

Validação do Patient Assessment of Chronic Illness Care (PACIC) em diabéticos brasileiros.

Validation of the Patient Assessment of Chronic Illness Care (PACIC) in brazilian diabetics.

Validación de la Evaluación del Paciente de Atención a Enfermedades Crónicas (PACIC) en diabéticos brasileños.

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RESUMO: Objetivo: validar o instrumento *Patient Assessment of Chronic Illness Care* (PACIC) em pacientes diabéticos no Brasil. **Métodos:** Trata-se de um estudo metodológico que incluiu 85 pacientes com diabetes tipo 2 no interior paulista. A análise fatorial utilizou-se o método com rotação ortogonal Varimax. Para a análise de correspondência utilizou-se o teste de qui-quadrado. A consistência interna foi verificada pelo alfa de Cronbach. **Resultados:** O instrumento apresentou alfa de Cronbach de 0,84, sendo que o terceiro domínio Estabelecimento de Metas/Adaptação apresentou o menor valor de alfa de Cronbach 0,78. Quanto à correspondência, o questionário separado por domínios, mostrou que as respostas aos itens sobre questionamento da opinião do paciente sobre o tratamento, receber uma cópia do tratamento, o profissional entrar em contato após a consulta e o encaminhamento ao profissional nutricionista foram avaliados como nunca realizados. Na análise fatorial houve a retenção de cinco fatores. **Conclusões:** A versão brasileira do

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PACIC é válida e reprodutível com diabéticos brasileiros e pode auxiliar na avaliação da qualidade da assistência de pessoas com condições crônicas.

PALAVRAS-CHAVE: Enfermagem; Enfermagem de atenção primária; Avaliação em enfermagem; Diabetes mellitus; Doença crônica

ABSTRACT: Objective: To validate the Instrument Patient Assessment of Chronic Illness Care (PACIC) in diabetic patients in Brazil. **Methods:** This is a methodological study that included 85 patients with type 2 diabetes in the interior of São Paulo. The factorial analysis was the Varimax orthogonal rotation method. For the correspondence analysis, it was used chi-square test. The internal consistency was verified by Cronbach's alpha. **Results:** The instrument presented Cronbach's alpha of 0.84, and the third Goal Setting / Adaptation domain presented the lowest alpha value of Cronbach 0.78. Regarding the correspondence, the questionnaire separated by domains, showed that the answers to the items about questioning the patient's opinion about the treatment, receiving a copy of the treatment, the professional getting in touch after the consultation and the referral to the professional nutritionist were evaluated as never performed. In the factorial analysis, five factors were retained. **Conclusions:** The Brazilian version of the PACIC is valid and reproducible with Brazilian diabetics and can help assess the quality of care of people with chronic conditions.

KEY WORDS: Nursing; Primary health care; Nursing assessment; Diabetes mellitus; Chronic diseases

INTRODUCTION

Chronic non-communicable diseases (CNCDs) are multifactorial diseases that develop over the course of life and are long-lasting. CNCDs are the result of several factors, social determinants and conditioning, as well as sharing individual risk factors such as smoking, harmful alcohol consumption, physical inactivity and unhealthy diet¹.

Therefore, a chronic condition can be considered with onset and slow evolution, presenting multiple causes that can vary with time and can lead the individual to present several symptoms and loss of functional capacity².

The socioeconomic impact of CNCDs is threatening the progress of the Millennium Development Goals, including poverty reduction, equity, economic stability and human security, and can act as a brake on the own economic development of nations due to premature mortality and conditions which disable people from working³.

The World Health Organization (WHO) estimates that annual deaths from this group of diseases account for 38 million, whose mortality rates are already much higher in low and middle income

countries. Of these deaths, the major cause is diseases of the circulatory system (17.5 million deaths or 46.2% of deaths due to CNCD), followed by neoplasms (8.2 million deaths or 21.7% of deaths from CNCD), chronic respiratory diseases (4 million deaths or 10.7% of deaths from CNCD) and diabetes (1.5 million deaths or 4% of deaths from CNCD)³.

In Brazil, approximately 72% of the deaths were attributed to chronic non-communicable diseases (CNCDs), 10% to infectious and parasitic diseases and 5% to maternal and child health disorders. This process was due to the rapid demographic transition, generating an age pyramid with a greater relative weight for adults and the elderly⁴.

CNCDs have several risk factors that are classified as modifiable or non-modifiable. Among the modifiable factors, are hypertension, large amounts of alcohol intake, smoking, sedentarism, stress, obesity and dyslipidemia. Among the non-modifiable factors, age, heredity, gender and race are highlighted³.

Among the four main CNCDs, we have Diabetes *mellitus* (DM) as a chronic disease that has its increasing prevalence due to population growth, aging and lifestyle modifications, lack of physical activity and poor nutrition, which lead to an increase in the incidence of obesity and sedentary lifestyle⁵.

Diabetes mellitus, is defined as a heterogeneous group of metabolic disorders characterized by hyperglycemia resulting from defects in insulin secretion, insulin action and/or both. Chronic hyperglycemia is related to long-term damage, dysfunction, and complications in various organs, such as eyes, kidneys, nerves, heart and blood vessels⁶.

A descriptive study carried out in Brazil, in the year 2014 that aimed to describe the mortality due to acute complications of diabetes *mellitus* in Brazil according to age, sex, regions and federative units from 2006 to 2010. It showed that mortality due to acute complications in Brazil was of 2.45/100.000 inhabitants corresponding to 6.8% and 22.9% of deaths due to diabetes as the basic cause. And it concludes that the mortality rate due to acute complications of diabetes was high, especially in the North and Northeast, considering its potential avoidability; this indicator was important for the evaluation of preventive actions and regional inequities in health⁷.

In Brazil, the Ministry of Health has built a Plan to Combat Chronic Non-communicable Diseases 2011-2022, with the definition of goals for the control of CNCDs and prevention of the main risk factors. The Plan focuses on the four main groups of chronic diseases (circulatory, cancer, chronic respiratory and diabetes) and its most common risk factors (smoking, alcohol, physical inactivity, unhealthy nutrition and obesity) and has as its main goal the reduction of premature mortality rates (30 to 69 years old) by 2% per year till 2022¹.

Another need is to evaluate the quality of care received by the patient with one or more chronic

conditions. In this direction, it is highlighted the Chronic Care Model that is based on six elements, the health care system constituted by the organization of health care; design of the service delivery system; support for decisions; clinical information systems and self-care supported, and community, such, as resources and community policies².

From this the *Patient Assessment Chronic Illness Care* (PACIC) instrument was developed, in the United States, emphasizing the elements of the Chronic Care Model⁸.

In this way, PACIC has been used in several countries in patients with DM. A study conducted in the United States shows that PACIC is a dynamic and patient-centered instrument⁹.

An Australian study showed that PACIC is a valid and reproducible instrument for the evaluation of the quality of treatment care in DM. This study recommended the application of PACIC as an instrument to evaluate the quality of care¹⁰. Finally, a study carried out in the Netherlands concluded that PACIC is a reliable instrument to measure DM treatment care¹¹.

Due to its reliability and ease of reproduction of the PACIC instrument our research group carried out the methodological study of cultural adaptation to the Portuguese language of Brazil and Portugal following the stages recommended by the literature: Translation, Committee of Experts, Back-Translation, Pre-Test and Cognitive Interview. The results showed that the instrument was considered very good by the study population, with easy-to-understand questions and categories of responses not difficult to be used¹². And the study resulted in a PACIC instrument culturally adapted and comprehensible for Brazil and Portugal. However, the need to proceed with the evaluation of the psychometric properties for the validation study of the instrument adapted in both cultural contexts has remained. Thus, it is intended in this study, to perform the factorial and correspondence analysis to validate the PACIC instrument in patients with DM in Brazil. Such need is justified by the importance of evaluating the quality of care for patients with DM and the scarcity of instruments that allow the follow-up and support offered by the health team.

METHOD

It is a methodological study, which included 85 patients continuously in a basic health unit of the interior of São Paulo. Inclusion criteria were: minimum age of 18 years; both sexes, have the medical diagnosis of type 2 diabetes mellitus; and have registration in the information system of a primary care health institution for insulin acquisition. Data collection was performed from March to August 2013, after acceptance by the participants and the signing of the free and informed consent form, an interview for the application of PACIC was initiated.

The PACIC consists of 20 items, with five domains: Active Participation of the Patient in Treatment; Model of Care System/Model for Practice; Establishment of Goals/Adaptation; Problem Solving/Context e; Follow-up/Coordination⁸.

The first domain: Active Participation of the Patient in Treatment ($\alpha = 0.82$) is composed of items 1, 2 and 3, which describe actions that request the starting point of the person with chronic disease and their involvement in decision making⁸.

The second domain, Model of Care System/Model for Practice ($\alpha = 0.77$), is composed of items 4, 5 and 6, which describe actions that organize care and provide information to people to improve their understanding of care⁸.

The third, Establishment of Goals/Adaptation ($\alpha = 0.84$), is composed by items 7, 8, 9, 10 and 11, which evaluate the acquisition of information for the specific establishment of collaborative goals⁸.

The fourth, Problem Solving/Context ($\alpha = 0.90$), is composed of items 12, 13, 14 and 15, which describe potential barriers that must be considered in the social and cultural environment of the person with chronic disease in the elaboration of plans of treatment. Finally, the fifth domain, Follow-up/Coordination ($\alpha = 0.86$), is composed of items 16, 17, 18, 19 and 20, which evaluate the promotion of continuity of care⁸.

The ranking of items is of the Likert type, of 1 (never) and 5 (always) and the total value of the PACIC score is obtained by the simple arithmetic mean of the 20 items of the instrument, being that the highest value corresponds to a reference of higher quality of care received by people with chronic conditions in the last six months. The original instrument presented reliability of 0.93 by Cronbach's alpha varying for each domain from 0.77 to 0.90⁸.

Data collection was performed at a Health unit in the city of Ribeirão Preto, SP, where the subjects received an invitation by telephone. Those who agreed to participate in the study signed the Free and Informed Consent Term, the one with difficulty to sign the name, or illiterate, the fingerprint was requested. All received a copy of the Term.

Statistical analysis was performed using the *Microsoft Office Excel 2007* tool and the SAS® 9.0 *software*. The results were expressed through descriptive statistics, factorial analysis and correspondence analysis.

The study was approved by the Research Ethics Committee of the University of São Paulo at Ribeirão Preto College of Nursing, under Protocol n° 324.098. The development of the study met national and international standards of research ethics involving human subjects.

RESULTS

Of the 85 DM patients enrolled in the study, the mean age was 63.6 years (SD = 9.61). There was a predominance of 49 (56.5%) women and 37 (43.5%) men, most of whom were married or

widowed. The mean educational level was 6.5 years of study (SD = 4.1). Regarding the occupation, 54.2% were retired and 22.8%, were housewives. The average income was R\$ 971,41 (SD = 857,54), indicating a low socioeconomic level. The predominant religion was Catholic (59.0%), followed by Evangelical (27.7%).

Regarding internal consistency, the instrument presented Cronbach's alpha of 0.84, and the third Establishment of Goals/Adaptation domain presented the lowest alpha value of Cronbach 0.78 (Table 1).

Table 1. PACIC domains according to the average, standard deviation and Cronbach's Alpha, Ribeirão Preto, 2014

PACIC domains	Average	Standard deviation	Cronbach's Alpha
Active Participation of the Patient in Treatment	2,25	1,26	0,85
Model of Care System / Model for Practice	3,40	1,22	0,80
Establishment of Goals / Adaptation	2,63	1,16	0,78
Problem Solving / Context	2,97	1,39	0,79
Follow-up / Coordination	2,48	1,06	0,82

The exploratory factorial analysis performed on the 20 items of the PACIC, with orthogonal rotation (varimax), revealed the retention of five factors that obeyed the Kaiser criterion of eigenvalue greater than 1.

Factor 1 (composed of items 4, 6, 7, 8, 9, 11 and 15) is what represents never; factor 2 (items 12, 13, 14 and 18), almost never; factor 3 (items 1 and 2), sometimes; the factor 4 (item 10, 16 and 17), almost always and factor 5 (items 3, 5, 19 and 20), always. These results are presented in Table 2 and each factor corresponds to the instrument responses, being factor 1 (Never), factor 2 (Almost never), factor 3 (Sometimes), factor 4 (Almost always) and factor 5 (Always). These results are presented in Table 2.

The points captioned in Figure 1 correspond to the items of the PACIC and the most frequent responses reported by patients according to the response items in each domain of the instrument. Each domain is represented by a color. The dark blue color corresponds to Domain 1; green, to Domain 2; red, Domain 3; light blue, Domain 4 and, pink, Domain 5 (Figure 1).

The numbers in black from 1 to 5 within the graph correspond to each of the PACIC response items. In the quadrant number 1, questions numbers 1,2, 9, 16 and 18 were the most frequent responses to the Likert scale response item, that corresponds to Never.

In the quadrant number 2, questions numbers 3, 7, 10, 11, 13, 14, 15, 17 and 20 were those in which the frequency was highest in the response item that corresponds to Almost never. In the quadrant of number 3, there were no questions corresponding to the item of the scale denominated Sometimes.

Figure 1. Correspondence chart for the questionnaire separated by the domains

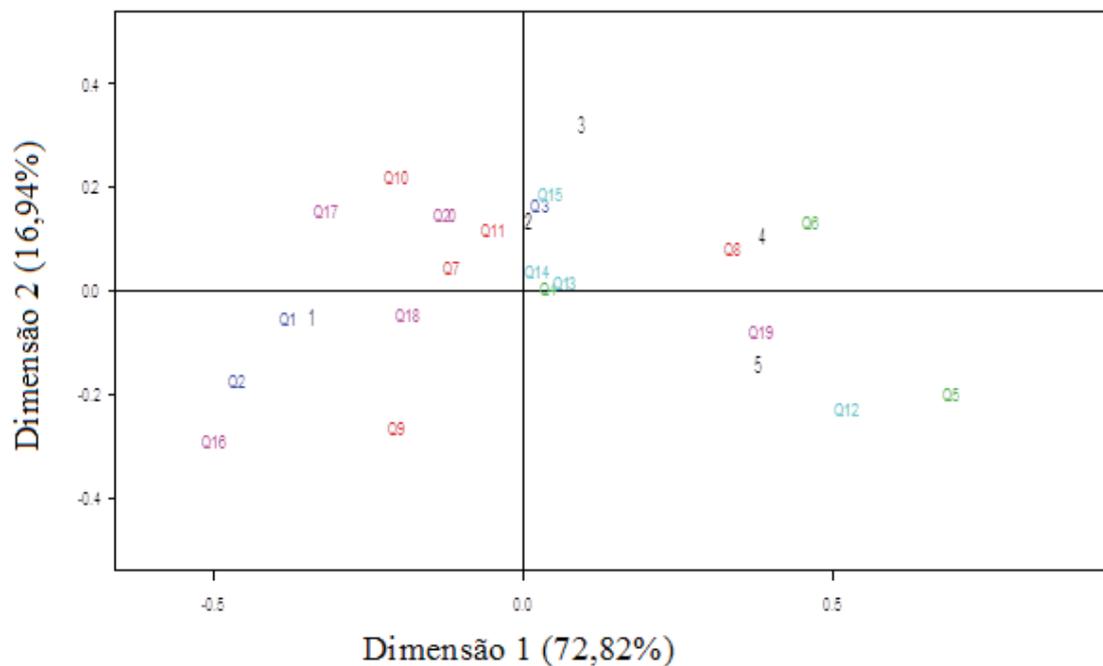


Table 2. Factor analysis matrix for the *Patient Assessment of Chronic Illness Care*, Ribeirão Preto, 2014

Items	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
1 – They asked my opinion, when the treatment proposal was made.	0,25	-0,06	0,71	0,12	0,18
2 – They gave treatment options so I could think about it..	0,18	0,11	0,84	-0,08	0,08
3 – They asked me if I have any problems with the medicines I take or with their effects.	0,00	0,12	0,43	0,11	0,56
4 – They gave me a written list of things I should do to improve or worsen my health.	0,70	0,15	0,11	0,21	0,01
5 – I was satisfied with the organization of care.	0,42	0,10	0,00	-0,07	0,69
6 – They showed that the way I looked after myself could improve or make my illness worse.	0,72	0,30	0,02	0,00	0,19
7 – They asked me what my goals were in treating the disease.	0,48	-0,04	0,32	0,08	0,40

Items	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
8 – They helped me to set specific goals to improve my eating habits or physical activity.	0,65	0,24	0,29	-0,06	0,26
9 – They gave me a copy of my treatment proposal.	0,44	-0,12	0,28	0,38	0,23
10 – They encouraged me to participate in specific groups or classes to learn how to live with my chronic illness.	0,48	0,15	-0,24	0,65	0,04
11 – They asked me, directly or through a questionnaire, about my health habits.	0,60	0,16	0,25	0,32	-0,02
12 – I was sure that my doctor or nurse respected my values and customs when they recommended treatments for me.	0,24	0,82	-0,04	0,13	0,18
13 – They helped me to make a treatment proposal that I could put into practice in my daily life.	0,22	0,70	0,39	0,21	0,11
14 – They helped me to plan my disease well in advance, even in difficult times.	0,40	0,65	0,39	0,15	0,12
15 – They asked how my chronic disease affects my life.	0,48	0,22	0,41	0,25	0,25
16 – They contacted me, after a consultation, to check on how my disease was being controlled.	-0,04	0,09	0,31	0,70	0,02
17 – They encouraged me to participate in programs in the community that could help me.	0,23	0,10	-0,10	0,78	0,19
18 – I was referred to a nutritionist and/or other health professional.	0,05	0,74	-0,11	0,00	0,14
19 – They talked about how consultations with other specialists, such as an ophthalmologist or surgeon helped in my treatment.	0,11	0,28	0,08	0,18	0,66
20 – They asked how my consultations with other doctors were going.	0,00	0,35	0,23	0,42	0,54

In the quadrant number 4, questions 6 and 8 were the most frequent in relation to the corresponding response item Almost always. And finally, in the quadrant number 5, questions of numbers 5, 12 and 19 were the most frequent in relation to the corresponding response item.

Finally, Figure 1 represents each item of the instrument and which response was most frequently cited by the participants of the research. The two dimensions (dimension 1 in axis 1 and dimension 2 in axis 2) refer to the two largest eigenvalues adjusted by the correspondence analysis, where together they presented 89.76% of the total variability of the data.

DISCUSSION

Regarding the sociodemographic data of the participants, the predominance of the female sex (56.5%) is emphasized, showing that women attend and seek more health care when compared to men. A study with patients with type 2 diabetes showed similar characteristics with a greater number of female participants¹³.

In relation to age, the average was 63.6 years, which makes it difficult to perform self-care in diabetes, another factor that is related to the difficulties of carrying out all the proposed treatment is the low average schooling. These data are similar to those of another study where the mean age of the participants was 62.4 years and the average schooling was 4.3 years of study¹³. Schooling is directly related to self-care, that is, the lower the schooling the lower the self-care.

The internal consistency analysis, using the Cronbach's alpha, was 0.84, lower than its original revised version ($\alpha = 0.93$), nonetheless, showing good results. In relation to each domain, Cronbach's alpha was superior to the original article in two domains, with Active Participation of the Patient in Treatment ($\alpha = 0.85$, original version $\alpha = 0.82$) and Model of Care System/Model of the practice ($\alpha = 0.80$, original version $\alpha = 0.77$). The alpha values show the reliability of the instrument, since they are higher than 0.70⁸.

Regarding the correspondence to the questionnaire, separately, for the domains, it was obtained that items 1, 2, 9, 16 and 18 had more responses issued by patients with DM such as **never**. When analyzing these answers it can be considered that there are gaps in the care of patients with DM, pointing out the difficulties in providing a continuous and systematic form of diabetes education in the health services.

The answers given in relation to items 1 and 2 of the **active participation of the patient in treatment** domain show the lack of autonomy of the patient. The answers point to the lack of recognition of the autonomy of the patient by the health professionals in considering the decisions of the patient regarding the treatment. This difficulty to fully achieve the autonomy in the treatment thus improving the quality of life of the patient with DM demonstrates the complexity of taking care of the patient with DM being necessary to combine different technologies to strengthen the actions of Health Promotion in the health services of Brazil, besides family support¹⁴.

Another study showed that the assistance to the user with DM is fragmented, since the professionals that compose the health team work according to the biomedical model, and the records of health actions were predominantly performed by physicians and nursing auxiliaries, there is also lack of integration and articulation of the work process¹⁵.

Another important factor of the active participation of the patient in treatment is that when he/she participates self-care is no longer passive and this personal behavior can influence health, however not in isolation, but in conjunction with environmental, social, economic, heritable and related to health services¹⁶.

The World Health Organization recommends education for self-care as a way to prevent and treat chronic diseases, since it facilitates the involvement of the person in their treatment and produces greater adherence to the therapeutic scheme, minimizing complications and disabilities associated with chronic problems¹⁶.

The **establishment of Goals/Adaptation** domain, in item 9, refers to the patient who received a copy of the proposed treatment and has difficulties remembering the guidelines received during the consultation, mainly, in the elderly with DM2 due to cognitive functionality. Several factors influence the non-adherence to the proposed treatment such as, for example, the side effect and complexity of the therapeutic regimen, inability to remember treatment and received orientations, as well as sociodemographic factors such as level of schooling and monthly income¹⁷.

In the study population, the main reason for non-adherence to treatment may be the high age of the patients, a study carried out with patients over 40 years old showed low adherence or non-adherence to the treatment of diabetes, when considering the changes recommended in the lifestyle. This may constitute a challenge for the health professional in patient education¹⁸.

Regarding item 16, of the **follow-up/coordination** domain, this corresponds to the follow-up contact in view of the complexity of performing diabetes education in person. Thus, the use of new information and communication technologies is associated with the improvement of glycemic control in patients with diabetes¹⁹. An innovative strategy that has been studied is the use of the telephone, and was used in patients with DM in a study of intervention called Telephone Support for Monitoring in Diabetes *mellitus* (ATEMDIMEL). This study offered 16 weekly telephone calls, over four months, to elderly patients with DM in a health unity. The calls were divided into four central themes: general definitions of DM; use of medications such as Insulin, oral antidiabetic agents and special situations; food planning and physical activity. This study showed that patients who had telephone support had a reduction in glycated hemoglobin and fasting blood glucose levels²⁰.

The technology can be used to supplement health care by providing educational and motivational support. Education can be provided by using technology that allows patients to learn new practices and routines related to the management of self-care in diabetes. The technology can support daily diabetes self-management activities, including blood glucose monitoring, exercises, healthy nutrition, medication, complication monitoring, and problem-solving. And among the resources

used are cell phone, internet, messages, among others²¹.

Finally, item 18 of the **follow-up/coordination** domain refers to referral to the nutritionist and/or other non-medical health professional. In this domain it was noticed the difficulty of working in a multiprofessional team in diabetes education. By contrast, most patients with DM referred in item 19 of the **follow-up/coordination** domain the referral to other specialists, such as ophthalmologist or surgeon.

The difficulty of multiprofessional teamwork impairs the integrality of health care, therefore a multidisciplinary approach is necessary to treat the patient with DM improving the quality of life and reducing the complications of the disease²².

It is necessary to learn from the experiences of professionals from different disciplines that can trigger a process of internal cooperation and the availability of knowledge to diminish technical and theoretical differences that favor the effective results regarding the quality of care for the patient with DM²³.

Despite the difficulties mentioned most patients with DM report satisfaction with the organization of the care provided (item 5) of the **model domain of the care system/model for the practice**. This perception of the patient, which uses the Unified Health System, was similar to those found in another study, where after a telephone educational process the patients who received the intervention showed a slight improvement in their glycemic control showing the relationship between satisfaction and adherence to treatment²⁴.

Instruments that allow evaluation of the quality of care provided, such as the PACIC can be an important tool for diabetes education, favoring multiprofessional teamwork and, consequently, the education of the patient and the quality of the care offered.

CONCLUSION

The *Patient Assessment Chronic Illness Care* is an important tool for assessing the quality of care about elements of the Chronic Care Model, from the perspective of the person with one or more chronic conditions.

The Brazilian version of the instrument showed satisfactory Cronbach's alpha reliability of 0.84 and its confirmatory analysis showed that the instrument is valuable in assessing the quality of care provided to patients with DM type 2, and it can also be used for other chronic conditions.

With regard to its applicability, the instrument is easy to interpret and needs little time to be filled, being a good tool to evaluate the quality of diabetes education and how this education is being carried out by health professionals.

Therefore, the use of PACIC must be diffused, since knowing the perception of patients with DM on the quality of care received is fundamental to improve the planning of the care provided.

Also should be used in the health service the Assessment of Chronic Illness Care (ACIC) which presents the perception of the health professional in order to complement the information on the care provided to the patient with a chronic condition, improving the health care of the patient.

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