four categories emerged: Fragility of UBS as a gateway to RAS, (Un) hosting in the different points of RAS, Health Education and Health Services in RAS, which summarized the perceptions of these users about their care path within the RAS, and highlighted difficulties in communication between the points of care, in the management of material and human resources. **Final considerations:** It is concluded the importance of the monitoring and evaluation of RAS with a view to the qualification of work processes and strengthening of services based on the critical reflection of the actions, having the user as protagonist of the system, besides the possibility of sensitizing managers and professionals on the articulation of services in the composition of RAS.

**Keywords:** Diabetes mellitus. Delivery of health care. Integrality in health. Primary Health Care.

## INTRODUCTION

The prevalence of Diabetes Mellitus (DM) in the world is increasing. In 1980 this disease reached 108 million of the world population. In 2014, it reached approximately 422 million and can reach 471 million people by 2035. In 2013, it was estimated that in Brazil 6.3% of the population over 18 years old was diagnosed with diabetes, with 7% being women and 5.4% men; 9.6% were uneducated or had only incomplete elementary education; 0.6% were 18 to 29 years of age and 19.9% were 65 to 74 years old. Still, it was estimated that in 2014 in Brazil there were 11.9 million people between 20 and 79 years with this disease and that in 2035 can reach a margin of 19.2 million<sup>(1-2)</sup>.

DM2 is a chronic condition that can cause micro and macro vascular complications: cardiovascular problems, retinopathy, renal damage, neuropathy, limb amputation. For diagnosis or resolution of these complications, the person living with DM2 needs to be referred to specialists and/or different points of the

Health Care Network (RAS)<sup>(3)</sup>.

In Brazil, in 2014, diabetes was related to the death of more than 48 thousand people between 20 and 60 years. The 2011 global declaration on the Prevention and Control of Noncommunicable Chronic Diseases (NCDs) places DM2 as one of the four priority conditions, since it impacts the quality of life of the person, family and society<sup>(4-5)</sup>. To minimize them, it is necessary to involve the person and his/her social network in the treatment, as well as the guarantee of access to the different health services, either in APS or in another point of RAS.

The protocols for the care of the person with diabetes point to the appropriate management, from the prevention of the illness to the rehabilitation, which are transversal in the RAS<sup>(3)</sup>. However, a study pointed out nurses with difficulties in recognizing the constitutive elements of RAS<sup>(6)</sup>, this may have repercussions on care for the person with DM2, since this professional is one of the main responsible for the classification of risk in APS<sup>(3)</sup>.

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Still in the health services, work is prioritized in a fragmented way and focused on acute and/or chronic acute conditions, based on the Flexner model. This model, on the other hand, weakens health care needs by reverting to low resolution the problems arising from the context that surrounds the NCDs<sup>(6)</sup>. The re-organization of the services according to the RAS<sup>(3)</sup> aims to qualify the care provided and ensure longitudinal care, covering all levels of care, from promotion, prevention, treatment and rehabilitation.

In this sense, Primary Health Care (APS) has three main functions: resolution, ordering and accountability. The first function is to solve most health problems; the second is to organize the flows and counter-flows of people and technologies through the various points of health care of the network; and finally, to be responsible for the health of the users, in any points of attention in which they are attended<sup>(7,8)</sup>. The RAS aim to meet the real needs of the population, chronic diseases, especially DM2, which has been showing exponential growth in the world population<sup>(9)</sup>.

Thus, the incidence of DM2 is still increasing and its morbidity and mortality impacts incalculably on society. Such scenario urges a model of health care organization that can effectively reverse, if not minimize, the costly search by people with diabetes for care services. From this perspective, this study was conducted in order to understand the user experience served by the Health Care Network.

Thus, in the literature, a study was carried out on the evaluation, by means of indicators, of RAS to the DM2 patient<sup>(10)</sup>; however, no study was found about the experience of the users that uses the different points of the RAS, justifying this study, with the purpose of subsidizing improvements and fostering critical reflection on the services provided.

From this, this research aims to understand the perspectives of SUS users with Diabetes Mellitus Type 2 on their care in the Health Care Network (RAS).

## METHODOLOGY

This is a qualitative study<sup>(11)</sup>, of a descriptive nature<sup>(12)</sup>, performed in a Basic Health Unit

(UBS) of the Federal District, located in a satellite city with a higher population density.

Initially, from contact with a responsible professional in the referred UBS, and with the authorization of the manager of the Administrative Region, a spreadsheet with the list of users with diabetes of the assigned area was accessed. Subsequently, all those who met the following inclusion criteria were selected: users of the service aged 60 or over, regardless of gender, with a previous diagnosis of DM2, regardless of time, enrolled and followed up by the health team professionals.

Progressively, selected users were invited, and clarification about risks/benefits in participating in the research was given, and signing the Informed Consent Term. Thus, after accepting the invitation to participate in this study, the day and time were scheduled according to the user's availability, and in a reserved environment, with the guarantee of confidentiality and discretion, the individual interview was started.

The data collection was carried out from May to June 2016, through an individual semi-structured interview, on average with a 30-minute duration, based on the guiding question "how have you been attended in different health services, including in the basic health unit?"

After twelve interviews, the saturation of the data was identified<sup>(13)</sup>, and, therefore, the field work was finished. The participants authorized, through the signature of the specific form, the digital recording of the interviews, which after transcribing and submitting to the technique of content analysis, thematic modality, following the operational steps proposed by Bardin<sup>(14-15)</sup>, that is, a) analysis organization (floating reading); b) coding (identification of sense nuclei); c) categorization; d) treatment of results, inference and interpretation of results.

Everyone invited agreed to participate in the survey, and were designated as E1, E2, E3 ... E12, being "E" for interviewee, followed by the interview order number. The Research Ethics Committee of the Health Sciences Teaching Foundation (CEP/FEPECS) approved the project, CAAE 50367215.5.0000.5553, with the opinion No. 1,355,211.

## RESULTS AND DISCUSSION

Regarding to gender, the sample consisted of one man and eleven women. All from the Brazilian Northeast. The level of schooling prevailed was complete elementary school, having some, incomplete high school. Most retirees, housekeepings and self-employed. The time of diagnosis of DM2 reported by participants, on average, was six years. These aspects of characterization of the participants, besides reflecting the population with DM2 mentioned in the introduction of this article, also signal people with greater chance of needing referrals to secondary and tertiary levels of RAS.

From the analysis emerged four categories called: "Fragility of the UBS as gateway to RAS", "(Un) hosting in the different points of RAS", "Health education" and "Health services in RAS" presented below and subsequently discussed based on the relevant literature.

### **Fragility of UBS as gateway to RAS**

The interviewees reported that the discovery of the diagnosis of DM2 did not originate from screening activities by APS, but that when they presented symptoms of health decompensation, they sought care in private service or in UBS, as indicated by the following statements:

"I suspected that I had diabetes, I came to the UBS, I had the test and I was over 500. Then the doctor told me to go to the hospital and I was there taking insulin until I had my blood glucose was normalized"(E2).

"[...] the first time, I went to the doctor at the hospital {private}, there I did the exam and he said: "Look, for now you will not take medicine. Go on a diet for sugar, pasta and such things. "Then I went through the cardiologist {private clinic} and he told me that he wanted to see my glucose again, he told me to take the test and he gave me the medicine to take" (E5).

[...] ah, I discovered this diabetes in an appointment with the cardiologist at a private hospital. Here, I only participate in the group because of the exercises (E8).

Thus, the diagnosis of DM2 with supplementary health specialist or when symptoms manifested, differs from the proposal that APS functions as the communication center of the RAS, that is, care coordinator, and to that end, a preferential gateway of the population in

RAS. The enrollment of the population by the UBS professionals becomes a fundamental strategy for investigating life habits and knowing the needs of the assigned area, with the possibility of preventing diseases and promoting health<sup>(1,16)</sup>.

In addition, RAS is organized as a set of health care points, which communicate to offer continuous and integral care to users of the Unified Health System, and the attendance by specialists should be referenced, when necessary, by the UBS<sup>(1,16)</sup>.

From these results, the initial non-attendance for qualified listening and conducting exams, correlating them with risk stratification in APS, drives the individual to attend to supplementary health services, reinforcing the fragmentation of care. Also, addressing health problems with specialists can also have a negative impact on the population's view of the services offered by APS.

### **(Un) hosting in the different points of RAS**

It was observed in the interviewees' reports that they do not feel welcomed in the points of RAS, in the sense that the work processes are confusing and the discourteous service, such as the distance between the professional and the user, pointed out by the difficulty of dialogue services. Aspects illustrated by the following statements:

"The other day I came to get my Diabetes and Pressure medications, then gave me only this one and turned his back" (E6).

"Nowadays it's difficult, people hardly look at our face, conversation is difficult to look at in the eye" (E7).

"... It's not everyone, but some of them, these people from the pharmacy ... The other day I came to get my Diabetes medication, he just handled it roughly and turned his back" (E10).

In order to guarantee the integral care and the resoluteness of the service, the professionals that make up the RAS need to identify and give effective responses to the real health needs of the individuals. The host, guideline of the National Policy of Humanization, is a valuable tool to make possible the principles of SUS and the objectives of RAS. By hosting the user's relationship of trust with the health service, the

commitment of both the professional and the user of the SUS is promoted, and it is opportune to solve the problems in the context<sup>(8,10,16-17)</sup>.

Thus, considering the characteristics of the host, all health workers have the responsibility, directly or indirectly, to provide an environment conducive to the well-being of the user in health services. This effective practice can also guarantee the (re) organization of work processes, since the hosting is not only about being educated or presenting a polite attitude, but also to be available for a sensitive and truly interested listening to the problem of those who demand care, including being committed to the development of their activities, whether in the pharmacy or in the provision of information.

### Health education

Respondents were satisfied with the explanations about diet as they reported gaining more knowledge and control over diet, although they also considered the subjects of repetitive lectures or understood them as access to individual consultations. Still, according to the participants, medical and nurses' consultations are usually performed by administrative demands, such as the exchange of prescription.

"I learn a lot, every time I stop eating some [inadequate food], I do not do the things that I used to do. His lectures are very good. I used to say, ah, what is the problem if I eat this, I did not know anything, then in the course we learn things" (E3).

"The problem of lectures that only talks about food, and that I already know, but we must come, right?" (E9).

"Lectures and exercises are our chance to get consultation [...] because in the consultations we can get prescriptions" (E11).

Health education in APS aims to promote healthy habits that minimize risks and thus prevent complications and improve quality of life. For this reason, through health education, it is possible to offer self-care of each individual, encouraging reflections that lead to changes in behavior and changes in users' practices, but that is built with the extension of the autonomy and will of the people

involved<sup>(16-18)</sup>.

Users with diabetes reported participating in group activities, such as lectures on appropriate eating and physical activity. Therefore, lectures were given with unilateral and vertical intercourse, in which the professional holds the knowledge and makes it available to those who attend it. In this sense, from the speeches of the participants, it is possible to articulate new educational practices, such as: arranging the chairs in circles, stimulating debates, giving an opportunity for the exchange of knowledge among all those involved. In addition, based on the criticism of single content for the lectures, several topics could be included, including complications of diabetes, medications (pharmacological and non-pharmacological), management of signs and symptoms, among others.

Physical exercises, such as aerobics, bring numerous health benefits: they improve mobility, prevent muscular atrophy and consequently extend well-being<sup>(19)</sup>. In fact, group activities also strengthen friendship bonds and, in a way, reduce suffering and stress<sup>(18,20-21)</sup>.

Nursing consultations<sup>(22)</sup> also provide another opportunity to exchange contextualized knowledge with subjects that the users prefer to treat under confidentiality, direct the singular care, combining the interventions with the reality of the person. These queries have a great potential to improve the organizational dynamics, especially when using demand-scheduled service, extinguishing too much request for consultations with specialists, and therefore cannot be reduced to get prescriptions.

### Health services in RAS

The slowness for scheduling consultations with medical specialists and scheduling tests or obtaining their results was considered as an obstacle to the RAS's resoluteness capacity, according to the interviewees, which is why they often seek care in the private network (consultations and examinations with direct cost.) Some mentioned periods in which drug distribution occurs insufficiently to the need and demand of all diabetic users, including the

shortage of drugs and supplies, such as glucose tape. In this way, the user/family is obliged to pay for the treatment, or even, cases that sought care through the judicialization.

“The ones I paid I still will have to do them ... I think it's the heart exam that the girl here says they don't have. [...] taking care of the eye at the Base Hospital because my daughter went to the Public Health Office there at Venâncio 2000 to get it and she said it's very expensive, right? [...]. Then the judge gave the injunction that she needed” (E1).

“Sometimes they request many exams, right? So I ... since here often takes too long and we want to know what we have quickly, will we wait thru here, since it takes too long? Then you have to pay, up to 400, 300 [...]the medicine I take for diabetes, they do not have, I have to buy, everything that they don't have, I need to buy, because I want to take it, right? Right now, this month was missing, it seems like it was 4 medications or it was 3, then I'll have to buy them, [...] when I have money left, I buy it” (E3).

“The doctor requested many exams, “electro” of the heart, blood ... close to the return date, I still did not have some exams, because they did not call me to do, so I paid ... because it was close to the appointment date. Then on the day of the consultation the doctor did not show up” (E12).

The APS communicates with various RAS operating structures to ordinate and coordinate patient care, thus allowing care to users that should occur in suitable time, place, cost, and quality. The APS refers the user to the consultations with specialists, when it detects necessity, guaranteeing the continuity of the care. Counter-referral and the return of these referrals is essential for the coordination of APS care<sup>(10,17)</sup>.

In addition, the structuring of the SUS establishes the guarantee to the integral therapeutic assistance of the population, including pharmaceutical assistance. Medicines are of great importance in the health-disease process, since they increase the expectation and quality of life of those who use them<sup>(22-23)</sup>.

Therefore, the application of financial resources in health should be rational and efficient, requiring a qualitative and quantitative diagnosis of the demands versus services offered

in the health production process, which permeate the entire articulated RAS network.

The SUS user sometimes feels lost in deciding which first point of care to look for in the face of their need, so it is important to increasingly disclose the functioning of the RAS, but that in fact the individual and his family can trust. Thus, in general, the participants reported displacements between services unnecessarily, since they are not clarified about the work process. For better communication between the points it is interesting the investment in technologies, that favors the reference and counter-reference.

Regarding the referral and counter-referral system, it is the responsibility of the service to respond to the demands and health needs of its population. Therefore, investment, qualified management, committed professionals and knowledge-empowered users are essential.

In this way, respondents reaffirm the complexity of living with DM2, and signal that new cases of this condition are diagnosed, since the eyes of these users pointed to obstacles from the doorway of the Health Care Network, the awakening of the autonomy of the user for involvement in their own care, in order to prevent complications.

Therefore, the practical implications of these results relate to the need to strengthen APS, whose potential exists for the prevention of diseases, but which still presents weaknesses. That is why continuous evaluation monitoring, in order to strengthen positive points and correct failures, promotes an RAS strengthened and in line with SUS principles.

## FINAL CONSIDERATIONS

The objective was achieved, that is, the paths taken by users living with DM2 in the health care network to have their needs met were understood, since diagnosis, once the thematic categories that emerged from the interviewees' statements summarize the perceptions of these users about their care path within the RAS.

The results show that although the proposal of care in RAS is adequate, the study participants pointed out aspects that deal with weaknesses in the reception of their needs in

APS, and of this in the active search of people predisposed to develop diabetes, as well as in the communication between the points of attention, management of material and human resources.

By understanding the unique perspective of

the user with diabetes, at the same time as we identify as a limitation of the study, it prompts us for other investigations, with the proposed research object in different health care points of RAS, as well as the other agents of the work process (managers and health professionals).

## REDE DE ATENÇÃO À SAÚDE NA PERSPECTIVA DE USUÁRIOS COM DIABETES

### RESUMO

**Objetivo:** Compreender as perspectivas de usuários do SUS com Diabetes Mellitus tipo 2 (DM2) sobre seu atendimento na Rede de Atenção à Saúde (RAS). **Método:** Trata-se de estudo qualitativo de caráter descritivo, desenvolvido por meio de entrevistas gravadas digitalmente, individual, posteriormente transcritas e aplicada a técnica de análise de conteúdo, modalidade temática. **Resultados:** Entrevistou-se 12 pessoas com DM2, predominando mulheres, de ensino fundamental completo, com média de tempo do referido diagnóstico de seis anos. Essas características reforçaram o uso de diferentes pontos da RAS. Emergiram quatro categorias: Fragilidade da UBS como porta de entrada à RAS, (Des) acolhimento nos diferentes pontos da RAS, Educação em Saúde e Serviços de saúde em RAS, que sumarizaram as percepções desses usuários sobre seu percurso assistencial dentro da RAS, e destacaram dificuldades na comunicação entre os pontos de atenção, na gestão de recursos materiais e humanos. **Considerações finais:** Conclui-se a importância do monitoramento e avaliação das RAS com vistas à qualificação dos processos de trabalho e fortalecimento dos serviços a partir da reflexão crítica das ações, tendo o usuário como protagonista do sistema, além da possibilidade de sensibilizar gestores e profissionais de saúde sobre as articulações dos serviços na composição das RAS.

**Palavras-chave:** Diabetes mellitus. Assistência à saúde. Integralidade em saúde. Atenção Primária à Saúde.

## RED DE ATENCIÓN A LA SALUD EN LA PERSPECTIVA DE USUARIOS CON DIABETES

### RESUMEN

**Objetivo:** comprender las perspectivas de usuarios del SUS (Sistema Único de Salud) con Diabetes Mellitus tipo 2 (DM2) sobre su atención en la Red de Atención a la Salud (RAS). **Método:** se trata de estudio cualitativo de carácter descriptivo, desarrollado por medio de entrevistas grabadas digitalmente, individuales, posteriormente transcritas y aplicada la técnica de análisis de contenido, modalidad temática. **Resultados:** fueron entrevistadas 12 personas con DM2, predominando mujeres, con enseñanza primaria completa, con promedio de tiempo del referido diagnóstico de seis años. Estas características reforzaron el uso de diferentes características de la RAS. Surgieron cuatro categorías: Fragilidad de la UBS como puerta de entrada a la RAS; Falta, o no, de acogida en los diferentes puntos de la RAS; Educación en Salud; y Servicios de salud en la RAS, que sintetizaron las percepciones de estos usuarios sobre su recorrido asistencial dentro de la RAS, y señalaron dificultades en la comunicación entre los puntos de atención, en la gestión de recursos materiales y humanos. **Consideraciones finales:** se concluye que es importante la supervisión y evaluación de las RAS con el objetivo de calificar los procesos de trabajo y el fortalecimiento de los servicios a partir de la reflexión crítica de las acciones, teniendo el usuario como protagonista del sistema, además de la posibilidad de sensibilizar a gestores y profesionales de salud sobre los trámites de los servicios en la composición de las RAS.

**Palabras clave:** Diabetes mellitus. Atención a la salud. Integralidad en salud. Atención Primaria de Salud.

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