DOI: http://dx.doi.org/10.12957/demetra.2014.8707

Compliance with dietary recommendations for users with type 2 diabetes

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Abstract

Introduction: diabetes mellitus (DM) is a chronic non-communicable disease and imposes on individuals major changes in their daily lives. To keep the disease under control, it is necessary that individuals change their eating habits and integrate a different, healthy diet totheir daily activities.n. Adherence to diet becomes a key issue for the quality of life and successful treatment. *Objective*: To understand compliance with dietary recommendations by patients with type 2 diabetes enrolled in the Hiperdia program at a Primary Health Unit in Pelotas-RS, Brazil. *Methodology*: Data was collected through semi-structured interviews with 16 people, analyzed and interpreted using the process of categorizing units of meaning, identifying the significant issues and compliance with dietary recommendations. *Results*: non-compliance with dietary guidelines occurs mainly by difficulties in recreating eating habits due to non-acceptance of dietary restrictions. *Conclusion*: dietary restrictions lead to negative changes in social life and create gaps of knowledge about the disease, with the consequent need for a new eating behavior. It is necessary to work deeply on the dietary guidelines and adherence of users in health care services.

Keywords: Compliance. Dietary Recommendations. Diabetes Mellitus. Food Habits.

Introduction

Diabetes mellitus (DM) is a major public health problem that affects a large number of individuals and causes early mortality.[1,2] Based on the current rates of morbidity and mortality and prevalence of type 2 DM, a continuous increase of this disease in all ages in low- and middle-income countries is expected.[3] Projections indicate that in the American continent about 64 million of people will develop DM until 2025. [3] In high-income countries, such increase is more evident among older people, as a consequence of the increase in average life expectancy and population growth. In the low- and middle-income countries, such increase will occur in all ages, especially in the group of people aged 45-64 years, the prevalence of which will triplicate. [3] In Brazil, DM already has a prevalence of 8% in the latter age group.[4]

The national public healthcare system faces up major challenges concerning DM, such as, for example, to assure a systematic therapeutic monitoring of the individuals with DM and take actions to promote health and effectively promote prevention. To execute these actions, in 2000 the Brazilian Ministry of Health implemented the National Plan for Reorganization of Care of High Blood Pressure and Diabetes Mellitus.[5] The objective was to set guidelines and goals for the reorganization of the Unified Health System (SUS), invest in training and qualification of Primary Healthcare professionals, offer a quality-assured diagnosis to the users and provide their access to the Public Healthcare Units for treatment and continued treatment. [5]

DM is a non-communicable chronic disease that imposes major changes in the individual's everyday life. To keep the disease under control, it is necessary that the individuals incorporate healthy eating habits into their daily activities, often different from those they were used to.[6] Adherence to a dietary plan becomes a key issue for the quality of life of individuals with DM and a successful treatment.[7] However, studies have shown that changing one's lifestyle is a very complex task.[6]

Non-adherence is an expected behavior in the treatment of diseases that require special care and/or behavior changes. Studies show that individuals with DM, in general, do not adhere completely to the recommended treatment.[8,9] Among the explanations for such behavior are low-effective guidance provided, difficulties in adapting to mealtimes,[8] problems in avoiding sweets[1,9] and changes in the meals preparation.[9] Most often, non-adherence to the treatment of DM is associated with socioeconomic, psychosocial and cultural factors.[1,6,7]

Considering the importance of the dietary recommendations for the health of individuals with DM, the aim of this study was to understand the reasons for individuals' non-adherence to the treatment in a Primary Healthcare Unit (PHU) located in the south of the country, using a qualitative research approach.

Methods

Considering the objective of this investigation, the methodological option was the qualitative approach. The universe studied was comprised of 16 adult respondents (seven males and nine females), with average age of 45 years among adults and 65 years among the older, and the average did not vary between the sexes. All individuals interviewed had a clinical diagnosis of DM, were in treatment at a PHU in the municipality of Pelotas-RS and were enrolled in the "Hiperdia" Program (Public System for the Registration and Monitoring of Individuals with Hypertension and Diabetes Mellitus).

The PHU was chosen based on the team's composition, which has teachers and interns from the College of Nutrition besides physicians, nurses, nutritionists, and/or nursing technicians and/or assistants.

After being authorized by the PHU's coordinator, the individuals with DM2 were contacted and, after their written and oral consent (all participants signed the Free and Informed Consent Form), data collection was initiated through interviews with the patients as well as from information contained in the Hiperdia records. Personal information collected from the records included: age, sex, address and health-related data (medications used, comorbidity and family history of chronic diseases).

Because of the impossibility of contacting all patients enrolled in the program, the universe of the survey consisted of the group of adults that used to meet regularly once a month. The choice of the day/group was made by convenience, a fact that did not prevent that diversity (age, sex, health conditions) was also present in the group.

Among 50 registered individuals, only 20 were invited to participate in the study in the first meeting, because 30 of them did not attend the meeting at the scheduled date nor the subsequent scheduled meeting. Therefore, the study included the statements of all individuals who attended two Hiperdia meeting days and agreed to participate in the survey. Of the 20 individuals selected, there were four losses, three for not being reached at the home address and one for death. Thus, the sample was comprised of 16 users.

Most of the interviews were conducted at the participants' homes; only four were conducted at the PHU. The eligible informants met the following criteria of inclusion: being ≥ 18 years old, having a clinical diagnosis of DM, being under treatment at a PHU in Pelotas-RS, being enrolled at the Hiperdia Program, and being or having any family member present in one of the scheduled meeting days, when the medications and dietary instructions are provided. This criterion was included to confirm the access of this group to the medicines and health professionals and to examine a possible non-adherent behavior.

The names of the participants were kept confidential, and code names were used in the explanation of the findings, in compliance with Resolution no.196/96 of the National Health Council, Ministry of Health, which regulates researches involving human beings.[10] The study was approved by the Research Ethics Committee of the College of Medicine of the Federal University of Pelotas - UFPel (Protocol no. 025/08).

Two semi-structured interviews were conducted with each participant, with duration of 40min to 1h30min in an interval of one to two months, focusing on the practices that promote or prevent adherence to the recommended diets. The interviews took place in between December 2008 and March 2009. The information was recorded and transcribed for further analysis by means of the identification of meaning units. The goal was to understand the adherence phenomenon, based on the categorization of emerging themes, and understand how the practices are conducive or not to adherence to the dietary recommendations and proper treatment of DM.

Results analysis

The criteria of reliability, coherence and meaning were followed, according to Wise.[11] Reliability was achieved by explaining the steps given to approach the participants, by full documentation of the material and validation of the findings by the subjects of the study. The coherence of the text was assured by the responses to the survey's questions. Meaning was given by the fidelity to the facts experienced by the subjects under study because they are real and part of the subjects' experiences.

Results and discussion

It is important that health professionals be prepared to understand the challenges of interaction with individuals with DM, once the doctor-patient relationship affects adherence to dietary recommendations.[11] Traverso-Yépez, in a study conducted with users of the public health network

in Natal-RN, showed that the respondents looked for quality services, based on listening, dialogue, attention and respect.[12]

Public healthcare institutions have usually been referred to as those whose users are often seen as a recipient or generator of health problems. [13,14] Such kind of relationship between professionals and users does not ensure the good rapport that is necessary for the user to feel welcome and comfortable in expressing their doubts and behaviors. According to Gonçalves et al., "many patients with chronic diseases spend most of their lifetimes playing the 'patient role', and in these cases, the doctor-patient relationship is a key factor in deciding whether they will follow or not the medical recommendations".[15](Authors' translation).

For a better understanding of some factors that influenced adherence to recommended diets, the representative data of the themes that structured the adherence phenomenon were presented according to the doubts relating to the etiology and development of DM, information and some factors that interfered with adherence to the dietary recommendations.

Cause and development of DM

DM develops silently, which makes some individuals to be unaware of being ill and consequently delay in seeking health care.[16] Such delay in seeking treatment, added to a poor communication between the health professional and the user, may worsen the health condition of the individual with DM. After diagnosis of the disease, the understanding of its causes is one of the factors that contribute to acceptance of the condition and a higher adherence to the treatment.[16] Welfer and Leite, in a study conducted in Ijuí-RS, emphasized the importance of providing information to the users to help them understand the need of changing their lifestyle to promote, maintain and recover health.[17]

When asked about their knowledge on DM, most of the survey's respondents reported having only information on the food restrictions that the disease imposes: *"I knew that my cousin had this disease, and because of that she couldn't eat a lot of things!"* (Hilda, 64 years). *"A friend of mine had his leg amputated because of diabetes, so you can see how serious this disease is."* (Heitor, 46 years).

In the reported case, the diagnosis of DM occurred almost by chance, often when treating other pathologies. Among the contacted individuals, it could be seen that the symptoms and causes of the disease were unknown, hindering prevention and immediate care. Moreover, lack of knowledge about the consequences of the disease may affect adherence to the dietary restraints even more strongly, once it requires changes of very ingrained eating and family habits.

Regarding the causes of development of DM some qualitative studies found similar doubts and behaviors. Maias Neto showed that unawareness of the disease is common when he studied the experiences and perceptions of subjects with DM.[18] Similar data found by Welfer pointed that before diagnosis, many diabetics did not know about the disease and did not notice its signs and symptoms. As a result, they delayed in seeking medical care and beginning treatment. [17]

A participant of this study (Carolina, 59 years), when she told about the symptoms that she had when was diagnosed with DM, reported that she had blurred vision, almost in advanced stage of blindness at the time that she sought a PHU for treatment of flue. She said that she does not understand why she became diabetics and thought that it might have appeared because of emotional problems that she had when she lost her husband, which occurred at the time she received the diagnosis. Explanations on such correlation were not explored in this study. However, several studies that investigated causal explanations for the occurrence of the disease showed that the logic of the individuals with the disease is different from the biomedical logic, which may entail treatments and adaptations not always conducive to the cure or control of the disease.[17,18]

Another informant (Heitor, 46 years), when asked about the factors that made him become diabetics, changed his voice when answering. The conversation became tense and he anxiously emphasized that he did not know *yet* about several aspects of this disease. Heitor then asked: *"Why did this disease appear?"* and questioned the interviewer asking her if she could clear up the reason, as a rant and a request for explanation. Seven years ago, he was diagnosed with DM and soon after began treatment with medication, but decided to stop it on his own because he felt better and not showing DM symptoms. After that, his blood glucose levels reached 600mg\dL, and he went into a diabetic coma. After this incident, Heitor began to use insulin along with medication. He returned to the PHU to adjust his diet and now he adheres quite well to the treatment and dietary recommendations.

Differently, Fernanda (63 years) reports that she got used to the treatment and follows the dietary prescriptions, but although being treated by doctors for more than 15 years, she never heard an explanation for the cause of DM. After being diagnosed, some patients usually ask about the origin of the disease: some believe it may be hereditary or emotional, but do not understand exactly what these factors mean and how they influence the onset of DM. However, heredity has been better accepted because the individuals with DM usually identify blood relatives that had or have the disease. This situation is described by Maias Neto[18] and can be observed in the following reports:

> *My mother was diabetic and my sister too. The doctor asked me if there was someone with diabetes in my family. Family is a factor to have diabetes, it passes from father to children, the doctor explained. (Carlos, 56 years).*

I remember the doctors saying that it was genetic, because there are diabetics in my family. That is why I believe that my diabetes came through my family. (Maria, 69 years).

In their reports, all individuals with DM revealed that healthcare providers did not explain the causes and symptoms of DM. In most cases, such practice makes it difficult to accept the disease and treatment. Studies have shown the need to consider humanization in the relationship with patients.[19,20]

Caprara examined the relationship between doctors and patients of the Family Healthcare team and emphasized that there are major problems in the communication between both. Doctors often do not explain the disease clearly and understandingly to the patient and do not check whether the patient had understood the diagnosis just received.[21] In addition, in more than half of the consultations, the doctors did not check whether the patient had understood the therapeutic indications. [22]

Even though relationships with healthcare teams and users not always allow for a larger or more open dialogue, it is worth noting that, for the treatment to proceed successfully, the role of individuals with DM should not be belittled. As per the fifth principle of the Letter of the Rights of the Public Healthcare Users issued by the Ministry of Health (2007), "every citizen also has responsibilities to assure that their treatment is managed properly" and should "express their understanding of the information and/or guidance received and, in case of doubts, ask for clarification".[23] (Author's translation).

The biomedical model encourages a separation between the observer and the observed, causing a gap between them. This model, predominant in health services, focuses exclusively on the biological process and causes difficulties in the communication between doctors and patients.[10,11] Doctors consider only the disease in question and does not incorporate to the treatment the feelings and knowledge of the individuals with DM. [11,1]It becomes clear, from this evidence, that there is no agreement between them, which makes adherence to the therapeutic instructions much more difficult. Doctors should build a relationship with the user beyond the limits of the disease itself by adding to the biological factor social and psychological characteristics. Such communicational practice develops an exchange process with continuing dialogue, which would be used to persuade the individual with DM to follow the treament.[22]

On dietary guidelines

In general, the dietary guidelines prescribed by the health service to the diabetics enrolled in this survey aimed to provide an appropriate control of blood glycemic levels. Thus, they prioritized the adoption of healthy eating habits.

When asked about the guidelines received, the users reported that they used a *sheet* with a list of dietary recommendations, where those relevant to their specific case were marked. This sheet, in general, was kept in a drawer or posted on the refrigerator door. Even those who kept it on the refrigerator did not pay more attention to the foods marked. Despite difficulties to incorporate such guidelines into their daily meals, not mixing complex carbohydrates in a same meal was the restriction more cited by the respondents and with more acceptance among the other actions proposed by the healthcare staff.

Regarding compliance with food recommendations, it was found that some individuals succeeded after adhering to them, after incorporating them into their daily lives. However, they reported that, despite succeeding in building new eating habits, they had difficulties to quit the habit of consuming fat meats, lard and sweets. The recommendation that proved to be more difficult to comply with was avoiding the intake of foods rich in simple carbohydrates. As reported by the participants, the use of dietary sweeteners was consistently recommended to everyone to sweeten the preparations.

The problem, though, does not lie on how to sweeten a preparation but in adhering to the food interdicts. The fact of being prohibited from eating foods that they used to eat is a key issue to the proper management of diabetes. A study conducted by Maias Neto shows that there are obstacles to adhering uninterruptedly to the diets by subjects with DM.[18] Preference for some kinds of foods, meals preparations and the price of foods were significant hindrances to the adherence to the guidelines. [16]

The prohibition, which also includes the size of the food servings, hinders the understanding that they should eat less than they did before. In general, food restrictions led them to a compensatory gain in social situations, like parties. A study by Peres found that people suffering from diabetes had difficulties in following the dietary prescriptions, because it was often associated with a negative image – that is, "the loss of the pleasure of eating and drinking, loss of autonomy and restricted freedom in choosing what and when to eat".[24] (Authors' translation).

Factors that prevent adherence to dietary guidelines

Food restriction. The foods suggested by the healthcare providers are incompatible with various aspects of the local culture, especially regarding the quantity and quality of the foods consumed in a meal. The cultural value and symbolism created on the large amount and presence of some foods in the daily meals determine the conception of the working class about health, strength and sustenance. [24]

The idea of health, in the universe studied, is associated with the vision of corpulent, sturdy bodies, more distant from the conception of eating light foods and small portions during the day. Therefore, eating smaller serving portions is associated with imminent weakness or illness, inhibiting adherence to new dietary recommendations after diagnosis. In a case study carried out by Barsaglini, as well as the study by Maias Neto, the same conception on diet was reported by the respondents.[18,25]

For individuals with DM, the diet prescribed to them make them stop from being "heavy eaters". As these issues are not addressed in the PHU, they might have affected adherence. Hilda (64 years) emphasized such current, widespread conception of health deterioration: *"I have good appetite, and if I do what the nutritionist says I can even become weak..."*. In order to avoid such (imminent) *weakness*, she does not comply with the recommendations and sabotages her diet, eating more than necessary for her condition.

Desire and prohibition. As mentioned earlier, one of the most important guidelines and difficult to get adherence to is to avoid consumption of sweets and sugars in general. Some respondents reported that forbidden foods become more coveted. Even those who usually did not feel much desire of consuming sweets before knowing they suffered from DM wanted them after the diagnosis. Others reported that they used to eat sweets, and even being aware now of the danger to their health, they could not resist the temptation. Similar situation was reported in studies conducted by Peres with women with DM and users of the Primary Healthcare Unit in Ribeirão Preto-SP. The author cites Santana to explain such relationship between prohibition and desire:

> *[...] The taste of forbidden makes honey sweeter. [...] From prohibition comes desire, and from desire comes transgression. Actually, prohibition sharps the object of desire, the more prohibited the more desired it becomes. [...] The desire to eat some foods is always present in the diabetics' life. Such same desire makes them suffer, repress, salivate, forget, transgress, lie, deny, admit, feel pleasure, control and feel guilty. (Author's translation).*

Pelotas is considered the Brazilian capital of sweets. Its economy and the media continually promote the consumption of all kinds of sweets, which make them largely available and desired. Sweets are easily accessible, available in any market of the city. In addition, sweets are often used as a source of household income. That is the case of Carlos (56 years), whose following statement shows his difficulty.

> *Some changes in my dietary habits I could make. Changing feijoada for beans, reducing fats, eating fruits and vegetables. However, the problem is to cut out the sweets! Because it is my job! I am always in contact with them, from preparation to sale and it is hard to resist. I used to eat lots of sweet, today I must control, but occasionally I can't help myself and eat some of what remains at the bottom of the pan.*

In a fetishistic conception of consumption, relations are set and make sweets reach the status of happiness and satisfaction. When the object of desire is the source of income or is associated with any social events, the individuals with DM find themselves in the middle of two conflicting situations: consumption of "prohibited" foods and social life.

Social isolation. The act of eating surpasses the physiological boundaries; it goes beyond the fulfillment of the nutritional needs; it is also a social need. Foods have social and cultural meanings that outline identities and join people in everyday life.[26,27] Often, food plays a social role in human relationships. Practices such as parties, reunions, meetings with friends, going to the movies, or a simple soccer game are occasions when eating adds or brings pleasure and produce meanings for many groups.

Regarding social events/parties, the respondents reported three different reactions: 1) some often abstain from socializing with other people as a way to avoid eating sweets and foods that are not allowed; 2) others go to the events and consume sweets and drinks, minimizing their concerns with the disease; and 3) only two respondents reported adherence to the recommendations and do not eat any of the prohibited foods.

However, those who go to social event more often and consume sweets and drinks are aware of how their bodies react to the prohibited foods. They eat such foods in small amounts, and are alert to the very first symptom (none of the respondents could exactly quantify this portion).

The individuals who transgress the recommendations have been diabetics for more than five years and are familiar with the symptoms, the body reaction and how to manage the disease. Thus, they can venture to the consumption of prohibited foods or beverages. It was interesting to notice that, even disregarding the medical guidelines, most of the respondents consider themselves adherent to the recommendations.

Financial aspects. Among the difficult aspects involving compliance with the diet are the users' economic conditions. Many users report having financial difficulties to vary the diet and/or buy diet or light labelled foods. Among the respondents this justification was also found.

The following reports show, briefly, how they justify the fact of not incorporating new foods to their diets, emphasizing the idea that the right foods are not for the *poor*. Diet and light foods are considered for the rich, for people who can afford them and receive treatment outside the public network and with more attention – perhaps to understand the origin of the disease and talk to the doctor.

What happens is that the poor cannot afford to eat better… they do what is possible; eat vegetables and fruits when they can afford it... (Lucas, 55 years).

It is difficult to follow a balanced diet. The poor eat what is affordable; foods are expensive and fruits and vegetables too... (Juliana, 51 years).

I do as I can. I would like to have a super nutrition, with diet and light foods, but I can't, it is too expensive, so I get along as I can … (Luciano, 50 years).

Even taking into account the influence of the purchasing power when shopping for fruits, vegetables and dietetic foods, which is an argument often used by the respondents to justify non-compliance with the recommended diet, one should question the concept that healthy eating is a privilege of people with high financial status only. Thus, it is necessary to discuss the idea that the high prices of organic foods are important factors for the refusal to use them in the daily meals of low-income families.

Conclusions

The complexity of DM management is a great challenge for the highly overburdened healthcare system. However, as a form of care and health education on DM, it should be considered that self-care is related to issues not always explicit at the time of the medical consultation or during the Hiperdia group meetings. New forms of control and communication should always be considered and become a permanent effort, in order to ensure that the goal of primary healthcare that seeks to deliver universal and comprehensive public healthcare is met.

The present study shows the importance of discussing the hegemonic healthcare model existing today in our country. It is necessary that healthcare professionals, users and managers turn to the debate to seek solutions that would change the present model. It is clear that the rationality of the care used as a guideline for healthcare does not meet the users' needs and hinders the actions of healthcare providers.[13]

Within this context, the Family Health Program was created in the 1990s, which postulates the attempt to redefine the primary care model. Other programs – e.g., the National Plan for Reorganization of the Care of Hypertension and Diabetes Mellitus and the System for Registration and Monitoring of Hypertensive and Diabetic Patients (Hiperdia) – were devised to support this change and improve the quality of healthcare.[5] Through Hiperdia, it is possible to obtain an inventory of hypertensive and diabetic individuals so as to ensure an early identification of the cases and establish a bond with the Public Healthcare Unit and healthcare providers, both indispensable elements in the control of the diseases and adherence to the treatments.

However, despite the efforts made by the government through policies of training and development of managers and professionals to act in the health area, it has not been possible to see real, effective changes in the care model yet. The traditional health education model considers users as individuals lacking information in this area. This makes the communication between the professional and users become vertical, where the former specifies the treatment to be followed, and the latter just has to adhere to it. Furthermore, it does not take into account psychosocial and cultural factors that are determinant in health-related behaviors.[25]

As shown it this study, the tactics used to encourage adherence to the recommendations cannot succeed because the traditional educational model used in healthcare services does not reach the daily lives of the users, i.e., it just has an informative feature and is not capable of converting the existing knowledge into health practices.

To confront this educational model, the dialogical approach arises, having dialogue as an essential instrument, in which the user's knowledge is considered in the doctor-user interaction. Through this model, it is possible to approach the user to the health system and health providers, making effective the treatment and adherence to it.[25] However, despite its importance, this model has not been much used in primary care, yet it has produced some debate in the area, especially among those who study health education. Such model requires changes that would lead to new professional attitudes, which would likely cause resistances and disagreements in many ways.

Disregarding or undervaluing a system that has "layman" values, symbols and meaning attributed to food and eating, different from medical experts, restricts the eating dimension to a survival perspective only. A better understanding of the eating habits and practices by health professionals can bring much more efficiency to the user's adherence to guidelines, and better interaction with individuals that suffer from DM, who are advised to subject themselves to food diets quite different from their usual ones.

It should also be noted that even in the case of the PHS studied, which is an educational unit that has students with partial training in nutrition, effective efforts to encourage patients to adopt healthy habits and adhere to dietary guidelines are few, as some individuals with DM expressed in their statements. As a result, actions on health education could also be prioritized, considering the sociocultural aspects that have impact on adherence to treatment and management of DM.

From this study certainly remain gaps to be filled, as well as some aspects that were not addressed and may influence on non-adherence to dietary guidelines. Among these, we would include the vision that the individuals with DM have regarding sugar in the blood, the feeling resulting from the disease and their understanding on how the biological mechanisms act and can help in the treatment of this disease. It is necessary an in-depth vision to understand the disease and treatment, the causes of DM and the aspects that lead to the adherence or not from the point of view of those who suffer from this disease.

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Received: Jan. 06, 2014
Reviewed: Mar. 19, 2014
Approved: Apr. 25, 2014