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# How people with diabetes evaluate participation of their family in their health care

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## How people with diabetes evaluate participation of their family in their health care

**Objective.** To understand how individuals with diabetes evaluate the participation of their family in their health care. **Methods.** This was a descriptive study with a qualitative approach involving 26 individuals in the Diabetes Association of Maringá. Participating in the study were 9 women and 17 men (age range, 38 to 83 years) who had attended at least one educational meeting of the “culture circles” of the association. We used the methodological reference of Paulo Freire for implementing an educational proposal directed at persons with type 2 diabetes mellitus that overcame the limitations of conventional health education approaches. Data were collected between May and July 2011. Testimonials given in meetings were recorded, transcribed, and analyzed according to thematic structures. **Results.** Three thematic structures appeared: 1) Recognizing the importance of family in the care of patients with diabetes, 2) blaming the family for non-adherence to healthy practices, and 3) perceiving a secondary gain of the disease: feeling cared for by family members. **Conclusion.** Patients with diabetes perceive family as a source of support and stimulus for adherence and healthy practice, which enable them to control the disease. Family participation in a patient’s care plan should be encouraged.

**Key words:** diabetes mellitus; family health; family relations; health education; nursing.

## Cómo las personas con diabetes evalúan la participación familiar en su proceso de cuidado de la salud

**Objetivo.** Conocer cómo las personas con diabetes evalúan la participación familiar en su proceso de cuidado de la salud. **Metodología.** Estudio descriptivo de naturaleza cualitativa en el que participaron 26 personas registradas en la Asociación de Diabéticos de Maringá-PR, siendo 9 mujeres y 17 hombres, con edades entre 38 a 83 años, las que habían asistido por lo menos a un encuentro educativo de los “Círculos de Cultura” de la asociación. Se adoptó el referencial metodológico de investigación de Freire, en la perspectiva de implementar una propuesta

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educativa direccionada a las personas con diabetes mellitus tipo 2 que superase el abordaje convencional de educación en salud. Los datos fueron recolectados entre mayo y julio de 2011. Los encuentros fueron grabados, transcritos y analizados según sus estructuras temáticas. **Resultados.** Emergieron tres estructuras temáticas: 1) Reconocimiento de la importancia de la familia en los cuidados con la diabetes, 2) Responsabilizando a la familia por la no adherencia a prácticas saludables, y 3) Recibiendo ganancias secundarias de la enfermedad: sintiéndose cuidado en el seno familiar. **Conclusión.** La familia es percibida por las personas con diabetes como fuente de apoyo y de estímulo a adherencia a prácticas saludables, lo que favorece el control de la enfermedad. Se debe estimular la participación familiar en el plan de cuidados de estas personas.

**Palabras clave:** diabetes mellitus; salud de la familia; relaciones familiares; educación en salud; enfermeira.

### Como as pessoas com diabetes avaliam a participação familiar em seu processo de cuidado da saúde

**Objetivo.** Conhecer como as pessoas com diabetes avaliam a participação familiar em seu processo de cuidado da saúde. **Metodologia.** Estudo descritivo de natureza qualitativa no que participaram 26 pessoas registradas na Associação de Diabéticos de Maringá-PR, sendo 9 mulheres e 17 homens, com idades entre 38 a 83 anos, as que tinham assistido pelo menos a um encontro educativo dos “Círculos de Cultura” da associação. Adotou-se o referencial metodológico de investigação de Freire, na perspectiva de implementar uma proposta educativa direcionada às pessoas com diabetes mellitus tipo 2 que superasse a abordagem convencional de educação em saúde. Os dados foram coletados entre maio e julho de 2011. Os encontros foram gravados, transcritos e analisados segundo suas estruturas temáticas. **Resultados.** Emergiram três estruturas temáticas: 1) Reconhecimento da importância da família nos cuidados com a diabetes, 2) Responsabilizando a família pela não aderência a práticas saudáveis, e 3) Recebendo ganhos secundários da doença: sentindo-se cuidado no seio familiar. **Conclusão.** A família é percebida pelas pessoas com diabetes como fonte de apoio e de estímulo a aderência a práticas saudáveis, o que favorece o controle da doença. Deve-se estimular a participação familiar no plano de cuidados destas pessoas.

**Palavras chave:** diabetes mellitus; saúde da família; relações familiares; educação em saúde; enfermagem.

## Introduction

Type 2 diabetes mellitus (T2DM) is a chronic degenerative disease of multiple causes that usually appears in adults and is responsible for 90% of cases of diabetes.<sup>1</sup> When the disease is not adequately followed-up and treated, complications may occur. In addition to being onerous, these complications also reduce the individual's ability to perform daily activities.<sup>2</sup> T2DM treatment often involves the use of antidiabetic agents and changes in life style, mainly food habits and exercise. For this reason, it is fundamental to make the individual with diabetes aware of the importance of adherence to treatment and to ensure the commitment and

support of health professionals and the patient's personal network.<sup>3</sup>

In this context, family has an important role in the treatment and care of patients with T2DM, especially those who are extensively involved in the patient's daily life. The family can either support or discourage adherence to treatment through changes in lifestyle; such changes affect not only the patient with diabetes but also the family.<sup>4</sup> This happens because changes in food habits, the frequency of health service visits, and, usually, the need to use antidiabetic agents interfere with a family's routine and incur expenses

that affect the family's financial status. In this sense, the family's support and understanding of the importance of their role in the care process are a valuable resource for controlling the disease. Published studies have reported on the family as a valuable social support for changes in lifestyle habits, adoption of healthy practices, and increased autonomy with regard to care, which may improve control of T2DM.<sup>4,5</sup>

Family support is also important for enhancing acceptance of and adaptation to the disease and, thus, for preventing or delaying the appearance or worsening of complications associated with the disease.<sup>6</sup> Therefore, it is important to train the family by providing orientation and information on their ability to support and motivate the diabetic individual. The participation of health professionals, especially nurses, in such efforts is critical. When requesting that the family help assumes responsibility and participate in the care of the sick family member, the nursing professional assures a greater family bond and acquires a partner in care; such an environment favors disease control and reduces the seeking for health services.<sup>4-7</sup>

Diabetes education offered by health professionals is the cornerstone to build conscious self-care, prevent complications, and help improve quality of life with the disease. The family can be involved in this process, and offering information to the family can help them participate an effective form of care.<sup>8</sup> Integrated care to patients with diabetes is, therefore, a challenge for the health care team because in addition to offering orientation and support, they must seek to understand the role of the disease in the patient's life. Hence, considering that family organization influences the health behavior of its member and that the health status of each individual also influences the functioning of the family unit, we believe in the importance of knowing how the person with diabetes evaluates his or her family participation in delivering care. This study aimed to determine how persons with T2DM perceive participation of their family in adherence to T2DM treatment.

## Methodology

This is a descriptive, exploratory study using a qualitative approach. Included were 26 individuals with T2DM of both sexes older than age 18 years who were registered in the Diabetes Association of Maringá (ADIM). This nonprofit institution is overseen by the Municipal Health Secretary. Its main objective is to provide more accessible prices, diet products, and equipment for DM control; measure blood pressure; and verify capillary glucose and cholesterol. The association also frequently sponsors lectures on several themes given by health professional volunteers. We used the methodological reference of Paulo Freire<sup>9</sup> for implementing an educational proposal directed at persons with T2DM that overcame the limitations of the conventional health education approach. We sought to conduct a problematized educational process with construction of knowledge by horizontal integration between professors and students.<sup>9</sup> Freire's pedagogical approach presupposes that health education is a mediating activity between theory and practice that is built in a dialogic-relational format using experiences and knowledge acquired over time. On the basis of this view, there is no absolute truth but rather a construction of a set of concepts that form this time as an action-reflection-action moment.<sup>9</sup>

To implement itinerary research, we used as a strategy the culture circles (CC) that serve as a dynamic strategy for learning and exchange of knowledge between professor and students. The CC occurs three times: 1) theme investigation and research for generating themes, 2) codification and discodification of themes, and 3) critical unveiling.<sup>8</sup> During these sessions, participants in a circle reported their experiences and discussed them. This method values cultural concepts and an individual's background, which are unveiled during discussions of themes of interest to the group. The reflection from this collective approach enables discodification, recognition of problems, and the seeking of adequate solutions to problems that tend to affect the group construction.<sup>10</sup> During

the stage of thematic investigation, generated themes were extracted from participants' daily life and from the development of some manual activities coordinated by researchers that involved writing, painting, collage, and drawing. These activities provided dialogic flow and reflection, enabling all to think about and discuss themes that appeared from the activities performed; hence, they enable the participants to talk about their feelings and reflect on the experience of living with diabetes.

During initial development, researchers observed and concomitantly registered the aspects that were considered relevant to posterior discussion. When manual activities ended, the registered themes were presented for validation by participants so that they could also indicate other themes not captured by the researchers. In this way, all discussed themes were relevant and addressed the interests of all participants. During this time, themes and generated words were codified and discodified in order to seek consciousness and identify limited situations and their meaning for participants; the goal was to enable an understanding of the reality and to approach it critically.<sup>9</sup>

During codification and discodification, wherein limit-situations were identified, discussed, problematized, and contextualized towards dialogicity for a critical view of that time on the group perspective. The time of critical unveiling aimed to create a consciousness about situations experience with the unveiling of limits and difficulties and possibilities facing the reality. During that time, themes that arose were discussed to identify possible solutions suggested by the group. Therefore, the action-reflection-action process occurred for the discussed reality.<sup>9</sup> Hence, CCs were conducted weekly at ADIM and involved all those who agreed to participate from May to July 2011. We conducted 12 meetings, each lasting 90 minutes. The meetings were advertised using banners hung in the ADIM building and by phone calls to persons registered with the program. Initially, we proposed creating three groups that would meet on different

days and times to enable participation of more persons. However, because few persons agreed to participate, a single group was created.

After the participants granted permission, meetings were recorded using an MP3 device and were transcribed afterward to increase recall of the details. In analyses we carefully read all transcribed content to identify limit-situations involved with living with T2DM. We generated themes and then proceeded to critical consciousness of the experience by individuals with the disease. It is important to mention that during CCs, researchers mediated, organized, and coordinated discussions to enable and incentive the participation of all persons in the group. In the following results section, the colloquial speech of participants was preserved, but some correction of the language was done to provide better flow.

This study followed the ethical principles stated by Resolution nº196-96 of the Brazilian National Health Council. This project was analyzed and approved by the Permanent Ethical and Research Committee in Human Beings of the Universidade Estadual de Maringá (expert opinion nº 148/2011). All participants signed two copies of the consent form. To guarantee confidentiality, participants are identified by the letters M (man) and F (woman), an identifier number, and a subsequent number indicating the age of the participant (example: M1-58).

## Results

In cycles, 26 persons with T2DM participated (9 women and 17 men). Women ranged in age from 38 to 64 years and participated in 1 to 7 meetings. Men were aged 42 to 83 years and participated in 1 to 9 meetings. The participants' monthly income ranged from two (R\$1 472) to four (R\$2 944) Brazilian's wages, and their family consisted of two to five members; one participant lived alone. Fifteen participants were married, 6 divorced, 3 widowed, and 2 single. Although the family did not constitute direct interest in the meetings,

several times they were mentioned as facilitating or impeding adherence to treatment. On the other hand, the role of the family and their participation in health care was a theme of discussion. The knowledge constructed in CCs from interactions analyzed/interpreted by researchers was organized into thematic structures.

These structures was divided into a) recognizing the importance of family in the care of diabetes, which indicates that participants perceive family as a source of support for improving control of and quality of life with the disease; b) blaming the family for nonadherence to healthy practices, which shows the relationship of transference of guilt to the family for participants' nonadherence to treatment and changes needed to control the disease; and c) perceiving a secondary gain of the disease, that is, feeling cared for by family members, which shows that the disease can promote a closer relationship among family members and favors the relations of care and support.

### **Recognizing the importance of family in the care of diabetes**

Testimonials enabled us to identify family care and valorization of family as a safety net and support for the sick person and for adaptation to lifestyle changes needed among those with diabetes: [...] *when the family helps, it is easier to live with the disease, we feel more supported, and feel that someone is concerned about you [...]* (F1-68); [...] *I was able to improve my health because she [spouse] is by my side. She takes care of food, helps with the medicines, and she takes me to task when I try to break the rules (laughs). To me, when you have someone to stay with you, by your side, it gets easier to live with the disease. It is not so stimulating walking alone.* (F10-67)

We also observed the need to feel a part of the family by ensuring all family members eat the same food and the difficulty of adhering to healthy practices when family members do not participate in them. [...] *If people who live with you help, it is quite possible to control the disease well; we*

*don't feel excluded, I mean by eating different things and living in a different way. It's bad when you have to eat other things, it seems you are different from them [...]* (F5-63); [...] *many times people at your home don't accept that they need to change. You have to eat something and they eat other kinds of food. Why do I need to eat a different food? It's complicated. I continue to eat everything I want* (M4-54); *I try to change things I eat, but my wife doesn't help me, she cooks the wrong things. And, she gives me rice, salad and chicken, but how could I be happy seeing her eating pasta and meat in front of me? It's complicated, isn't it?* (H9-63); *It's very easy to ask the others to exercise while you stay at home watching TV and eating everything you can.* (M10-67)

We also identified the lack of family support, which triggers sadness because the person does not have anyone with whom to share the difficulties. When the disease exists, there is the possibility that dealing with it is more difficult: [...] *I don't know, but in my opinion I think that is why I can't control my diabetes. I live by myself, I don't have no one to help me, to take care of me; no one to take care of me. It's hard to do it by yourself, and especially with that disease, and when you don't have no one to share the problems [...]* (crying). (M3-66)

### **Blaming the family for non-adherence to healthy practice**

In some testimonials, especially in F1 and M12, we identified the difficulty in adhering to healthy practices when such changes are not also implemented in the rest of the family. In these cases, the patients may tend to blame the family for treatment-related problems because they do not follow up with the sick person in implementation of changes, especially concerning food: [...] *it is difficult to control, especially because my son always brought chocolate home [...]*. (F6-61); [...] *my wife don't think about me! She makes cakes, pasta. How can I recover eating such things? [...]*. (F12-63); [...] *I try, but my family always bought sweets, and I can't resist the*

*craving and I end up eating what I see, normally sweet. They don't help me [...]. (F11-72); [...] you do your best to eat right, but someone brings ice cream, sweets, cake, and you end up eating [...] my family should know that is hard to control yourself, and to put those things in front of us. (F1-68)*

In the report of F5, the patient associates “have to do” with certain types of food for family members with eating inappropriate food. This shows some of the difficulties patients face in changing food habits and also reveals a lack of effort or time to prepare meals; it is easier to prepare the same food instead of adapt it to the needs of someone with diabetes: *In my house, we used to make a lot of deserts, because my husband and daughters are not diabetic and they like sweets and pasta, so I have to prepare for them. So, I end up eating everything they eat, I mean cake, sweets, pasta, soda. (M5-63)*

### **Perceiving secondary gains of the disease: feeling cared for by family members**

Some reports showed that people with T2DM can perceive positive gains because of the disease. For example, the requests for assistance from the family, and even the imposition on the family, is seen as a way of getting attention and care that can improve the bond among family members: *[...] now my son always call me, he takes much more care with me [...] I believe that after I became diabetic, he became more close to me, he takes care of me, is concerned about me; every time I'm eating he asks: What is it? At night he comes directly to ask how was my day, if I took the medicines, if I slept well... even his girlfriend calls me, asking things about my disease. This disease made us more close. (H8-64); My daughter behaves like a sergeant (laughs). Sometimes I make [the wrong food choices] on purpose and I take a piece of bread with cheese and ham, and I eat in front of her. She gets crazy and angry with me...it's nice to feel that someone is taking care of you, I feel that she's concerned about me, and it gives me*

*the willingness to take care of me, for her. (F2-47); [...] When I'm not feeling well, my husband stays with me. It's good to feel this caring [...] I think the disease made us closer. (F21-61)*

Also part of the perception of secondary gain, the disease promotes improvement in well-being and clinical conditions of others' disease, triggering positive changes in families' habits as a whole. In such cases, we perceive that when people with T2DM start to understand the positive aspects related to the disease and deal with it—and not just see it as a burden—they tend to better accept life with the disease: *Now, because of the diabetes, I always exercise, eat fruits and vegetables, types of foods that, by no means, I ate before (laughs). I think to have diabetes helps me to consume healthy food, and to be sincere, even my bowel habits improved, to become diabetic was not that all bad (laughs). (M20-56); I also exercise, eat better, and now I cook healthy food for my family. Because, if I have to eat better, my family also has to, or they will become diabetic like me. (F1-68); In going to exercise I took my wife with me. She goes more because of me. So, besides walking around we exercise too, right? (M12-63).*

## **Discussion**

The main focus of the treatment and care for T2DM is changes in lifestyle, and this requires the individual to be continuously stimulated and aware of the importance of such changes. Food and life habits are guided by cultural, social, and economic aspects, which may positively or negatively influence the acceptance and adherence to the changes needed.<sup>2</sup> Cultural reference is made up of a set of values, beliefs, and knowledge constructed throughout life through family living and from interactions with other persons who are significant. This guides the way in which an individual deals with and experience the disease.<sup>11</sup> We observed in testimonials that several people with T2DM perceive support from their family and are stimulated to implement changes in their lifestyle. These cases show that

when family support is present, it is easier for the individual to adapt to the disease and the changes needed to control the disease.<sup>5</sup>

The support and incentives become even more efficient when the family knows and understands the disease, the morbidity process, and the types of care needed to control the disease. With this information, the family can offer adequate support and stimulus to changes.<sup>11</sup> Therefore, when the patient experiences the disease along with his or her family during all diagnostic processes and adaptations to treatment, the disease is more easily accepted.<sup>13</sup> This finding was confirmed in the reports of F1 and M10 when they associated the good control of the disease with the presence of family support. For this reason, when changes in food habits and practice of physical exercise are experienced only by the person with T2DM, without any stimulus or understanding from the families, it is more difficult to incorporate such changes into daily life. This fact can be observed in the report by M4 and M5, who were dissatisfied because they had to eat a different food from the other members of the family, or even in testimonials by M9 and M10, who were unhappy that some of the lifestyle changes advised for them were not practiced by their families.

To emphasize the need for support, represented, for example, by food equality, persons with diabetes show the desire to feel accepted and to be understood within the restricted universe of diabetes. To perceive that the food the diabetic patient is eating differs from what the other members of the family eat can trigger nonacceptance of the disease, causing considerable difficulty in implementing changes and increasing the probability of complications.<sup>6</sup> The testimonials show that families constitute the greatest source of support for patients with T2DM, whether the support takes the form of preparing meals, administering medications, or attending follow-up health care visits with the patient.<sup>4</sup> Care implemented by the family has the aim of preserving the life of the diabetic patient, and it has the advantages of being provided in a

manner best suited to the patient's own cultural standards, individual needs, and environmental conditions.<sup>12</sup>

When family is absent, diabetic patients feel less motivated to take care of their disease, as mentioned by M3, who feels sad about the lack of someone to take care of him or with whom to share the problems related to T2DM. This reaction is understandable because it is human nature to need a companion, especially when experiencing an illness such as T2DM, in order to feel he or she is being taken care of.<sup>13</sup> Studies<sup>13,14</sup> demonstrate the growing importance of family participation and integration in planning the treatment of patients with DM, considering the need of contextualize health care. Therefore, it becomes necessary to inform health professionals, especially nurses, about the importance of including families in the care plan and providing them information and directions that enable them to offer for persons with T2DM adequate support in caring for the disease in the best way possible.

Family support includes emotional, practical, material, and/or financial support, in addition to counseling. Different ways of support enable the establishment of a variety of connections and interconnections to form social networks that not only help persons to face the disease but also interact better with them.<sup>15</sup> However, some testimonials suggest the existence of responsibility transference. In these cases, sick persons blame nonadherence to new health behaviors on family members who do not adopt the same food habits as the patient; this negatively affects adaptation to the new food routine. It is essential that persons with T2DM see themselves and are seen by their family and health professionals as active participants in their care, as well as being autonomous, conscious, and responsible for their health. This responsibility and autonomy could be strengthened by the family; if such support does not occur, however, its absence cannot be used to justify nonadherence to healthy practices and habits. It is important to emphasize that transference of guilty is perceived in a more stressed manner when the sick person is a



woman. F5, for example, uses her responsibility for preparing family meals that satisfy the family's preferences as an excuse to not follow the diet necessary to control T2DM. However, she could use her position as the "cook" to prepare more healthy meals for herself and her family. This attitude would help to control her glycemic levels and, at the same time, prevent the development of health problems in her family.

Concerning the knowledge produced in the CCs, another aspect that deserves attention is the fact that some participants liked to be monitored by families because they perceive such focus to be a form of attention and care. In addition, some reports show that disease resulted in more approximation among members of the family, along with the transference of responsibility: That is, a person who always has the role of caregiver, as in the cases of M8 and F21, switched roles to receive care, especially from children and spouses; the patients accepted this change well. Getting sick presents several challenges to the patient, especially, when it comes to a chronic disease. However, each person reacts in uniquely in such situations with regard to what the disease represents in his/her life, the experience with disease, or the effect on the family and other resources used to face the situation. In general, chronic disease triggers the need for care, which can be provided by the patient or by others. When dependency or the need for more complex care exists, increased closeness among family members could develop; this is seen as a positive aspect of the disease.<sup>16</sup>

This type of positive relationship among the sick person, disease, and social group is called *secondary gain*,<sup>17</sup> which is characterized as any benefit that a specific situation of sickness could provide to the sick person. In our study, the secondary gain was easily identified when persons perceived requests and impositions to change behavior as favorable. In this sense, a study has reported cases in which persons with problems often seek more power within the family system, and this results in personal privileges.<sup>18</sup>

However, the perception of secondary gain may negatively affect disease control because the person with T2DM may not adequately adhere to treatment as a way to draw family attention. This could be observed in the testimonial of F2, who reported consuming inappropriate food in front of her daughter because she obtained satisfaction in seeing her daughter concerned about her. In addition, positive aspects of secondary gain of the disease were also identified, e.g., a change in the family's lifestyle habits as a whole in order to prevent new cases of disease among its members. It is not uncommon for the disease promote health in the family environment, raising the attention of all members to adopt healthy practices.<sup>18</sup>

In situations of disease, the family constitutes the main caregiver, offering physical, psychological, and financial support to the sick person.<sup>19</sup> Because of its high potential for improving patient care, the family can and must be used as a strategic resource, especially in cases of chronic condition, considering the need to prevent complications. For this reason, the family needs to be trained and advised by health professionals, especially nurses. The nurse is the professional who more often provides care to the patient with T2DM and interacts with the patient's family. The nurse, along with the patient's family, is responsible for implementing care processes to prevent complications.

In this way, it is necessary to substitute the professional-patient care model with the professional-patient-family model.<sup>19</sup> In this dialogic perspective, as proposed by Freire,<sup>9</sup> the nursing professional needs to adopt different behavior. By careful listening, it is possible to better understand the reality of those living with a disease and all that is really relevant for them. The use of an action-reflection-action process enables the positive transformation of behavior in persons with T2DM and, as a consequence, in the relationship they have with the disease. In this respect, the health education group, based on a dialogic model, appears to be an appropriate tool with which to approach persons with T2DM because it enables the reporting of experiences

and exchange of knowledge. It also works as a supportive measure and allows participants to interact with others with the same disease and understand what they are experiencing. Group activities should be developed using a problematic approach that values the differences and particularities of each participant. In addition, the presence of the family during meetings should be encouraged.

Family inclusion and participation in the care of patients with T2DM should be authorized and encouraged. In addition, family members more involved with care should receive support, guidance, and information in order to deliver the best family care as possible. It is necessary to adopt new care approaches based on the value of integration between family and professional care and the recognition of the importance of care delivered by the family in situations of both health and disease.

The results of this study cannot be generalized; they include only the points of view of patients with T2DM, which does not permit comparison with family experience. The findings of this study reinforced its validity and importance. Therefore, qualitative studies such as ours enable understanding of the reality of the study participants and allow us to comprehend the meaning of living with T2DM and the aspects of this experience that patients consider really relevant.

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