

Difficulties to Treatment Adherence according to the Perception of People Living with Type 2 Diabetes

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Abstract

Objective: Our aim was to identify the difficulties about treatment adherence as perceived by individuals suffering from type 2 diabetes mellitus who were being assisted in primary healthcare units in Brazil. **Method:** The semi structural interviews were carried out and all responses were analyzed according to the qualitative content analysis. **Results:** The final number ($n = 12$) of people with diabetes (PWD) interviewed was determined on the basis of data saturation. The difficulties were identified as poor relationships between PWD and healthcare professionals, insufficient information provided about diabetes, poor infrastructure and mismanagement in primary healthcare units, and the impact of the disease on quality of life. **Conclusions:** Although healthcare for PWD is guaranteed by federal legislation in Brazil, modifications to the system are required in order to improve the quality of the care provided. **Practice Implications :** the primary healthcare units could implement a few simple and feasible modifications such as: improving communication skills of healthcare professionals, improving communication and interaction between members of the medical team using readily available technology, implementing educational programs addressed to PWD and their families, putting into practice the home visits, stimulating healthcares to adopt a more concerned attitude towards the subjective needs of their patients.

1. Introduction

Diabetes mellitus (DM) is one of the four chronic diseases selected by the World Health Organization (WHO) for priority intervention since the number of people with diabetes (PWD) worldwide has surged from 108 to 422 million during the period 1980 and 2014. The global prevalence of DM, which has climbed from 4.7 to 8.5% during the 34-year period, is associated with changes in diet, lifestyle, mobility and ageing. Considering that the treatment of PWD represents a significant challenge for healthcare professionals, it is expected that the economic cost of DM will exert a substantial impact on public health systems over the next decade [1].

Type 2 Diabetes mellitus (T2DM) is largely preventable by adopting a healthy diet and participating in regular physical activities. Moreover, the risk of complications in T2DM can be averted by controlling blood pressure, hypercholesterolemia and hyperglycemia, and undergoing regular foot and eye examinations. While the diagnosis and treatment of DM are well defined scientifically, a large number of people remain without diagnosis. In addition, adherence treatment is affected by many factors, such as previous emotional experience, communication between patients and health care providers, medication regimens, social and cultural beliefs and financial issues [2]. The primary healthcare services could be effective in providing basic interventions, such as medication, health education, counseling and longitudinal follow-up, to people with chronic diseases and in need of lifelong treatment.

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In Brazil, the national healthcare system, known as *Sistema Unico de Saude* (SUS), was designed to be universal and care-comprehensive with an emphasis on primary healthcare. Since 1994, the Brazilian primary healthcare service has followed a family program known as *Programa de Saude da Familia* (PSF), which is carried out in primary healthcare units by teams of multidisciplinary professionals, normally comprising a general physician, a nurse, two nursing assistants and six community carers.

These teams are responsible for the healthcare of entire families, from newborn infants to elderly individuals, and their terms of reference include diagnosis and follow-up of PWD [3,4]. In this manner, the PSF model represents an integral and continuous approach that prioritizes treatment as well disease prevention. Although PSF is regulated by federal law, and should have been implemented throughout Brazil, some municipalities still adopt an older, non-preventive approach based on individual medical consultations and actions deriving there from. Considering that this scenario is not uncommon in developing countries, including Brazil, the aim of the present study was to identify the difficulties associated with treatment adherence as experienced by individuals suffering from T2DM who were being assisted in primary healthcare units.

2. Method

2.1 - Patients and procedures

The exploratory qualitative study was designed and potential participants were recruited from among patients with T2DM who had been hospitalized for an ambulatory care sensitive condition (ACSC) in a public hospital. All of them was users of the National Brazilian Public Health System. The ACSC are health condition that could be avoided with a timely and effective action of primary health care (PHC). A previous study on ACSC conducted by our research group in a medium-sized town in south-eastern Brazil [5]. Of the 2775 hospitalized patients interviewed in 2012, 96 were identified as suffering from T2DM. After 18 months of discharge we contacted the participants for a new study with objective was understanding what happened with them and what changes in their life after hospitalization. This study was divided in two parts: a medical approach and a quantitative study and a qualitative approach. However, 32 (33.3%) of these potential participants had died after hospitalization, 15 (15.6%) declined to participate in the present study, nine (9.4%) had moved away and two could not be traced after three attempts.

The inclusion criterion to participate of the qualitative study applied to the remaining 40 possible participants was the possession of normal cognitive and communication functions that would allow participants to respond to a questionnaire without assistance. In practice, 12 patients were interviewed since the final number was determined on the basis of data saturation ⁽⁶⁾. We used semi structured interview topic guide (Figure 1) [7] for data collection. The guide was development considering the literature and the focus was to understand how is to “living with diabetes” and how the health services gives support to them after the diagnosis.

A pilot study was performed prior to the interviews so that the experts could familiarize themselves with the questions and standardize their interview protocol. The interviews were conducted during November 2015 in domiciliary settings so that patients could freely express their opinions, preferences and experiences relating to the disease and the treatment offered by the primary healthcare units. All meetings were recorded, transcribed and validated by the same trained interviewer (JS). The analysis of data was conducted based in the recorded material by two experienced researchers in a independent way (DAG & CPG). Data were evaluated using the qualitative content analysis method [8]. According to this method we identified the exclusive categories that shared a commonality, that means, a group of content related to the same descriptive level of content. We also used the inductive approach described by Elo et al [9]. The data saturation was obtained when all the content would be classified into one of the categories created and none new ideas emerged from the interviewers [6]. The transcribed testimonials presented in this article were annotated as follows: subject number (S)/gender (M or F) followed by age.

Figure 1. The semistrutural interview topic guide.

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|---|--|
| 1 | ● Could you tell us why, when and where the diagnosis of diabetes mellitus was performed? |
| 2 | ● Did you already know about diabetes? What do you know and what would you like to know about the disease?
○ Includes meanings, beliefs and uncertainties about the disease and its treatment. |
| 3 | ● Could you tell us what changes have occurred in your life after diagnosis of diabetes and how this has affected you?
○ Includes changes in lifestyle, social network, diet and medication |
| 4 | ● Have you been able to adapt to the treatment?
○ Includes changes demanded by the treatment and difficulties associated with these changes. |
| 5 | ● How do you view your relationship with the health service? What is your evaluation of the conditions in the health unit to accompany a person with diabetes?
○ Includes relationship with health professionals and infrastructure of the health unit. |

Ethical approval of the project was granted by the Ethical Committee of the Federal University of São João del-Rei (N.258574). The purpose of the study was carefully explained to all participants, who then read and signed the document of informed consent.

1- Results

3.1 Sociodemographic Characteristics of the Participants

The sociodemographic characteristics of the PWD interviewed in the context of the study are presented in Table 1. Subjects were aged between 50 and 90 years and the majority were males with elementary school education, retired from work and living with a partner.

Table 1. Characteristics of participants distributed according to gender.

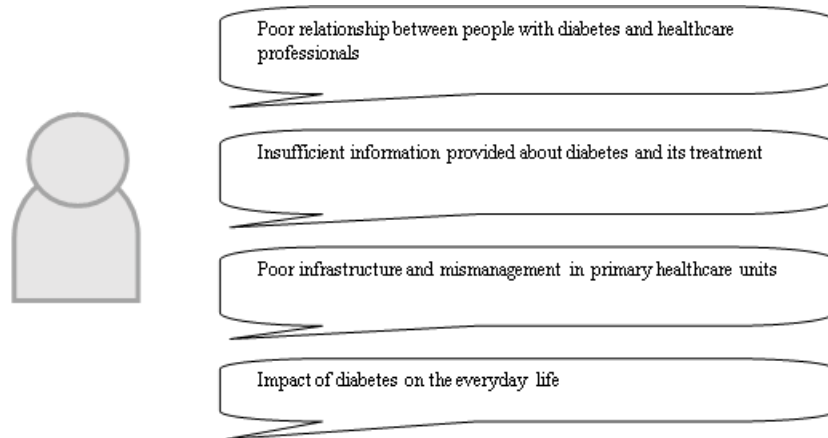
Variable	Male <i>n</i> (%)	Female <i>n</i> (%)	Total <i>n</i> (%)
Participants	8 (66.7)	4 (33.3)	12 (100)
Schooling			
None	1 (8.3)	1 (8.3)	2 (16.7)
Primary school	6 (50)	3 (25.0)	9 (75)
Secondary school	1 (8.3)	0	1 (8.3)
Occupation			
Housekeeper	0	2 (16.7)	2 (16.7)
Retired	5 (41.6)	2 (16.7)	7 (58.3)
Employed	1 (8.3)	0	1 (8.3)
Self-employed	2 (16.7)	0	2 (16.7)
Civil status			
Married/cohabiting	6 (50)	2 (16.7)	8 (66.7)
Widowed	2 (16.7)	1 (8.3)	3 (25)
Divorced	0	1 (8.3)	1 (8.3)

Most of the PWD had a history of late diagnosis, which had been performed either in a primary healthcare unit or during hospitalization because of a DM complication. The duration of DM varied between 3 and 40 years, and seven PWD (58.3%) had experienced complications that had led to lower limb amputation, chronic kidney failure or visual impairment. All participants mentioned the occurrence of comorbidities, such as arterial hypertension, high cholesterol and depression, and each reported the use of several medications to control glycemia or to treat other related conditions. Eight PWD (66.7%) were insulin-dependent.

3.2- Barreirs and difficulties Perceived by PWD

Analyzes of the testimonials of the PWD revealed the ‘diabetes experience’ as perceived by those who actually live with the disease. Participants tackled issues including what it is like to be diagnosed with and treated for T2DM. The four main barriers to treatment perceived by the PWD are illustrated in Fig. 2 and each is supported by transcripts from the interviews.

Figure 2. Barriers to treatment adherence as perceived by people with diabetes mellitus.



3.2.1-Poor Relationship between PWD and Healthcare Professionals

Many participants claimed that it was difficult to establish a good communication with the healthcare professionals, particularly with physicians. The majority of the PWD reported a lack of interest of medical staff in understanding their situation and that of their families and described contact as uncommitted. Some participants reported that healthcares showed little interest in their medical history and did not try to clarify their worries about the treatment. Any instructions/recommendations were given very quickly and superficially, making it difficult to establish a dialogue. Moreover, the PWD observed that there was no change in attitude when DM was aggravated; normally the physician prescribed the same medication as previously without reassessment of pressure or blood tests. Some PWD stated that the physician did not even make eye contact during the session as exemplified by the statements below.

“He barely looks at people's faces. He just writes a prescription. They do not look after us very well. It is not nice. The problem of a patient living with diabetes is very difficult here. (S2/M65)”

3.2.2-Insufficient Information Provided about Diabetes and its Treatment

All of the PWD presented low levels of awareness about DM and lack of orientation regarding the importance of following-up the evolution of the disease and the avoidance of complications.

“No, I am treated well, but this business about if I get advice and everything. I think it is missing more attention. (S10/M50)”

All participants revealed poor knowledge about dietary requirements. The majority of PWD stated that they had received recommendations regarding diet but were unable to recall these instructions with any confidence, thereby demonstrating a lack of understanding of the issues. Some participants explained that they understood DM as "sugar in the blood" but showed embarrassment when asked about the importance of diet in the control of blood sugar. Misunderstandings regarding this topic seem to be generalized among the PWD with many explaining that although information was provided it was not well understood.

“You should have ... [reference to guidance on diet] because you don't know what you can eat and what you cannot. And what can you drink? They do not say. They only prescribe medicines. (S3/M59)”

The PWD also expressed a lack of clarity regarding changes in basic body functions associated with health-illness processes. For example, the participants were not aware that intense sweating, dizziness, extreme thirst and difficulties in wound healing are signs and symptoms of DM. Many reported that there was nothing wrong with them in that they felt no symptoms either prior to or after diagnosis, demonstrating that DM is indeed a silent disease.

“... I discovered the disease because I worked for a doctor. I got weak in the body and drank a lot of water, around five liters per day or more. Then my boss came, and I said to him, "I think I am lazy or I don't know what is happening". The glucose was high, it was almost 900 already. (S6/M60)”

Some participants reported an inability to remember the recommendations issued by medical staff or to follow a routine. They stated that they used the medicines depending on convenience and in accordance with their own deliberations, without systematic criteria or follow-up. The explanations for such practices were side effects, constant changes in medication and intake of too many drugs a day.

“It is that sometimes, for example, when I feel well ... I don't keep taking the medicine, I don't go to the doctor because I am ok. I always tried to make appointments; they always made a note but never rang me back. So, that is to say if there was a fault, the fault rests with me. (S5/M52)”

Some PWD also reported difficulties with the application of insulin, as well as with the manipulation and conservation of the drug.

“Regarding insulin (silent) I think is difficult to apply, the diet I think is difficult. I eat anyway and that's it. (S2/M65)”

3.2.3- Poor Infrastructure and Mismanagement in Primary Healthcare Units

The participants reported the existence of a number of issues relating to infrastructure, work management and communication between the primary healthcare units and other sectors of the public health system. Most of the PWD were not satisfied with the quality of care provided by medical staff and reported the absence of home visits.

One of the most common criticisms was the lack of clarification and proper advice about DM either during consultations at the primary healthcare unit or in home visits, when they occurred.

“... because of the diabetes, they should give us more attention. I don't know, because they take too long, right? I think that diabetics should receive more help and more rapid solutions, but this does not happen. (S8/F68)”

Additional difficulties reported by the PWD included long distances from home to the primary healthcare unit, extended waiting times for initial or return medical appointments, and delays in referral to a specialist and in arranging laboratory tests. “To schedule an appointment with Dr. Z (cardiologist) takes years, do you know? It takes more than five or six months to get an appointment. It's only when we feel bad that we go to the emergency unit. (S10/M50)”

Other issues mentioned included the lack of medical equipment and materials at the primary healthcare units, especially blood glucose test strips, examination kits and medicines. According to the participants, glucose meters and test strips for self-monitoring were provided only to patients on insulin therapy, a situation that rendered it impractical for non insulin-dependent sufferers to monitor their own blood glucose levels.

“Materials ... they do not have enough materials to look after the diabetics! (S2/M65)” Because of the deficiencies of the public outpatient clinics, participants had to purchase medicines and self-monitoring materials themselves and pay for private physicians and laboratory tests, all of which exacerbated their domestic economic burden and their ability to adhere to treatment recommendations.

3.2.4- Impact of Diabetes on everyday life

All participants described how the process of the disease gave rise to serious impacts on their lives that were linked to the limitations imposed by T2DM. They expressed various reactions to their predicament including discouragement, sadness, anxiety, annoyance, resentment and depression.

“Because my legs hurt a lot...before diabetes I used to walk a lot, I was very active but now my legs hurt to walk up a hill. I have no appetite for getting up in the morning or going to town, it's over. I don't feel this keenness anymore. (S1/F52)”

Some participants found it difficult to cope with the consequences of the disease and the associated changes in life, especially in regard to the inefficiency and indifference of healthcare providers, delayed treatment and the infringement of their rights to a good health service.

2-Discussion

The quality of the relationship between PWD and medical staff is considered a key factor in adherence to treatment of the disease [10] . In Brazil, the SUS/PSF proposes the assignment of patients to primary healthcare units

according to area as a strategy to facilitate the longitudinal follow-up of users of the public health system, to strengthen links between patients and care providers, and to facilitate the interchange of information between the two.

Analyses of our interviews with the PWD corroborate previous studies suggesting that patients perceive their relationship with medical staff as hierarchical, and this represents an obstacle to the transfer of information, understanding of instructions and discussion about treatment [11,12].

Previous studies have emphasized that the lack of bonding between the parties involved make patients reluctant to discuss their self-care behavior either for fear of being judged or because of feelings of guilt and shame. Faced with difficulties of non-adherence, some medical staff adopt common parental behavior and apply pressure by threatening negative consequences, thereby generating even more anxiety in their patients [13,14].

Other reports have described the difficulty of medical professionals to establish relationships with PWD, particularly when patients have social and emotional needs. According to physicians, such issues are associated with lack of time, absence of psychological qualifications and paucity of alternative treatments. Moreover, DM-related comorbidities and the need for change in life style as part of the treatment make meaningful relationships with patients hard to establish [10,15].

Graffigna et al. (2014) [12] consider that a satisfactory patient relationship can only be achieved when healthcare professionals understand that sufferers give meaning to their illness and its management through a complex framework of cognitive, behavioral and emotional dimensions. Most physicians believe in the self-reliance, rational choice and personal responsibility of PWD as if all individuals respond in a standard manner taking into account evidence-based medicine. Moreover, healthcarers, including those working in the PSF, tend to follow a traditional biomedical model that is limited to understanding the biological mechanisms of DM and does not consider the role of interrelationships and the events of daily life care. The resulting frustration of physicians regarding the poor knowledge of the sufferer about their disease and its potential consequences leads to a paternalistic attitude that induces anxiety in the patient [16]. Since healthcare-patient relationship and non-adherence behavior are difficult issues, it is important to improve communication among team members to ensure that patients receive consistent information. Furthermore, a change in approach is required by focusing more on the needs of the patients rather than their strict observance of instructions and recommendations [12,13,16].

A number of suggestions have been put forward to overcome the barrier of poor relationships, and these include improving the communication skills of healthcare professionals [10,16], establishing trusting and non-judgmental communication with patients [14], increasing the number of home visits [15], upgrading the treatment and follow-up of PWD with multidisciplinary teams and regular communication among team members [11,15], improving contact time and supporting patients in learning self-care [17] and focusing on health education aimed at self-care [14,15].

The barriers associated with insufficient information about DM and its treatment need to be understood within specific contexts, taking into consideration the reality of the individuals involved in the dynamics of care and health promotion. Issues regarding healthcare-PWD relationships clearly influence information transfer, since it is possible to perceive in the testimonials of the interviewees that communication between the two parties is difficult. It seems that healthcare professionals are not prepared to deal with patients with poor schooling, low income and advanced age, suggesting that a more proactive attitude is required to improve communication. On the other hand, it was possible to observe that participants in our study were quite passive in relation to their situation.

Some participants claimed that they received no information regarding DM while others stated that they did not understand the information that they had been given. One explanation may be that the interviewees had not had the opportunity to learn about the anatomy of the human body, the functions of the various organs, and the chemistry of food metabolism, even though this basic knowledge is essential to the understanding of DM. In addition, poor self-perception of the body, low level of schooling and advanced age were contributing factors to late diagnosis whereby DM was only identified, in the majority of cases, at an emergency health unit following exacerbation of symptoms and/or development of comorbidities.

Explanations about DM and its treatment and dietary requirements offered by healthcare professionals involve scientific terminology that do not make sense to people with little education. Such individuals cannot correlate the symptoms with the disease and, consequently, cannot practice self-care. For example, we observed that some participants confused the main dietary restriction (i.e. intake of sugar) with the disease itself, which is an oversimplification of the problem and demonstrates a lack of understanding of the processes involved in food

metabolism. However, even when people understand the disease and its consequences, they cannot assimilate new habits because old customs are integrated in the family dynamics as well as in cultural preferences. Following interviews with 12 PWD from a Pakistani background who had received dietary education in Denmark, Hempler et al. (2015) [17] reported that the perceived barriers to the implementation of health food recommendations included the difficulty of applying the information received into everyday life, the lack of support from their social networks and the failure to include their taste preferences in the educational setting.

Regarding the repercussions of issues associated with poor infrastructure and mismanagement in primary healthcare units, as reported by the PWD in the present study, it is important to emphasize that these two aspects are essential prerequisites for the provision of quality healthcare. In this context, is adequate physical areas, well-trained human resources, availability of materials and equipment, an efficient information network, standardized procedures and financial and governmental support as necessary requirements for a satisfactory healthcare service [18].

Home visits are regarded as one of the priority activities of the primary healthcare professionals involved in PSF, since the purpose of the program is to monitor individuals with chronic conditions, such as DB, and mobility problems. However, only one participant in our study was registered in SUS/PSF and this patient never received home visits.

According to the testimonials, another difficulty perceived by the PWD was the lack of communication between members of the healthcare themselves and with other sectors of the SUS system. Such disorganization impacts negatively on the health of PWD since treatment compliance and adherence cannot be properly supervised when physicians are not kept informed about the evolution of their patients. Failure in the longitudinal follow-up of PWD leads to the exacerbation of DM symptoms.

In Brazil, comprehensive therapeutic care, including the free distribution of medicines, is guaranteed by federal legislation to all registered users of SUS. For those living with diabetes, blood glucose test strips, OADs and other supplies must be made available without restriction in the SUS network in order to promote disease control. However, the unavailability of medicines, test materials and equipment at some primary healthcare units, coupled with the economic difficulties encountered by some participants, were held responsible for poor adherence to treatment. The financial burden imposed by DM has been considered by some studies one important barrier to adherence to treatment and disease control [19].

As established in previous studies, DM is positively associated with depression and deterioration in the quality of life. Indeed, the risk of depression among PWD is two-fold higher than that of people without DM. Approximately one in three PWD present symptoms of depression and the risk is considerably greater among women. However, it is not possible to establish a causal relationship between DM and depression since these two conditions have a cyclic association in which aggravation of one produces direct and indirect effects on the other. Acceptance of the disease and the ability to cope with the changes that the illness imposes on daily life are determinant factors that correlate with depression, and this explains why PWD who receive better social support are less affected and more able to undertake self-care [20].

Despite the clinical relevance of the relationship between DM and depression, diagnosis of the latter in PWD is difficult because of overlapping symptoms and the absence of adequate training of healthcare professionals to evaluate mood changes. Furthermore, there is a myth that depression is a natural outcome of DM. It is, therefore, important to carry out mental health assessments of PWD with depressive complaints, particularly those who do not carry out proper metabolic control. Often physical limitations, difficulties of adapting to the disease and an inability to implement changes in lifestyle augment depression and generate frustration and feelings of impotence, such that sufferers gradually lose the motivation to seek help [20].

Some limitations of this study need to be pointed. First of all, the study included patients with complications of disease and it would overestimated the problems for the treatment. The study findings may not be applicable to other settings where health care services are better organized. Beside the limitations this study brings contributions about the difficulties perceived by PWD.

4.2 Conclusions

The PWD interviewed in the present study were characterized by poor schooling, low income and advanced age. Although healthcare to PWD is guaranteed by federal legislation and covered by SUS/PSF, significant changes are required to improve the quality of this care. Despite the current Brazilian financial constraints, we believe that the primary healthcare units could implement a few simple and feasible modifications such as: (i) augmenting the number

of families in the PSF program in the ascribed areas of the municipality as projected by law; (ii) improving communication skills of healthcare professionals to facilitate information transfer to underprivileged PWD; (iii) improving communication and interaction between members of the medical team, using readily available technology, in order to save time and increase the efficiency of working practices; (iv) implementing educational programs addressed to PWD and their families to allow them to understand the causes of the illness and its treatment, as well as the importance of self-care and self-management; (v) putting into practice the home visits as required by PSF to facilitate the follow-up of PWD, particularly those with physical disabilities, and to help them cope with the disease; and (vi) stimulating healthcares to adopt a more concerned attitude towards the subjective needs of their patients, rather than a paternalistic approach focused on medication, in order to build trust and prevent/minimize comorbidities such as depression.

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Declaration of Conflicting Interests

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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Ethics

Ethical approval of the project was granted by the Ethical Committee of the Federal University of São João del-Rei (N.258574). The purpose of the study was carefully explained to all participants, who then read and signed the document of informed consent.

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