Social representations of people with diabetes regarding their perception of family support for the treatment

REPRESENTAÇÕES SOCIAIS DE PESSOAS COM DIABETES ACERCA DO APOIO FAMILIAR PERCEBIDO EM RELAÇÃO AO TRATAMENTO

REPRESENTACIONES SOCIALES DE PERSONAS CON DIABETES RESPECTO DEL APOYO FAMILIAR PERCIBIDO EN RELACIÓN AL TRATAMIENTO

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ABSTRACT

The objective of this qualitative study was to identify the social representations that people with diabetes have on their perception of family support for the treatment. The Theory of Social Representations was used as the theoretical and methodological framework. Participants were 41 people with diabetes assisted at a university in the state of São Paulo in 2007. The focal group strategy was used for data collection, and thematic content analysis was performed. Results revealed three categories: family support is present in the everyday life of people with diabetes; the family does not always support the person with diabetes in his or her needs; the person with diabetes assumes the responsibility to trigger family support. Participants see family support as a relevant factor for the treatment, but they also point out that excessive control from relatives limits their autonomy and originates ambiguous feelings. The multiprofessional team must take into consideration that knowing social representations helps improve the health care delivered to people with diabetes.

DESCRIPTORS

Diabetes mellitus
Primary health care
Family
Social support

RESUMO

Estudo qualitativo, que teve como objetivo identificar as representações sociais de pessoas com diabetes acerca do apoio familiar percebido em relação ao tratamento. Como referencial teórico-metodológico utilizou-se a Teoria das Representações Sociais. Participaram 41 pessoas com diabetes atendidas em um centro universitário do interior paulista em 2007. O grupo focal foi utilizado como estratégia de coleta dos dados. Os dados foram submetidos à análise de conteúdo temática. Os resultados possibilitaram identificar três categorias: o apoio da família está presente no cotidiano da pessoa com diabetes; a família nem sempre apóia a pessoa com diabetes em suas necessidades; a própria pessoa com diabetes toma para si a responsabilidade de despertar o apoio da família. Os participantes reconhecem o apoio familiar como um fator relevante para o tratamento, porém também apontam que o excesso de controle exercido pelos familiares restringe sua autonomia e desperta sentimentos ambíguos. A equipe multiprofissional precisa considerar que o conhecimento das representações socialmente construídas contribui para potencializar a atenção em saúde à pessoa com diabetes.

DESCRITORES

Diabetes mellitus
Atenção primária à saúde
Família
Apoio social

RESUMEN

Estudio cualitativo que objetivó identificar las representaciones sociales de personas con diabetes respecto del apoyo familiar percibido en relación al tratamiento. Se utilizó como referencial teórico-metodológico la Teoría de las Representaciones Sociales. Participaron 41 diabéticos atendidos en centro universitario del interior paulista en 2007. Para recolección de datos se usó el grupo focal. Los datos fueron sometidos a análisis de contenido temático. Los resultados identificaron tres categorías: el apoyo familiar está presente en el cotidiano del diabético; la familia no siempre apoya al diabético en sus necesidades; la propia persona diabética toma la responsabilidad de despertar el apoyo familiar. Los participantes destacan al apoyo familiar como factor relevante para el tratamiento, sin embargo reportan que el exceso de control ejercido por familiares restringe su autonomía y despierta sentimientos ambiguos. El equipo multidisciplinario necesita considerar que el conocimiento de las representaciones socialmente construidas contribuye a potencializar la atención sanitaria al diabético.

DESCRIPTORES

Diabetes mellitus
Atención primaria de salud
Familia
Apoyo social

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Portuguese / English:
www.scielo.br/reeusp

Received: 02/18/2009
Approved: 10/05/2010

INTRODUCTION

Diabetes Mellitus (DM) is a chronic disease that requires adjustments in the dynamic and organization of the family of the patient, due to the imposition of permanent and continuous care(1). This process of adaptation to the new condition starts from the establishment of the diagnosis and may trigger some level of disorganization in the family dynamic. Depending on how the patient and family attribute meanings to the disease and to the treatment, the situation may allow an opportunity for learning and living with a chronic condition. After the initial impact of the confirmation of the diagnosis, patients and family members are mobilized in order to seek ways of coping that facilitate the psychosocial adjustment faced with the demands that the complexity of treatment imposes(1-2).

The search for social support(3) is one way of coping with the adverse factors caused by the treatment complexity. It includes, among other things, the search for professional resources for use in the treatment, among which the diabetes education group stands out. From the perspective of integrality in health, an education group must offer support in the physical, psychological, spiritual, and other aspects, including the family as the unit of treatment(4).

Considering that the family organization strongly influences the health behavior of its members and that the health status of each individual, in turn, also influences the functioning of the family unit, studies show the family as an institution that has a strategic importance, in the sense that it can help or hinder a person with diabetes in their correct management of the complexity of the disease and the achievement of the goals of the treatment(2,5). Studies highlight the growing importance of the participation and integration of the family in the treatment plan of people with DM due to the need to contextualize healthcare(6-8). The characteristics of the family context are significantly related to the self-care behavior of patients(7). The family, when properly guided, can constitute a support unit for the care actions in the quotidian of people with diabetes, such as stimulation to perform physical activity, motivation to follow the dietary plan, encouragement in the adjustment of the medicinal therapy when performing capillary blood glucose monitoring in the domicile, the development of skills for the management of insulin and foot care, among other measures(1-2). Family support can be defined as a dimension of social support which, in turn, refers to information or material resources supplied by groups (family, friends, health professionals, among others), which provide emotional or behavioral benefits for those who receive them. It is a reciprocal process and therefore, proactive, in which both parties benefit from the positive effects, strengthening the sense of control over their own lives as much for those who offer the support as for those who receive it(9).

In the present study the focus is on the family support perceived by the person with type 2 DM. High levels of perceived family support and increased self-efficacy are significantly associated with elevated levels of self-care behavior, such as diet and the performance of physical exercise. The family behavior, in turn, is associated with self-care of the patient regarding the diet and physical activity(10). A study showed that the association between the support of family and friends and the performance of self-care strategies was stronger for glucose monitoring than for the other strategies, demonstrating the importance of increasing this type of support(8). In addition to family support, people with DM and their caregivers, still need to rely on psychological support to strengthen themselves emotionally in order to cope with the therapeutic demands of self-care(11). Recognizing the importance of providing psychological counseling to people with DM, a psychological support group was implemented at a university in the interior of São Paulo State. The multidisciplinary team which offers this service recognizes that, in addition to specialized care, the social support network, including the family, contributes to coping with the difficulties encountered in relation to the alterations necessary in the quotidian for the management of the disease.

> The family, when properly guided, can constitute a support unit for the care actions in the quotidian of people with diabetes...

The experience with people who participate in DM education groups has shown that the representation regarding family participation in treatment does not always correspond to their health needs. Moreover, the literature is scarce in relation to this theme, suggesting the need for studies that seek to elucidate the meanings the person with DM attributes to the family participation in their treatment.

Given the above, this study aimed to identify the social representations of people with DM regarding the perceived family support in relation to treatment.

METHOD

This is a descriptive, exploratory study with a qualitative approach. The theoretical-methodological framework used was the Social Representations Theory (SRT)(12-13). This framework was chosen to facilitate greater comprehension of the psychosocial aspects and the meanings attributed by the people with DM to the social support of the family in their treatment. It is believed that the framework adopted makes it possible to uncover how people with DM construct their social representations, considering socially constructed beliefs and values.

Among the different aspects of SRT, the theoretical approach adopted comprehends the social representations as modalities of practical knowledge, directed towards communication and the understanding of the social, material and ideational context in which people live(12). Social representations are forms of knowledge that manifest as cognitive elements, images, concepts, categories and theories. This theoretical framework has been applied in the context of health, particularly in studies with people with chronic conditions, including DM(11,14).

It starts with the premise that learning about the representations that the people with DM construct regarding received support from the family about care, contributes to promote new perspectives and approaches of the professionals regarding the educational intervention required to manage the disease, through more humane and effective actions, which are, therefore, closer to the quotidian of the individuals.

The study was conducted in a Research and University Extension Center of a city in the interior of São Paulo State, in November 2007. This Center was selected as the study site because people with diabetes are treated by a multidisciplinary team consisting of nurses, nutritionists, psychologists, physical educators and undergraduate students in Nursing and Psychology. This Center offers a Diabetes Education Program. The number of persons with DM attended is subject to the limitations of physical space and human resources available. In this program the people are subdivided into four groups. This division into small groups is designed to facilitate good communication between the person with diabetes and the work team. Every Tuesday the four groups are attended simultaneously, on a rotation system through the specialties of: Nursing, Nutrition, Psychology and Physical Education.

Adults with type 2 DM, enrolled in the Diabetes Education Program and who agreed to participate in the investigation were included. A total of 41 people with type 2 DM recruited at the previously mentioned Centre participated, with 30 women and 11 men, between 32 and 80 years of age, with predominant schooling levels equivalent to incomplete elementary education. The majority of participants were married and declared themselves Catholic. This sample represents the population enrolled during the study period in the Diabetes Education Group.

The focus group was used as a research strategy for collecting information(15), according to the self-referential groups approach(16). This type of focus group is used as the primary source of data collection in qualitative research. Self-referential focus groups are intended to explore new areas, still little known by the researcher, and to investigate issues, opinions, attitudes, previous experiences and future prospects. The groups were comprised of participants who had characteristics in common. They were conducted by psychologists that, in the role of moderators, encouraged the participants to converse with each other, valorizing the exchange of experiences, ideas, feelings and values, as well as the expression of advantages and difficulties encountered within the family context.

The patients were subdivided into four closed groups, with an average of 10 participants per group. The groups were heterogeneous regarding age and sex and homogeneous regarding pathology. Data were collected in meetings of approximately 90 minutes, performed on Tuesdays, from 14:00 to 15:30, with a total of four meetings.

The participants were informed about the aims and nature of the study. The freedom to choose to participate in the study was guaranteed, and it was clarified that a refusal would not result in prejudice to their care. Once the agreement to conduct the research was obtained, there was a collective reading of the Terms of Free Prior Informed Consent and the doubts of the participants were clarified as necessary. The anonymity of the collaborators was guaranteed, who are identified by fictitious names.

After an initial warm up, the focus group participants were invited to reflect on the trigger question: *How do I see the participation of my family in my treatment?* The coordinators sought to maintain a welcoming and permissive environment, encouraging the free expression of thoughts and feelings. To record the statements a recording device was used, with the prior consent of the participants. The records of the meetings were transcribed verbatim and in full, constituting the *corpus* of analysis. Subsequently, the thematic analysis was undertaken(17), identifying the nuclei of meaning contained in the statements of the participants. The method used can be divided into three stages: pre-analysis, exploration of the material and processing of the results obtained, and interpretation. In the pre-analysis successive readings of the collected material were carried out, which permitted the establishment of an exhaustive contact with the content evoked and the identification of the nuclei of meaning, keywords or phrases which could explain ideas, thoughts and meanings relevant for the elucidation of the aims of the study; following this, the segments that contained central ideas in common were extracted and grouped, which constituted the themes that delimit the context of the study. In the second step, the extracts were analyzed and the criteria for classifying them established. In the third phase of the analysis the extracts from the previous step were categorized, which allowed the definition of the social representations of the people with DM regarding perceived family support.

The project was approved by the Research Ethics Committee of the Ribeirão Preto College of Nursing (protocol No. 0667/2006).

RESULTS AND DISCUSSION

Three categories were identified: Family support is present in the quotidian of the person with diabetes mellitus; the family does not always support the person with diabetes mellitus in their needs, the person with diabetes mellitus assumes the responsibility for arousing the family support.

1. Family support is present in the quotidian of the person with diabetes mellitus

In this category the statements are contemplated that suggest that family support occurs in the form of excessive control by the family members. The central axis of the social representations that the person with DM elaborates regarding how the family approaches the treatment is founded on the notion of punitive and coercive control, which deprives the affected person of the full satisfaction of the pleasures related to dietary-behavior and social interaction.

> It's because my wife is always nagging...she wants to know if I measured the glycemia, if I took insulin [...] even my five year old granddaughter nags me, she says: *You cannot drink soda!* (José).

> She (wife) is too controlling, everything that you do she questions and talks about (João).

> When I go to a birthday party I cannot even go near the table of candies because they are looking at me and stopping me... (Márcia).

The social representations bought by the participants place the family in a position of vigilance, which monitors and, eventually, punishes the excesses and transgressions committed by the person with DM. The person with DM is, in turn, seen as someone that should be kept under constant surveillance due to their lack of capacity for self-control, which puts the success of treatment at risk. They, therefore, are seen with suspicion, as if they are always about to give in to the temptations and commit some sort of dietary transgression. These data are consistent with those obtained by other studies(11,18).

> My granddaughter was at the sink and put a small piece: *Grandma, you can only have this piece* (Joana).

> Every time I went there to get a small piece hidden. Every time I heard a yell: *Hey, Cláudio!* (Cláudio).

> And she [sister] gave me a scolding, she started saying so everyone could hear: *you're not going to eat this, you're not going to eat that* and stayed there, policing me, you know, took things too, you know: *Oh, no, you will not eat*; and took it, saying: *You will not eat this* [...] She said: *No, you will not eat this*; *She cannot, she is a diabetic*. So, these things about being diabetic sounded heavy, right (Cristina).

According to SRT it can be apprehended, in the statement below, that the emphatic attitude of the family does not respect the free will and freedom of choice of the other, but conversely, seeks to impose a decision, to direct their behavior, smothering their autonomy:

> *You cannot* - when they serve the coffee, it is being served and you keep quiet, before you choose the sweetener the person who is there says: *No, she cannot!* (Luana).

> They said: *Do not eat*. To the point of taking it away and saying: *no*! There was a day, a birthday, they were going to serve me cake and they said to me*: No, you cannot.* [...] it is also their concern, of the importance they give to me too, right (Cristina).

In this last statement another dimension can be understood regarding the representation that the patient constructs in relation to the attitude of the family members, that excessive control can also represent caution, care, and protection in relation to their health. This finding is relevant because it demonstrates that the social representations of family support do not have a univocal character, but are polysemic. Health professionals need to be alert to these nuances contained in the social representations of people with DM, which are not always easily apprehended in quotidian speech, often going unnoticed.

The control of the dietary behavior of the person with DM is often naturalized and crystallized, which can also be easily transferred to other people of the family life that are unrelated, as related in the following statement:

> I like string candy a lot, then the girl who works in my house threw all the green candies in the trash, then I looked and said: *My candies!*. She said: *They are rotten*. I said this: *I bought them yesterday*. She looked and said: *You cannot eat them* (Luana).

The fact that they are continually exposed to the rigors of dietary control exercised by a third party may create intense emotional reactions. The resulting frustration can lead the person with DM to experience feelings of rage or rebellion:

> That [family control] makes us so angry and there's something else too: *Have you taken insulin?* I KNOW about my responsibility and that I have a schedule to take it, do you need to remind me? Ah, but at home there is a fuss (Luana).

The social representation of the care offered by family members is incorporated by the people with DM as an often unbearable burden, which compromises their self-esteem rather than contributing to help them to reduce their dependency and organize their quotidian lives considering their limitations. Thus, the control imposed in a continuous way does not appear to enhance their personal competence for self care. In the representations of the participants the need to be recognized as individuals capable of coping with their treatment, preserving their margin of autonomy and freedom of choice can be apprehended. Seeing themselves confronted in their quotidian lives with successive impositions of the other, they are made to feel inferior and childish faced with the multiple demands of treatment.

2. The family does not always support the person with diabetes mellitus in their needs

The family support network constitutes one of the pillars which sustain the care in chronic health conditions. Considering that this care is permanent, onerous and may cause intense emotional distress in the caregivers(1-3,.5), resulting in physical and emotional overload, the person with DM does not always have their family support needs conveniently met.

The social representations indicative of the absence of family support of the participants are illustrated in the following excerpts:

> Me, more and more abandoned. [...] I lost everything: mother, brother, everything. [...] Nobody wants to take care of sick people, no (Susana).

> Loneliness, I say loneliness because I am a widow, you know, a widow, I do not have a shoulder to cry on, you know... So I feel myself alone...alone, I have nobody to talk to, I do not have anyone to let off steam to (Laura).

Feelings of abandonment, helplessness and loneliness pervade these representations, indicating their potential deleterious effects on the emotional life of these people, which may undermine the motivation for treatment. These negative feelings, when crystallized, can predispose to the formation of depressive symptoms, such as low self-esteem, depression, hopelessness, low expectation towards the future, loss of vital tone and of interest in daily activities - including those considered important for maintaining good metabolic control.

The difficulties of communication within the family may reinforce the feelings of loneliness and helplessness experienced by people with DM, as shown by the statements related below:

> My husband is a good husband, a good father, he just doesn't talk, but he is a good husband, sometimes a little clumsy... My husband is a family problem, it is the lack of conversation, of guidance, this was not in his family, you understand? (Mara).

> We have to live with a person who lifts you up, who gives you courage, who does not make you depressed, right (Sônia).

The psychological suffering entailed by intrafamilial communication problems is intense and persistent in the discourse of some participants. This finding allows the postulation that one of the factors that motivates the search for DM support groups is the search for social support, sharing common problems and opportunities of sociability, which is consistent with the results of other studies that highlight the potential of the groups in terms of offering these therapeutic factors(4).

Conversely, the social representations indicating the presence of family support were also prominent.

> Yeah, my children, right, they saw that I was very concerned with the disease; so, now they try to help me, take me everywhere, you know... it is a way to acknowledge what I did (Mara).

> Mine [children] say: *Mom, are you feeling anything? Do you want to go to the doctor?* (Paula).

> They [children] are concerned about our health, if we are doing well… if I try to stay in bed a little longer in the morning, one of them will go there to check (Mário).

> The affection they have, that the grandchildren have with their grandfather, that the children have with us (Júlio).

> I have my son with whom I live, we live together in the same apartment, he is a person who helps us greatly in this part because he works with sick people. [...] He comforts us, wants to know how things are, how it's going (José).

> ...they end up taking care of us, you know (Mara).

Thus, the children appear as important sources of family support, both for the men and women. This proximity maintained by the children is felt as a relief, as a comfort that helps to mitigate the difficulty of living with the limitations entailed by DM.

Another support figure highlighted is the spouse:

> My husband said to me: *Start drinking skimmed milk!* (Mara).

> My husband also began administering insulin because I was not feeling well to inject that needle... One day he said: *You have to do it yourself* (Renata).

Other family members can enhance the circle of social support for people with DM, including children, who seem to have a keen perception of the needs of the patient:

> I have a five year old granddaughter... she said: *I love you, Grandma*. Wow! [Sigh] It's a blessing! So, I think that all this helps, it's all good! (Júlia).

The attitudes of the family regarding the treatment may represent a powerful stimulus to the independence and the search for autonomy, as can be perceived in the statement of the husband who advised his wife to take skimmed milk and in the other, where the administration of insulin was encouraged. The conjugal relationship is represented as an exercise in mutual tolerance, particularly in long-term relationships, in which, after decades of cohabiting, the couple have learned to cope with their differences, minimizing the sources of discord that disturb their harmony.

> She [wife] tolerates me and sometimes I tolerate her as well, it is this that makes us live together, when she makes a blunder, I tolerate it, she does the same (José).

This tolerance, learned in the conjugal relationship, may be a protective factor in moments of greater vulnerability for people with DM. These moments are expressed as episodes of dietary transgressions or forgetting to use medication, the *blunders* committed by the person, conforming to the expression used by José, as well as the physical limitations related to the loss of visual acuity, impairment of sensitivity in the lower limbs, among other complications.

It was observed, therefore, that the participants elaborated social representations about the family as caring, affectionate and involving, which makes living with the treatment less painful, facilitating the incorporation of the care in to the quotidian of the person with DM.

> When I ask for a lift [to the consultation], they take me (Ruth).
>
> Ah, the help of the family, you know, everybody tried to help in the best way, you know (Helena).

However, as might be perceived in the representations related to the lack of family support, the presence of care does not always only arouse feelings of comfort and subjective well-being. There is another aspect, the excess of care, which runs tangent to the overprotection and arouses intense and ambiguous feelings. The following statement is illustrative of this problem, in revealing feelings of insecurity produced by excessive dependence on care provided by the family.

> I have no courage to administer it [insulin], it is my daughter who prepares. I stay here, thinking about the day that my daughter is to marry... she has been dating for five years, plans her wedding, what will happen when she leaves home? How am I going to take insulin? (Flávia).

In summary, the social representations show that both the absence and the presence of family support are connected with the way the person with DM copes with the chronic condition and the complexity of treatment. The presence or absence of such support is related to diverse factors, such as: environment and family life, existing patterns of communication between the members, lack of preparation of the family to live with the chronic condition, among others. Therefore, the social representations regarding the presence or absence of family support are related to psychological comfort or discomfort. The loss of well-being and social support is often associated with chronic health conditions(19). For this reason, some people seek in the diabetes support and education group, not only to fulfill their health needs but also to supplement the support they feel lacking in the family environment(1-2).

It should also be noted that accommodations exist in the family context faced with the illness. The following statement is a social representation of progressive adaptations of the family environment in relation to the needs of the person with DM.

> The people you live with start, start to adapt to your illness, start to make the meals accordingly. In my house, it has totally changed from what it was, formerly, there was frying, pasta... but now I realize that my mother does not make what she used to. She no longer makes candy, why? She no longer makes because she is afraid she will give me the urge to go there and eat and harm myself... Everywhere I go, I feel that they have changed; changed the way, the way they live related to my disease (Raul).
>
> When there is a party a lot of people worry about what I can eat (Zélia).

The adaptations that occur within the family are not isolated, but have a systemic impact. It is not only the person with DM who feels the consequences of the disease, the family is also influenced by the chronic sickening of one of its members(1-2,6-8). When one of the members of the family system *becomes diabetic*, not only the individual, but the entire system will have to reorganize to assimilate this new information and learn to live with it(19).

3. The person with diabetes mellitus assumes the responsibility for arousing the family support

The central axis of these social representations is grounded in the way the individuals take upon themselves the responsibility of producing the conditions that foster the support that the family members direct back to them in the context of coping with the disease.

As becomes explicit in the statement below, the transformation is produced from a decision of personal change of the participant, which affects their family context. In this case, the person with DM does not expect the family members to change from a singular and spontaneous movement, but becomes active in promoting these transformations.

> I put myself first at home... the food is lacking a little salt? Do me a favor, put the salt on your plate; I'm diabetic, hypertensive, and mine cannot be fixed, so, I put less salt (Joana).
>
> My children complain: *Mom, you do not make candy, do not make a cake* (Ruth).

In summary, in the analysis of the third thematic category two distinct movements of the alterations that the disease produces in the family were observed: one movement that parts from the individual affected by DM, which propagates as a wave that affects the other family members, involving them and inviting them to alter, together, certain previously crystallized lifestyle habits. However, the other movement follows a different direction: the individual is not simply waiting for their family members to become sensitized and permeable to the need to change their habits, but is in some way co-responsible for the production of their self-care.

The set of social representations of people with type 2 DM in relation to perceived family support suggests that the multidisciplinary team must recognize the sociocultural dimension of care. The interventions outlined should be directed to strengthen family support, so as to reduce the barriers in relation to self-care(5,10) related to established sociocultural beliefs and values, particularly regarding diet. The study of the representations of family support showed that the adults with DM not only presented different concepts regarding this support, but that these representations can sustain diverse attitudes, that range from, assuming a more passive and resigned attitude regarding the availability of help by relatives, to an active attitude in order to produce conditions conducive to the provision of such support within the family context. Depending on the type of social representation that prevails, the person with DM will be more vulnerable to negative feelings, such as sadness, hopelessness and rebellion that arise from living constantly with the requirements imposed by a rigorous treatment, which requires discipline, renunciation of certain pleasures and a good dose of personal sacrifice.

Family support, when perceived as present, is seen as a resource that brings relief, promoting well-being and improving quality of life. Its absence seems to interfere directly in the motivation to maintain the adherence to treatment behavior. Thus, this study demonstrated that the central nucleus of the social representation of family support is grounded in the desire to preserve an external source – the family – which stimulates the maintenance of health-seeking behavior. Therefore, behavior related to self-care may be strongly impregnated with representations of family support, which need to be adequately accepted and comprehended by the health team. Identifying these social representations demonstrates how the people with DM recreate scientific knowledge, spread by the mass media and transmitted by contact with the health professionals, combining it with popular knowledge, which is called the anchoring(12-13). Within the SRT framework, this phenomenon of anchoring allows people with DM to appropriate the experience of illness and treatment(11,20) through the elaboration of knowledge that is constructed and constantly reconstructed in the collective space.

Diabetes mellitus influences the various dimensions that constitute the quotidian of the affected individual, from their most trivial routine to the desire to continue living and to maintain their quality of life. The affected person lives with quotidian clashes between their own basic impulses, on one hand, and the imperative need to have control over their desires, resulting in difficulties to accept limits(18). For this reason, the desire to live and the assumed compromise in relation to the patient's own life are essential elements in the treatment of chronic diseases(11). Because it is a condition for which there is no cure and considering the necessity of the commitment to medicinal therapy, dietary planning and physical activity, DM requires, from the affected person, a renewed ability to cope throughout the entire life(3). The commitment to carefully follow the prescribed treatment or, conversely, the desire to interrupt treatment, even for a short period, is always present in the quotidian of people with DM, which requires a daily negotiation with their diseased part and a concomitant strengthening of their healthy part. In this context, the family emerges as one of the most important sources of support for maintaining the attitude of perseverance necessary for treatment adherence(1-2) and for preserving the spirit of struggle and maintaining an optimistic expectation regarding the future.

CONCLUSION

By identifying the social representations elaborated by the person with DM regarding family participation in treatment, three thematic categories were evidenced, which comprise the following central representations: family support is present in the quotidian of the person with diabetes mellitus; The family does not always support the person with diabetes mellitus in their needs, the person with diabetes mellitus assumes the responsibility for arousing the family support.

In relation to the category: *family support is present in the quotidian of the person with diabetes mellitus,* it was found that the participants identified positive aspects in the zeal that family members assume in relation to the treatment, however, they also indicated that family care can promote psychological suffering and the restriction of personal freedom and autonomy. Thus, when the family is included in the care, it must be clear that the social representations regarding the support of the family members in the treatment are not univocal, as they have complex and multifaceted, often ambiguous and even contradictory dimensions.

Regarding the category: *the family does not always support the person with diabetes mellitus in their needs,* the social representations encountered were shown to be polarized. Participants who feel the presence of family support evoked the benefits of it, translated as stimulating independence, respect for autonomy and the quotidian exercise of tolerance of the existing differences among people; it was also possible to apprehend another type of social representation related to the presence of family support as a generator of dependence on health care, characterizing an overprotective attitude that, ultimately, does not protect the person as it hinders their learning process. Those who perceive a lack of family support elaborate social representations based in feelings of abandonment, helplessness and difficulties of intrafamilial communication, making living with the disease an arduous, lonely and challenging task.

Concerning the category: *the person with diabetes mellitus assumes the responsibility for arousing the family support,* it was possible to apprehend two basic axes: dependency and autonomy. In the first movement, the person with DM has the expectation that it is from the family that the changes will occur. In the second movement it is the person with DM who is responsible to *make* the change happen within the family context. In the latter case, the patient is perceived as an agent of their own change and appropriates a place of potential and responsibility for their self-care in relation to treatment.

The health team, in implementing the DM education groups, must consider more than the health needs of the patients, because what they often seek is related to the social representation of family members about the treatment and not their real needs. If the patient internalizes the representations of the family members in relation to the treatment (e.g. the need to learn to control their dietary behavior at any cost), the team can work with an unreal demand, because in that case there still was not, on the part of the patient, the formation of an authentic con-science regarding their own needs. The professional may inadvertently reproduce a pattern of behavior of the family, for example, when they try to impose very strict dietary control rules or when they become complicit in the overprotective attitudes of the family members. This attitude can lead the patient to resist or transgress the proposed therapeutic regimen or even to abandon the treatment.

To understand the social representations of people with DM in relation to family support in the treatment and to explore their symbolic meanings favors the integrality of care, as it sensitizes the team, leading them to reflect on the sociocultural dimension of care. In this way, it is possible to integrate the family into the care, so that it can also constitute a treatment unit that adds quality to health, with less stress and discomfort for all.

One of the limitations of the study is that it contemplates only the point of view of people with DM and does not allow comparisons with the social representations of the families in relation to the treatment. It would also be important to know the characteristics of these families, their peculiarities of functioning and demands, from the perspective of the family members. Considering the family as a support network for the patient with DM, it is necessary to deepen the investigation and to know the type of support that the patient has in the domicile and in what way the availability of this support contributes to reinforce their self-care activities. Thus, further studies are recommended that can explore, more broadly, the investigated issue from the perspective of the patient-family dyad. Another aspect to be stressed is that the results presented reflect the characteristics of the group investigated and cannot be generalized to other contexts.

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