



Daily care for the control of *Diabetes mellitus*

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ABSTRACT. This is a descriptive exploratory qualitative study developed with the purpose of knowing daily cares adopted by diabetic and his/her caregiver for the control of glucose levels. The collection of data was accomplished in 2010, through semi-structured interview, which were later subjected to the content analysis. Eight diabetics and seven family members participated in this study. Our results showed that diabetics find it hard to keep the disease under control and despite the concern of the family with the change of habits they present low adherence to recommended care for metabolic control, especially in relation to food. It is concluded that there is a need to develop strategies aiming the systematization care to people with diabetes involving the sick and the family in the planning of education actions in health, contributing with the development of abilities to a persistent and effective care in the metabolic control according to the reality of each family nucleus.

Keywords: Diabetes Mellitus. caregivers. control. family.

Os cuidados cotidianos para o controle do *Diabetes mellitus*

RESUMO. Estudo descritivo-exploratório, de natureza qualitativa, realizado com o objetivo de conhecer os cuidados cotidianos para o controle dos níveis glicêmicos, adotados pelo indivíduo com *diabetes* e seu cuidador. Os dados foram coletados no período de maio a julho de 2010 por meio de entrevista semiestruturada junto a oito indivíduos diabéticos e sete familiares, após submetidos à análise de conteúdo, modalidade temática. Os resultados mostraram que apesar da preocupação e apoio da família em relação à mudança de hábitos, as pessoas com *diabetes* consideram complexo e muito difícil manter a doença sob controle, especialmente no que depende da questão alimentar. Conclui-se que os profissionais de saúde precisam conhecer mais de perto as dificuldades enfrentadas por estas pessoas e encontrar meios que efetivamente as ajudem a lidar com estas questões no cotidiano.

Palavras-chave: *Diabetes mellitus*. cuidadores. controle. família.

Introduction

Diabetes mellitus (DM) is considered a chronic health condition whose treatment and control require knowledge and commitment by the patient and also his/her family (ZANETTI et al, 2007), because there is need for changes in lifestyle (AMERICAN DIABETES ASSOCIATION, 2008). Behaviors, actions and life habits of the family can influence the health status of the individual. Likewise, the existence of a chronic disease affects the way the family unit operates. In this context of mutual influences, the family is now considered as the primary group of relationship and articulation for its members (ZANETTI et al., 2008). It is an important unit of care for the individual affected by a chronic health condition, and in these cases, almost always one of the members comes to assume the role of caregiver.

Thus, the primary informal caregiver is a family member who, in private domestic space, performs or

assists diabetic patients in their basic and instrumental activities of daily living, according to their needs, with the goal of preserving their autonomy and their independence for DM control (BRASIL, 2012).

In the case of DM, family support and help the primary caregiver is essential and is an ally to obtain appropriate health guidelines and best conditions for coping with the disease. The approach to the diabetic individual and family involved with the care should promote knowledge about the disease, as unconditional part of care. In this context, the application of experience and prior knowledge of both about the disease is needed (SANTOS et al., 2005), because the control of the DM is related to changes in lifestyle that must persist for life, including care with feeding and body, daily use of medications, programmed physical exercise, self-monitoring of

blood glucose, constant education and general changes in behavior (BIRAL et al., 2005).

Thus the care given to DM not only involves behavioral changes, but also a friendly interaction between family and diabetics, because the care for the disease takes place grounded on home conviviality. Therefore, considering that training diabetic and primary informal caregiver with the daily care of the disease is the key to the control of blood glucose levels, it is essential that professionals especially nurses know the reality of each patient and family. Given that, they can better support their care actions with guidelines and information consistent to family needs, enabling the family to an efficient and competent care in relation to the control of DM.

In this sense, this study aimed at knowing daily cares adopted by the individual with diabetic and his/her caregiver for the control of glucose levels.

Material and methods

This is a descriptive exploratory qualitative study conducted in a medium-sized city in the northwest Paraná State. The study included patients with diabetes who in a 12-month period required two or more hospital admissions due to loss of glycemic control. Therefore, we surveyed all hospitalizations of people diagnosed with DM (codes E10 – non-insulin dependent and E11 – insulin-dependent from the International Code of Diseases - ICD10) that occurred in the three hospitals in the city in 2008 and 2009.

Initially, it was identified that in 2008 and 2009 there were 101 hospitalizations that met the specified criteria, but only 88 were related to individuals living in the city. After careful survey of the full name and length of hospital stay it was found that 13 individuals had been hospitalized two or more times within 12 months and all were selected to be visited and invited to take part in the study. However, during the visits, it was found that three of them had died and two had moved to another city, so that the participants of the study were eight individuals with diabetes and seven caregivers because one patient lived alone and was responsible for his/her self-care.

Data were collected from May to July 2010, at the homes of the individuals, through semi-structured interviews, which were recorded with the consent and later transcribed. These interviews were based on the following guiding question "talk about home care practiced daily to control the disease". For analysis, interviews were initially transcribed verbatim and further subjected to thematic content

analysis (BARDIN, 2011). It is a set of techniques that allows inferences from the objective content of the speech, consisting of three phases: pre-analysis, material exploration and processing of data (BARDIN, 2011).

Pre-analysis is the process of organizing the documents in which occurred the initial reading, the choice of reports, the formulation of hypotheses, the choice of indices and the development of indicators to support the interpretation. The material exploration phase consisted in finding groups and associations that responded to the objectives of the study giving rise to the categories. The phase of processing of results included the time when were made inferences and interpretation of results (BARDIN, 2011).

The development of the study complied with the criteria of Resolution 196/96 of the National Health Council and the project was approved by the Standing Committee on Ethics in Research Involving Human Subjects of the State University of Maringá (Opinion 670/2009). All participants signed the Informed Consent Form in two copies. To ensure the anonymity of respondents, their speeches were identified by the letters 'D' sick or 'C' caregiver, followed by the letter 'M' for male and 'F' for female and number regarding age.

Results and discussion

Of the eight individuals with diabetes, five were male, aged between 47 and 71 years. The three women aged between 18 and 36 years. As for the education level, two were illiterate and the remaining had from four to 11 years of schooling. Regarding occupation, four were retired, two were housewives, one was babysitter, and other tractor driver.

In relation to duration of the disease, there was a range from two to 21 years of diagnosis. All were insulin-dependent and six were on continuous medication for other comorbidities. One patient had Down syndrome and was totally dependent on care and two women (aged 18 and 22 years) had no other associated diseases.

Considering the main informal caregiver, most were women, aged between 46 and 73 years. Only one man was identified as the primary informal caregiver. Caregivers had between two to 11 years of study, all could read and write. As for their occupation, two were retired, two housewives, one maid, one janitor, and one worked in a hospital laundry.

In relation to health, five caregivers were taking continuous medication for hypertension, one of

them also had congestive heart failure, diabetes and back problems, one had labyrinthitis and gastralgia and one has suffered an acute myocardial infarction.

With regard to speeches of participants relative to daily care, four thematic categories emerged: 'Food as a complicating factor in controlling the disease', 'Recognizing signs of lack of control', 'Taking care of himself/herself in daily life' and 'Taking care of others'.

Food as a complicating factor in controlling the disease

Living in the world of a diabetic person is an existence entangled in feelings of fear and uncertainty, due to the double game built between the mechanisms of acceptance and transgression for disease control (FARIA et al., 2009). Thus, when investigating with the patients how it is for them to keep diabetes under control, we observed that they live an existential paradox, marked by the desire to eat foods that are not recommended and the fear of a loss of glycemic control.

Oh my diabetes is hard, at the same time it is 50, 60 if I eat a little something, it rises to 300, I cannot overlook food and medicines. (DM47)

More or less, once in a while I eat a little extra food, take a candy sometimes, and sometimes delay the timing of insulin. (DF18)

In the reports it was noted that daily life with DM brings important care with the administration of insulin and dietary restrictions, which make the person feel trapped in time of their care.

DM causes significant changes in the relationship the individual has with his/her own body and the world around. Thus, it is important that the patient is aware of his/her condition of chronically ill and adopt changes in habits and lifestyle permeated by restrictions that imply feeding management, practice of physical activity, monitoring of capillary blood glucose and the need for judicious use of medication (LAGACCI et al., 2008).

It's difficult, there's a lot we can't do, much that we can't eat, but it is mainly because we can't eat all that we want to. (DF36)

Oh it's difficult because we can't in any way forget to take the right medicine, some other time we forget we can't eat a lot of pasta, much meat, and then diabetes rises. It's difficult because of the food restriction [...]. (DM71)

Despite the difficulties involving the use of hypoglycemic agents, it is important to highlight that the judicious use of medication promotes a beneficial effect to the person with DM, since it

allows the metabolic control of DM (LAGACCI et al., 2008). The limitations experienced by these people are diverse, however, it is evident that food restriction is the most striking being an unvarying in their daily lives (ZANETTI et al., 2008). On this issue, the study states that food is a fundamental part of the way that society is set up and sees the world (XAVIER, 2009).

Through the speeches it was also observed that nutritional education may become an important factor in their lives, being necessary to rethink the food planning for the whole family (ZANETTI et al., 2008; BAGGIO et al., 2011).

By giving attention to the speech of DF22, it was apprehended that the disease represents a difficult burden to carry, since it makes her prisoner of the disease and of herself, limiting their dreams, desires and particularly draining the essence of her life. We also deduced in her speech that the social life influences her glycemic control, because it makes her feel like a healthy person who can have attitudes like the others around. The study demonstrates that the human diet seems to be much more tied to traditional requirements than to own physiological needs (XAVIER, 2009)

[...] I hang out with my friends and they do everything, so sometimes I forget that I am diabetic and I end up doing the same things, and then I lose control (DF22)

In spite of all difficulties experienced, it is necessary that the person with DM to actively participate in monitoring his/her disease, especially with regard to the quality and quantity of food eaten. Thus, it is important that the person has regularity in mealtimes, in physical activity, in self-monitoring of blood glucose, in self-examination of the feet and the use of medicines. It is also very important to be accompanied by a multidisciplinary team, so that the patient knows recognizing signs and symptoms of hyperglycemia, among other care (BAQUEDANO et al., 2010). It should be noted that the promotion of health in DM involves searching for subsidies to face all the limitations imposed by the disease and compliance with treatment and concomitantly that enable an individual to have a life healthy and as normal as possible, even with the reality that the patient lives with the diagnosis of a chronic disease (COSTA et al., 2011).

Recognizing signs of lack of control

The knowledge of people with DM about the disease and its control enables make them more active in their own treatment, providing a greater safety and improved acceptance of the disease. This

in turn promotes the development of healthy living habits and behavior marked by a preventive action, reducing thus the damage from natural disease progression.

People with DM said that the perception of the presence of signs / symptoms of hyperglycemia or hypoglycemia is the primary resource for identifying the lack of metabolism control.

[...] in the day-to-day I know if it's altered because my vision becomes blurred [...]. When it lowers too much I feel weak, have tremors, I remain trembling and need to eat something, a dough or a juice so that it rises again. But, I know if it's under control or not, when I feel these symptoms, but if I don't it's all right. (DM48)

Clinical manifestations of hyperglycemia expressed in speeches differ from those identified in a study on type 1 DM, which reported as major symptoms, headache, hand sweating, thirst and polyuria, aggression, hunger and gastralgia. On the other hand, they are similar to symptoms of hypoglycemia - tremors and weakness, although participants of that study also reported hunger, headache, drowsiness, unconsciousness, dizziness, gastralgia and crying as signs of hypoglycemia (GÓES et al., 2007).

Besides presenting knowledge of the signs and symptoms of metabolic disorder, some people with DM confirm the glycemic change by checking capillary glucose performed at their homes, others use this care to monitor frequently blood glucose, allowing them to take appropriate conduct on the result.

[...] I have the device and always measure and control the blood glucose level [...]. (DM48)

Oh I always get tested, because I have the device, then it's easier you know, we test and already know how is diabetes, if it's high, then I take care of myself. (DF36)

For these respondents, monitoring blood glucose enables direct the actions involving the treatment of DM. Also, it also allows the construction of a glucose profile, allowing the individual with DM and families recognize the characteristics that may suggest hypo- or hyperglycemia as well as other disease complications (BAQUEDANO et al., 2010).

The absence of signs of hypo- or hyperglycemia results in the perception of well-being in the face of blood glucose control, providing a stimulus to the adoption of behaviors that favor metabolic control.

Oh know when you breathe that fresh air; this is what I feel inside when it's under control. When it's high I feel something bad inside, like if I had a wound in the stomach, a bad thing that starts to

burn when it's high. However when it's low, I begin to tremble, cold sweat [...]. When it's normal, it's like that fresh air inside, we breathe well, and that's when everything is fine. (DF18)

The person with DM therefore needs to be sensitized about the importance of adopting measures of self-care and health promotion in order to achieve improvements in his/her daily life. A study conducted with people newly diagnosed with DM at a clinic in Fortaleza, Ceará State, observed that for them, being diabetic is to face and confront the treatment, i.e. to possess the spirit of courage and know that welfare appears with disease control. To reach this control they seek to live harmoniously with the chronic disease, respecting their limitations and constraints, and that to avoid the loss of glycemic control they are supported by family and friends (FRAGOSO et al., 2010).

Taking care of himself/herself in daily life

Care for the control of DM should be continuous, planned and added to the family routine. In this way, family members have a key role in changing the behavior of the patient, which may become it either easier or harder.

We have to follow the rigorous diet just right [...] need to eat 2/2 hours or 3/3 hours [...], eat a fruit every 3 hours, but sometimes I have no desire to eat, so I eat a soup. (DF36)

Controlling the food, because it's difficult you know, diabetes causes much hunger, I try to control, avoid eating more pasta, but regarding other foods I eat anything, a little of everything [...], ah I eat rice, beans, meat, salad, fruit. (DF18)

In the speeches, it is verified the difficulty of diabetics to adhere to recommended care, but the need to change feeding habits and agree with restrictive therapeutic regimens is adamant for diabetics' life, so that live the entire life with the disease requires the diabetic individual to definitely readjust feeding, searching for a way among their singularities to coexist better with the disease.

A study conducted with 54 people with DM aiming to understand the impact on family the care provided to diabetic person pointed out that changes in the frequency with which they fed, as well as the fractionation of food, allowed observing that the change in the amount of food intake is a key point for disease control (COSTA et al., 2011). Moreover, it is essential to consider the characteristic of food at meal time, with a careful attention to have a balanced meal while respecting the dietary restrictions imposed by DM (GÓES et al., 2007).

Also, we recorded on the family reports concerns and difficulties they face with the patient dietary

control. It is evident also that they have willingness to snuggle, embrace, and mainly protect them from the world around.

[...] If I could I'd place him inside a bubble and I'd give his food by a little window that only his hand could reach, so he would eat properly as should a diabetic. (CF49)

As a mother, we worry too much, if I could do as a broody hen that puts its chicks under the wing, then I'd place her this way, and I'd do what I wanted. (CF48)

It was noticed that the ability of acceptance of the disease by family leads to greater involvement in treatment, expressed by means of worry and incessant desire to control limitations imposed by the disease. About the messages of the family, it is needed involvement and interaction of all members of the family in the search of healthy eating habits, and that the guidelines need to take into account the economic, cultural and social aspects and meet the needs, concerns and feelings of the family as for the quality, quantity and fractionation of food (ZANETTI et al., 2008).

Another care pointed by people with DM and their families for control of DM is the proper use of medication. The judicious use of medication is a mainstay in the treatment of DM, and part of a set of daily observations to reach the goal of metabolic control, not disregarding other care that diabetic and caregiver must have daily (BAGGIO et al., 2011).

Oh for this I have the medicine prescribed, then I take it. (DM71).

Wow, the only way to control diabetes is giving the remedy [...], we have nothing that can be done, so I prepare insulin leaf tea, a popular tea to help out. (CF62)

Furthermore, we note the difficulty faced by people with DM and their family members in control of DM and the importance they assign to hypoglycemic agents. In fact, medication is a mainstay of treatment of DM, and should include a set of actions that need to be practiced to achieve metabolic control, i.e., cannot be an isolated care (BAGGIO et al., 2011).

On this issue, a study on 55 diabetic patients showed that the knowledge and concern about the medication can contribute to the health status of people with DM and thus consist in significant addition to metabolic control and prevention of complications (FARIA et al., 2009).

The practice of physical activity as a form of care for metabolic control, besides being reported by only three people with DM it is not performed regularly by any of them, demonstrating that this

type of care deserves greater attention from health professionals. Therefore this topic needs to be included in the planning of health education to be implemented with these individuals.

An extra care that we must have to achieve control of diabetes is exercise [...] walk, but lately I'm not caring, I'm not exercising. (DF22)

Except for the diet to control of diabetes, we must do some walking, but I'm forbidden to walk because of the diabetic foot. (DF36).

Besides insulin and eating right, exercising, but exercise is rare, I practice every once in a while I'm at home, but it is rare. (DF18).

The physical activity is an essential care in the patient life. The most recommended physical activity for people with DM is aerobic exercise, which should be performed at least three intercalary days a week, or daily if possible, with a minimum duration of 20 minutes daily for the benefits to be gained, reaching 60 minutes or more, depending on the pre-exercise blood glucose level. However, it is highly advisable that the proposed activity is defined and appropriate to the physical condition of the patient (SOCIEDADE BRASILEIRA DE DIABETES, 2010).

However, the practice of physical activity can be of difficult adherence, because it involves changing personal habits, change in routine, motivation, values, beliefs and self-esteem. Starting and/or implementing the physical activity is one of the challenges of the treatment given to the person with DM and should occur with guidance and support from a multidisciplinary team (ZANETTI et al., 2008).

A survey developed showed that over the follow-up period of a group of people with DM1 adapted to food restriction and practice of physical activity, many participants have succeeded in glycemic control, even leaving the use of insulin after the adoption of daily care, which proved to be active in metabolic control (GÓES et al., 2007).

Feeling cared for within the family

Living with DM requires an attitude of confrontation by those who experience it. This experience commits his/her whole being and reveals itself from diverse aspects: acceptance of the disease and the limitations imposed on many spheres (OVIEDO, 2009). This scenario is easily evidenced in practices developed by the family for health and well-being of the person with DM:

[...] I take care of food, bathe, cut the nail, hair, I clean, always have to moisturize his legs, arms, every morning I put moisturizer cream on him, give him some water [...].(CF62).

I take care of food, medicines on time. I clean his house, wash the clothes, I control everything. Do not let him eat candy, smoke, drink alcohol [...] I live nagging him. And I take him to the doctor when he's not good [...] below God is the physician (CF73).

Given the speech, it is evident a character of general care, where the family does not stop only to specific care of the disease, but goes beyond, developing hygiene and comfort, health care, maintenance of skin integrity. This reflects the involvement and concern of responsible care for the full well-being of the diabetic patient.

The comfort of being cared for at their own homes is also a factor that reinforces the importance of working with the family to care for the diabetic patient (MOREIRA et al., 2008), because the chronicity of the disease results in various organic impairments and frequently simple care become difficult or impossible to be implemented (MOREIRA et al., 2008).

The change in family behavior contributes to an easier and more pleasurable adherence to changes of habits by the diabetic person, working as a stimulus for the awareness of the need to adopt daily behaviors aimed at metabolic control (ROSSI et al., 2009). The involvement of family in the care was evident when the caregiver elucidated the changes in family household and daily routine in favor of the treatment and control of DM of its member:

Oh we had a lot of changes at home you know [...] the whole family adopted the changes but the main change was the food, the food changed to everyone [...] sometimes there's something different to others, but most food is almost fat-free, almost no salt, very little frying. If you put something on the table that he cannot eat, for example, regular soda, because his is diet, everyone is watching him not to take the wrong. (CF62)

It is interesting to note that the first concern of the family is keeping the disease under control. The family deprivation of certain foods in favor of the diabetic person, and when possible the acquisition of diet foods, highlights the care of all members of the family, so that the patient consume the recommended amount and the right drink, showing the responsibility and commitment of the family with diabetic individual.

A study developed on type 1 diabetic individuals showed that family support is decisive in the adaptation of the patient to the necessary behavioral changes, especially in regard to food, usually the most infringed by diabetics. It was also highlighted that the family adhesion to the food plan is a

positive factor that supports the new eating habits, confirming the importance that diabetics give to the involvement and participation of the family in control of DM (ROSSI et al., 2009).

Nevertheless, behavioral changes in family household should not withdraw from chronic patient the responsibility for disease control, but through them family seeks to condition the diabetic individual to his/her new reality of life, empowering him/her and providing autonomy to develop self-care by encouraged by family involvement.

It is noteworthy that some family members associate the changes that may occur to patients with their emotional state, and this is why they bother to provide a healthy home environment.

I assist in his diabetes control not letting him nervous; I let him calm because I think his diabetes has a nervous cause. He cannot get nervous that glucose level rises up there, then by keeping inside the house a peaceful place is what I can do for him. (CF46)

In addition to the nutritional care, insulin, I and all the family give much love, much caring for him; we don't want to see him stressed, because we know that the nervous condition can affect diabetes. (CF49)

Some participants of a 'Group of Diabetics' from the city of Ijuí made reference to certain stressful situations they consider that caused the change in blood glucose levels, because when they experience these situations they realized that the blood sugar level was changed, leaving them worried (WELFER; LEITE, 2005).

Another study found that during an episode of physiological stress, the blood glucose level may rise due to the increase in the level of stress hormones (epinephrine, norepinephrine, glucagon, cortisol and growth hormone). Moreover, a person under stress may increase the usual number of meals, physical activity and medications, cooperating to hyper- or hypoglycemia (MARCELINO; CARVALHO, 2005).

In contrast, when the emotional aspect is supported by the union and affection among family members increases the likelihood of adherence to treatment, favoring therefore, glycemic control and metabolic stability. On the other hand, family conflicts may represent a barrier to adherence by significantly compromising disease control.

Conclusion

Our results show that people with DM consider complex the disease control and explain that such domain often escapes from his/her autonomy. It is even evident that among the care cited dietary restrictions confer greater difficulty and individuals generally have low adherence to physical activity.

Notably, there was a major concern of the family in metabolic control, resulting in behavioral changes in the family especially with respect to eating habits and involvement and family participation in daily care at home, contributing to greater adherence of the patient to the treatment.

Considering the results, it is concluded that the health professional should plan and promote actions that value the knowledge that the patient and his/her family possess and their experiences with the disease and also to recognize the family relationships that permeate the care in different contexts. Thus, professionals may act in order to build or enhance the knowledge of those involved about the disease, contributing to the development of practices of daily care that are healthy and safe for the patient and the family unit as a whole.

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