

Diabetes care: comparison of patients' and healthcare professionals' assessment using the PACIC instrument

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Running head: Evaluation of diabetes care

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Abstract

(i) Rationale and objective: The Patient Assessment of Chronic Illness Care (PACIC) is a validated instrument to measure the extent to which care received by patients is congruent with the Chronic Care Model. We aimed at comparing diabetes care, as reported by patients with diabetes and by healthcare professionals (HCPs), using this instrument.

(ii) Methods: Two independent samples, patients with diabetes (n=395) and HCPs (including primary care physicians, primary care nurses, diabetologists and diabetes specialized nurses; n=287), responded to the 20-item PACIC and the six 5As model questions. The PACIC-5A (questions scored on a five-point scale, 1=never to 5=always) was adapted for HCPs (modified-PACIC-5A). In both samples, means and standard deviations for each question as well as proportions of responses to each response modality were computed, and an overall score was calculated over the 20-item PACIC.

(iii) Results: Patients' and HCPs' overall scores were 2.6 (SD 0.9) and 3.6 (SD 0.5) respectively, with HCP reporting higher scores for all questions except one. Patients' education and self-management, referral/follow-up and participation in community programs were rated as insufficient by patients and HCPs.

(iv) Conclusion: HCPs, particularly diabetes specialists, tended to report better PACIC scores than patients, suggesting that care was not reported similarly when received or provided. To decrease evaluation differences, a closer collaboration between patients and HCPs, as well as the implementation of community-based interventions considering patients' perspectives and including, among others, patients' education and self-management, may be necessary.

(1) Introduction

The burden of chronic diseases is increasing rapidly worldwide. Since persons with chronic diseases are the most frequent users of healthcare, a shift towards a chronic rather than an acute healthcare system is required. The Chronic Care Model was created within this context. It is an evidence-based framework developed by Wagner *et al.* [1] to improve outcomes of patients with chronic diseases. While aiming at creating beneficial interactions between informed, actively participating patients and prepared proactive practice teams, it identifies six key elements: organization of health care; community resources and policies; self-management support; delivery system design; decision support and clinical information systems [2]. To assess this evidence-based model, two questionnaires were developed: the Assessment of Chronic Illness Care (ACIC) [3], which enables teams of HCPs to assess care provided to chronic patients at the organizational level, and the Patient Assessment of Chronic Illness Care (PACIC) [4], which measures patients' evaluation of their chronic illness care. While a version including the six questions of the 5A model (ask, advise, agree, assist, arrange; PACIC-5A) was developed by Glasgow in 2005 [5], Carryer *et al.* more recently created the modified-PACIC [6] in order to allow individual HCPs to report the care they were providing to their own patients. Despite the fact that the structure of the PACIC remains debated [7-8], it is being used increasingly to evaluate care of patients with chronic conditions [9-13].

Diabetes, a frequent chronic disease with an increasing prevalence, is often the target of integrated care initiatives [14-20]. The PACIC and PACIC-5A have often been used as instruments for the evaluation of these initiatives [21-23]. Within such studies, the PACIC and PACIC-5A are more frequently used than the ACIC, which doesn't address the HCPs' opinion on the quality improvement of integrated care interventions. Despite the interest to get both patients' and HCPs' points of view on diabetes care, the use of the PACIC and the ACIC/modified-PACIC instruments in a same study, and, by extension, the evaluation of chronic care as reported by patients

and by HCPs, from a same region, at the same period of time and using the same questionnaire, has rarely been carried out [6]. This study aimed at filling this knowledge gap. Its objective was therefore to compare diabetes care, as reported by patients with diabetes and by HCPs caring for diabetic patients, using the PACIC-5A and the modified PACIC-5A, respectively. As a secondary exploratory objective, we aimed at comparing the evaluation of diabetes care between primary care and specialized providers.

(2) Methods

(2.1) Setting, participants and data collection

This study took place in the canton of Vaud, one of the 26 Swiss cantons, which has approximately 700'000 inhabitants (10% of the Swiss population) and is located in the French speaking part of Switzerland. Two independent samples of participants were considered: first, the patients' sample, which consisted of non-institutionalized adult patients with diabetes participating in the 2013 follow-up of the CoDiab-VD cohort [24]; second, the HCPs' sample which consisted of HCPs practicing in the same canton, and included primary care physicians, diabetologists, primary care nurses and diabetes specialized nurses. These different HCPs were contacted during the same period of time to participate in an online survey assessing inter-professional collaboration and HCPs' practices in the field of diabetes care [25].

(2.2) Measures

(2.2.1) PACIC and PACIC-5A questionnaires

Whereas the PACIC instrument [4], developed by Wagner *et al.* in English, is a 20-item questionnaire measuring patients' evaluation of their own chronic disease care, the PACIC-5A instrument [5] includes six additional questions in line with the 5As model [26]. Each question is answered on a 5-point response scale (1=never,

2=generally not, 3=sometimes, 4=most of the time, 5=always), and scores for each question and for the overall score (20 PACIC items) as well as proportions of responses to each response modality can be computed. In this study, we used a French version of the PACIC-5A [24].

(2.2.2) Modified-PACIC-5A questionnaire

Bound to the PACIC-5A, a modified version allowing individual HCPs to report the care they are providing to their own patients was adapted by Carryer *et al.* in 2010 [6]. For example, the question “Over the past 6 months, when I received care for my chronic condition, I was asked to talk about my goals in caring for my illness” was adjusted to “When caring for a person with a chronic condition, how often do you ask them to talk about their own goals in caring for themselves”. Similarly to the PACIC-5A, each question is answered on a 5-point response scale (1=never, 2=generally not, 3=sometimes, 4=most of the time, 5=always), and scores for each question and for the overall score (20 modified PACIC items) as well as proportions of responses to each response modality can be computed.

(2.2.3) Other variables

Other patients' and HCPs' variables were considered in this study. For the patients' sample, the following characteristics were collected: mean age; gender; education level (primary, secondary, tertiary); smoking status; Body Mass Index (normal and underweight (BMI <25 [kg/m²]), overweight (BMI 25-29.9 [kg/m²]), obesity (BMI ≥30 [kg/m²])) and number of co-morbidities (0, 1, 2, ≥3). Diabetes characteristics included: type of diabetes (type 1, type 2, other); duration of diabetes (≤10 years, >10 years) and treatment (oral antidiabetic drugs, insulin, oral antidiabetic drugs + insulin, other). For the HCPs' sample, both physicians' and nurses' subgroups included three categories: primary care physicians, diabetologists and unspecified, and primary care

nurses, diabetes specialized nurses and unspecified, respectively. For each subgroup, mean age was established.

(2.3) Data analysis

First, we performed descriptive analyses to characterize the patients' and HCPs' samples. Then, in both samples, means and standard deviations as well as proportions of responses to each response modality were calculated for each question of the PACIC-5A, and the overall score was computed over the 20-item PACIC [7]. Comparisons of results across the two samples were performed for each question and for the overall score. Exploratory subgroup analyses (including means for the four HCPs' categories) were performed additionally. Finally, the proportion of questions with a mean score between 1 and <2; 2 and <3; 3 and <4; 4 and ≤5 were calculated for the patients' and HCPs' samples, as well as for the four HCPs' categories.

(3) Results

(3.1) Participants' characteristics

Participants' characteristics are presented in Table 1. Mean age of the 395 patients with diabetes was 65.5 years (SD 10.8), 61.3% were male, 84.8% reported type 2 diabetes and 45.1% had a duration of diabetes >10 years; also, whereas 16.3% of patients were current smokers, 46.7% had a BMI above 30 [kg/m²]. The HCPs' sample (n=287) comprised 34.5% physicians with a mean age of 51.7 years (SD 9.0) and 65.5% nurses with a mean age of 43.7 years (SD 10.1). Among HCPs, 8.7% reported to be diabetes specialists (diabetologist and diabetes specialized nurse).

Table 1

(3.2) PACIC-5A and modified PACIC-5A scores

Table 2 presents the PACIC-5A and the modified PACIC-5A results. Patients' (PT) and HCPs' overall scores were 2.6 (SD 0.9) and 3.6 (SD 0.5), respectively. In the patients' sample, a score lower than 2 was found for 23% of the questions (Figure 1); the other questions had scores between 2.1 and 3.9 and no question had a score ≥ 4 . In the HCPs' sample, scores varied between 2.7 and 4.2, and 88% of the questions had scores >3 . The comparison of patients' and HCPs' scores showed that HCPs reported higher scores for all questions except one – "satisfied how care was organized" – for which the mean scores were identical in the two samples (PT sample: 3.9 (SD 1.2); HCP sample: 3.8 (SD 0.6)). When HCPs reported high scores (>4), patients also reported higher scores (>3), except for two questions – "given a copy of the treatment plan" (PT sample: 2.1 (SD 1.4); HCP sample: 4.2 (SD 0.9)) and "asked questions, either directly or on a survey, about health habits" (PT sample: 2.7 (SD 1.4); HCP sample 4.2 (SD 0.7)). For a few questions, low scores by patients were mirrored by low scores by HCPs – "given a written list of things to do to improve health" (PT sample: 1.9 (SD 1.2); HCP sample: 2.7 (SD 1.0)); "encouraged to attend programs in the community that could help" (PT sample: 1.7 (SD 1.1); HCP sample: 2.9 (SD 1.0)); "given a book or monitoring log in which to record the progress made" (PT sample: 2.2 (SD 1.5); HCP sample: 2.8 (SD 1.3)).

While the score differences between patients and HCPs varied between 1 and 2 for most questions (>1 SD), one question – "given a copy of the treatment plan" – showed a difference higher than 2 (>2 SD) and a few others presented differences <1 . Question 5 – "satisfied how care was organized" – showed identical scores across the two samples.

The distribution of results of the five response modalities (never, generally not, sometimes, most of the time, always), presented in Table 1, permits a quick side-to-side comparison between patients and HCPs. Whereas a high proportion of patients responded that they "never" had received the care mentioned in the questions,

similar responses were rarely obtained from HCPs: HCPs often responded that the care was “most of the time” or “always” provided.

The PACIC-5A results, presented by HCPs’ categories (Table 3), showed that scores from diabetes specialized nurses and diabetologists were overall higher than those from primary care physicians and primary care nurses for most of the questions. In fact, primary care providers had scores between 2.5 and 4.4 and diabetologists as well as diabetes specialized nurses presented scores ranging from 3.3 to 4.4 and 3.5 to 4.8, respectively, except for two questions with scores <3 - “given a written list of things to do to improve health” and “given a book or monitoring log in which to record the progress made” (only diabetes specialized nurses). These two questions had low scores among both patients and HCPs. In addition, diabetes specialized nurses and diabetologists reported scores >4 for 81% and 58% of the questions, respectively, compared to only 27% for primary care physicians and 23% for primary care nurses (Figure 1).

Table 3

(4) Discussion

This study used the PACIC-5A and the modified PACIC-5A to compare diabetes care as reported by participants in two independent samples from the same region and during the same period: patients with diabetes and HCPs caring for diabetic patients. Results showed that HCPs tended to assess provided diabetes care as being more congruent with the recommendations of the Chronic Care Model than what was reported by patients. In addition, results from subgroups of HCPs suggested that diabetes specialists (diabetologists and diabetes specialized nurses) reported results closer to the Chronic Care Model than non-specialists (primary care physicians and primary care nurses).

The patients’ overall score (computed over the 20-item PACIC) is in agreement with the CoDiabVD cohort’s baseline results [7, 27] and with those reported in several

other studies. In fact, Aung *et al.*, who conducted a population-based study in Australia, found a score of 2.4 at baseline [28-31]. In Denmark, Kusnetsov *et al.* also found a similar overall score (2.4) but, contrary to our study, participants were recruited in primary care practices, yet mean age and sex of participants were similar to our sample [32]. Finally, Ku and Kegels obtained a somewhat higher PACIC score (2.8) in a study that took place in the Philippines, in which patients were recruited in primary care practices and the sample was mainly composed of female participants [21]. In contrast to these studies, a number of others reached higher PACIC scores. The first examples stem from two studies carried out in Switzerland by Frei *et al.* Whereas one study comprised patients from non-managed care (score 3.2) and managed care organizations (score 3.4) somewhat older than our study participants [33], the second study recruited patients in single or group practices (score 3.1) of overall similar age and gender [34]. These latter results are in fact close to those from studies conducted in the United States: three in primary care practices [5, 35-36] and one in an ambulatory care clinic [37], with scores ranging from 3.0 to 3.2. Similarly, two surveys conducted in the Netherlands obtained scores of 3.3 and 3.2 [38-39], and Ku and Kegels, in their 2015 study, obtained a score of 3.2 [40]. Finally, the highest PACIC scores were obtained from a sample from Taiwan, mainly composed of female patients, with a score of 4.2 for the patients enrolled in a pay-for-performance program [41].

The HCPs' overall score we observed was lower than Carryer's first Australian exploratory study using the modified PACIC (score 4.0) [6]. In that latter study however, only primary care nurses participated. If we compare Carryers' results to those of our sub-sample of primary care nurses, it is interesting to note that, overall, our results nevertheless remained inferior. Yet, the overall score obtained in Carryer's study was consistent with the scores reported by the specialized providers of our sample. A recent study, conducted by Doolan-Noble *et al.*, used the modified PACIC to compare the perception of care between primary care providers, with

primary care nurses reporting better scores than primary care physicians [42]. Such differences were not found in our study, primary care physicians and nurses assessing provided care similarly.

The overall score difference between our two samples (1 standard deviation = 1 point, on a five-point scale) suggests that HCPs tended to report provided diabetes care as more congruent with the Chronic Care Model than what was reported by patients. Three main hypotheses could explain this rating difference. First, a difference of understanding – by patients and HCPs – of the care aspects to be assessed, second, an “over”-evaluation by HCPs that could represent social desirability bias [43], and third an “under”-evaluation by patients that could be the cause of recall bias [43]. The first hypothesis we will discuss is the difference of understanding, between patients and HCPs, of the content of the items. In fact, the reasoning and interpretation behind each question may be different because of divergent perspectives on the quality of diabetes care [44], with different care aspects not having the same meaning for patients and HCPs. In addition, the perception of the disease also diverges. Whereas patients emphasize their personal and social contexts, medical significance predominates for HCPs [45]. The latter divergences of perception of the disease also represent a barrier to patient-provider collaboration and communication [46]. The second hypothesis, an “over”-evaluation of care provided by HCPs, relates to the fact that HCPs’ data is self-reported, and therefore subject to social desirability bias [47]. In fact, it is possible that HCPs, implicitly or explicitly, report better level of care than what is truly provided, which could be the underlying cause of some score differences between our two samples of participants. The last hypothesis, an “under”-evaluation by patients, relates to the possible presence of recall bias. Whereas the elements targeted in the questions may often be easy to remember for HCPs, they could represent one conversational element among many others for patients and consequently not being remembered by patients [48].

The single questions analyses of both patients' and HCPs' samples showed that the worst results related to patients' education and self-management, patients' participation in community programs and referral/follow-up, as well as family and community participation in patients' care. These negatively rated aspects are those important to target in future field projects, especially since it is known that patients' education and self-management are relevant for diabetic patients' care and that targeting education and self-management has been shown to be effective [17-18, 49-52]. In Switzerland, within the development and implementation phases of the "Programme cantonal Diabète", which aims at reducing the incidence of diabetes and improving care provided to diabetic patients [53-55], a qualitative study highlighted insufficient patients' self-management and collaboration between patients and HCPs [56]. The quantitative results of our study confirm these gaps previously identified by patients and HCPs. They still remain underdeveloped in Switzerland and need to be considered in future initiatives targeting integrated and coordinated care for patients with diabetes. This is particularly appropriate since integrated care programs, which emphasize patient's self-management and education, have been shown to have a positive impact on chronic illness care [19-20, 57].

The secondary objective of this study was to compare the scores across HCPs' categories. Although specialists and primary care providers work in collaboration towards the improvement of outcomes of diabetic patients, scores from specialized nurses and diabetologists were overall higher than those from primary care physicians and nurses for most questions. Divergences in care provided, between primary care and specialized providers, have already been shown in various situations. For example, treatment plans for chronic diseases such as asthma, heart failure or diabetes, have been shown to be more aggressive, when implemented by specialized vs. primary care providers [58-60]. Also, since types of patients cared for by specialized and primary care providers differ (specialized providers often having patients with more comorbidities and diabetic complications [61]), specialists perform

additional interventions, which would be reflected in their responses. Interestingly, primary care providers' scores were closer to patients' scores. Since primary care providers see their patients within their global health context, they better understand their needs and develop partnerships [62-64]. Being more aware of patients' healthcare needs, their point of view about the care they are providing is closer to the patients' perception of care. The primary care providers' perspective therefore matches patients' understanding better. This contrasts with care provided by specialists, which may be more focused on biomedical aspects of diabetes care. Specialized providers have a better knowledge of the last evidence-based recommendations and apply guidelines more thoroughly [65]. From their point of view, they report doing more, but it isn't necessarily seen and perceived as such by patients.

The results of this study need to be interpreted taking into account the following two limitations. First, both study samples were independent and patients' and HCPs' data were stemming from two different surveys. Despite the fact that both samples' data came from the same canton and year, it remains difficult to appropriately interpret a direct comparison of results. However, participants of the two samples are considered to represent patients with diabetes residing in [54-55], and HCPs practising in, the canton of Vaud [25]. This allows a first interesting insight on the topic. Second, the number of eligible specialists and the proportionate number of specialists having participated in the study (diabetologists n=8, diabetes specialized nurses n=17) was low compared to the number of primary care physicians (n=78) and primary care nurses (n=143). Statistical subgroups comparisons may be weakened by those small numbers.

This study showed that patients and HCPs didn't report care received or provided in a similar way. Whether these results correspond to a difference of understanding between patients and HCPs, an "over"-evaluation by HCPs, an "under"-evaluation by patients or a combination of those phenomena remains unknown. Further research is

needed, both to better understand differences between patients and HCPs and to perform analyses of results from pairs of patients and HCPs, in order to confirm our findings. In the meantime, to decrease evaluation differences, a closer collaboration between patients and HCPs, as well as the implementation of community-based interventions considering patients' perspectives and including, among others, patients' education and self-management, may be necessary.

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(7) Figure legends

Figure 1: Proportion of questions with a mean score between 1 and <2; 2 and <3; 3 and <4; 4 and ≤ 5 for the patients' sample and the healthcare professionals' sample, including for the four subgroups of healthcare professionals.

(8) Tables

| Patients (n=395) | |
|--|------------|
| Mean age | 65.5 years |
| Men | 61.3% |
| Education level (n=385) | |
| Primary | 17.4% |
| Secondary | 56.1% |
| Tertiary | 26.5% |
| Active smoking (n=380) | 16.3% |
| Body Mass Index [kg/m ²] (n=366) | |
| Normal and underweight (BMI < 25) | 19.4% |
| Overweight (BMI 25-29.9) | 33.9% |
| Obesity (BMI ≥ 30) | 46.7% |
| Number of co-morbidities (n=384) | |
| 0 | 18.2% |
| 1 | 30.0% |
| 2 | 27.9% |
| ≥ 3 | 24.0% |
| Type of diabetes (n=395) | |
| Type 1 | 11.9% |
| Type 2 | 84.8% |
| Other | 3.3% |
| Duration of diabetes (n=390) | |
| ≤ 10 years | 54.9% |
| > 10 years | 45.1% |
| Treatment (n=386) | |
| Oral antidiabetic drugs | 45.6% |
| Insulin | 20.2% |
| Oral antidiabetic drugs + insulin | 22.0% |
| Other | 12.2% |

| Healthcare professionals (n=287) | |
|---|------------|
| Physicians (n) | 99 |
| Primary care physicians | 78 |
| Diabetologists | 8 |
| Unspecified | 13 |
| Mean age | 51.7 years |
| Nurses (n) | 188 |
| Primary care nurses | 143 |
| Specialized nurses | 17 |
| Unspecified | 28 |
| Mean age | 43.7 years |

Table 1. Patients' and healthcare professionals' characteristics

| | Mean (SD) of PT sample | Mean (SD) of HCP sample | Score difference | Distribution of results of the PT sample | Distribution of results of the HCP sample |
|---|------------------------------|-------------------------------|---------------------|---|--|
| Overall score | 2.6 (0.9) | 3.6 (0.5) | 1 | | |
| Per question | | | | ■ Never ■ Generally not ■ Sometimes ■ Most of the time ■ Always | |
| 1. Asked for ideas when treatment plan made | 3.0 (1.5) | 3.9 (0.1) | 0.9 | | |
| 2. Given choices about treatment to think about | 2.4 (1.4) | 3.4 (1.1) | 1 | | |
| 3. Asked to talk about any problems with medicines or their effect | 3.1 (1.5) | 4.1 (0.8) | 1 | | |
| 4. Given a written list of things to do to improve health | 1.9 (1.2) | 2.7 (1.0) | 0.8 | | |
| 5. Satisfied how care was organized | 3.9 (1.2) | 3.8 (0.6) | - 0.1 | | |
| 6. Shown how taking care influenced the condition | 3.5 (1.3) | 4.2 (0.7) | 0.7 | | |
| 7. Asked to talk about goals in caring for the condition | 2.7 (1.4) | 3.6 (0.8) | 0.9 | | |
| 8. Helped to set specific goals to improve eating or exercise | 2.6 (1.3) | 3.7 (0.9) | 1.1 | | |
| 9. Given a copy of the treatment plan | 2.1 (1.4) | 4.2 (0.9) | 2.1 | | |
| 10. Encouraged to go to a specific group or class to help coping with the chronic condition | 1.8 (1.2) | 3.0 (1.0) | 1.2 | | |
| 11. Asked questions, either directly or on a survey, about health habits | 2.7 (1.4) | 4.2 (0.7) | 1.5 | | |
| 12. Thought about values, beliefs, and traditions when recommending treatments | 3.7 (1.3) | 4.0 (0.9) | 0.3 | | |
| 13. Helped to make a treatment plan for daily life | 2.5 (1.5) | 3.9 (1.0) | 1.4 | | |
| 14. Helped to plan ahead to take care of the condition even in hard times. | 2.5 (1.5) | 3.8 (0.8) | 1.3 | | |








| | | | | |
|---|-----------|-----------|-----|--|
| 15. Asked how the chronic condition affects life | 2.6 (1.4) | 3.6 (0.8) | 1 |  |
| 16. Contacted after a visit to see how things were going | 1.9 (1.2) | 3.0 (1.1) | 1.1 |  |
| 17. Encouraged to attend programs in the community that could help | 1.7 (1.1) | 2.9 (1.0) | 1.2 |  |
| 18. Referred to a dietitian, health educator, or counselor | 1.9 (1.3) | 3.6 (0.8) | 1.7 |  |
| 19. Told how visits with other types of doctors, like an eye doctor or other specialist, helped the treatment | 3.1 (1.5) | 3.6 (0.9) | 0.5 |  |
| 20. Asked how visits with other doctors were going | 2.5 (1.5) | 3.6 (1.0) | 1.1 |  |
| 21. Asked what to discuss about the illness at that visit | 2.1 (1.4) | 3.1 (1.0) | 1 |  |
| 22. Asked how work, family, or social situation related to taking care of the illness | 2.2 (1.4) | 3.4 (0.9) | 1.2 |  |
| 23. Helped to make plans for how to get support from friends, family or community | 1.7 (1.2) | 3.2 (0.9) | 1.5 |  |
| 24. Told how things done to take care of the illness (e.g., exercise) were important for health | 3.3 (1.4) | 4.2 (0.7) | 0.9 |  |
| 25. Set a goal with the team about what to do to manage the condition | 2.6 (1.5) | 3.7 (0.9) | 1.1 |  |
| 26. Given a book or monitoring log in which to record the progress made | 2.2 (1.5) | 2.8 (1.3) | 0.6 |  |

Table 2. Mean (SD) PACIC overall score and scores of the 20 PACIC + 6 5As items for patients and healthcare professionals, and the distribution of results of the five response modalities

PACIC-5A: Patient Assessment of Chronic Illness Care (items 1 to 20) and 5As model (ask, advise, agree, assist, and arrange; items 21 to 26), 5-point scale (1=never, 2=generally not, 3=sometimes, 4=most of the time, 5=always). PT = patient, HCP = healthcare professional, SD = standard deviation

| Healthcare professionals' means | | | | |
|---|--------------------------------|----------------------------|-----------------------|------------------------------------|
| Questions | Primary care physicians | Primary care nurses | Diabetologists | Diabetes specialized nurses |
| Overall score | 3.6 | 3.5 | 4.0 | 4.2 |
| Per question | | | | |
| 1. Asked for ideas when treatment plan made | 4.1 | 3.6 | 4.4 | 4.5 |
| 2. Given choices about treatment to think about | 3.9 | 3.0 | 4.4 | 4.1 |
| 3. Asked to talk about any problems with medicines or their effect | 4.2 | 4.0 | 4.3 | 4.6 |
| 4. Given a written list of things to do to improve health | 2.6 | 2.7 | 2.8 | 2.9 |
| 5. Satisfied how care was organized | 3.7 | 3.9 | 3.6 | 4.0 |
| 6. Shown how taking care influenced the condition | 4.1 | 4.1 | 4.4 | 4.8 |
| 7. Asked to talk about goals in caring for the condition | 3.5 | 3.5 | 4.0 | 4.5 |
| 8. Helped to set specific goals to improve eating or exercise | 3.7 | 3.5 | 4.3 | 4.4 |
| 9. Given a copy of the treatment plan | 3.9 | 4.4 | 3.6 | 4.2 |
| 10. Encouraged to go to a specific group or class to help coping with the chronic condition | 3.2 | 2.7 | 3.8 | 3.9 |
| 11. Asked questions, either directly or on a survey, about health habits | 4.2 | 4.1 | 4.4 | 4.7 |
| 12. Thought about values, beliefs, and traditions when recommending treatments | 4.0 | 4.0 | 4.1 | 4.6 |
| 13. Helped to make a treatment plan for daily life | 4.0 | 3.7 | 4.4 | 4.6 |
| 14. Helped to plan ahead to take care of the condition even in hard times. | 3.5 | 3.9 | 3.8 | 4.5 |
| 15. Asked how the chronic condition affects life | 3.3 | 3.6 | 4.4 | 4.2 |
| 16. Contacted after a visit to see how things were going | 2.5 | 3.2 | 3.3 | 3.5 |
| 17. Encouraged to attend programs in the community that could help | 3.0 | 2.6 | 3.5 | 4.0 |
| 18. Referred to a dietitian, health educator, or counselor | 3.6 | 3.5 | 4.0 | 4.1 |
| 19. Told how visits with other types of doctors, like an eye doctor or other specialist, helped the treatment | 3.7 | 3.4 | 4.1 | 4.1 |
| 20. Asked how visits with other doctors were going | 3.6 | 3.5 | 4.4 | 3.8 |
| 21. Asked what to discuss about the illness at that visit | 3.0 | 3.0 | 3.8 | 4.3 |
| 22. Asked how work, family, or social situation related to taking care of the illness | 3.3 | 3.3 | 3.8 | 4.4 |
| 23. Helped to make plans for how to get support from friends, family or community | 2.9 | 3.3 | 3.4 | 4.1 |
| 24. Told how things done to take care of the illness (e.g., exercise) were important for health | 4.2 | 4.1 | 4.4 | 4.6 |
| 25. Set a goal with the team about what to do to manage the condition | 3.7 | 3.6 | 4.4 | 4.5 |
| 26. Given a book or monitoring log in which to record the progress made | 2.9 | 2.6 | 3.6 | 2.6 |

Table 3. Mean modified PACIC-5A scores by subgroup of healthcare professional

1=never, 2=generally not, 3=sometimes, 4=most of the time, 5=always

(9) Figures

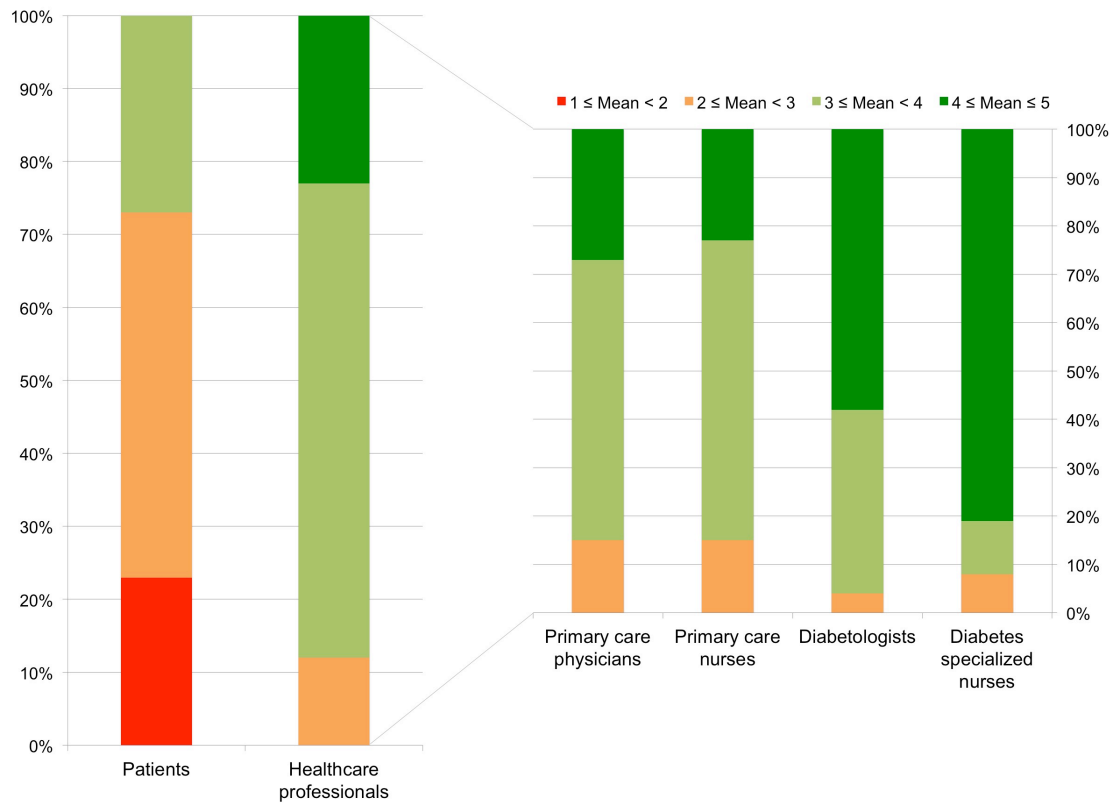


Figure 1. Proportion of questions with a mean score between 1 and <2; 2 and <3; 3 and <4; 4 and ≤5 for the patients' sample and the healthcare professionals' sample, including for the four subgroups of healthcare professionals.

1=never, 2=generally not, 3=sometimes, 4=most of the time, 5=always

| Patients | | Healthcare professionals |
|-----------------|--|---|
| n° | PACIC-5A items | Modified PACIC-5A items |
| | <i>Over the past 6 months, when receiving medical care for my chronic condition, I was</i> | <i>When caring for a person with a chronic condition, how often do you</i> |
| 1 | Asked for my ideas when we made a treatment plan. | Ask for their ideas when making a treatment plan? |
| 2 | Given choices about treatment to think about. | Give them choices to think about regarding treatment? |
| 3 | Asked to talk about any problems with my medicines or their effects. | Ask them to talk about any problems with their medicines and their effects? |
| 4 | Given a written list of things I should do to improve my health. | Provide a written list of things they should do to improve their health? |
| 5 | Satisfied that my care was well organized. | Feel satisfied that you are doing a good job in organizing their care? |
| 6 | Shown how what I did to take care of my illness influenced my condition. | Show them how what they do to take care of themselves influences their condition? |
| 7 | Asked to talk about my goals in caring for my illness. | Ask them to talk about their own goals in caring for themselves? |
| 8 | Helped to set specific goals to improve my eating or exercise. | Help them to set specific goals in caring for themselves? |
| 9 | Given a copy of my treatment plan. | Give them a copy of their treatment plan? |
| 10 | Encouraged to go to a specific group or class to help me cope with my chronic illness. | Encourage them to attend a specific group or class to help them cope with their illness? |
| 11 | Asked questions, either directly or on a survey, about my health habits. | Ask questions, either directly or in a survey, about their health habits? |
| 12 | Sure that my doctor or nurse thought about my values and my traditions when they recommended treatments to me. | Consider their values and their traditions when recommending treatments? |
| 13 | Helped to make a treatment plan that I could do in my daily life. | Help them to make a treatment plan that they can carry out in their daily life? |
| 14 | Helped to plan ahead so I could take care of my illness even in hard times. | Help them to plan ahead so that they can take care of themselves even in hard times? |
| 15 | Asked how my chronic illness affects my life. | Ask them how their chronic illness affects their life? |
| 16 | Contacted after a visit to see how things were going. | Contact them after a visit to see how things are going? |
| 17 | Encouraged to attend programs in the community that could help me. | Encourage them to attend programs in the community that could be helpful? |
| 18 | Referred to a dietitian, health educator, or counselor. | Provide referrals to other health professionals? |
| 19 | Told how my visits with other types of doctors, like the eye doctor or surgeon, helped my treatment. | Tell them how visits with other health professionals help with their treatment? |
| 20 | Asked how my visits with other doctors were going. | Ask about how appointments with other health professionals are going? |
| 21 | Asked what I would like to discuss about my illness at that visit. | Ask them what they would like to discuss about their illness at that visit? |
| 22 | Asked how my work, family, or social situation related to taking care of my illness. | Ask them how their work, family, or social situation related to taking care of their illness? |
| 23 | Helped to make plans for how to get support from my friends, family or community. | Help them to make plans for how to get support from friends, family or community? |
| 24 | Told how important the things I do to take care of my illness (e.g., exercise) were for my health. | Tell them how important the things they do to take care of their illness (e.g., exercise) are for their health? |
| 25 | Set a goal together with my team for what I could do to manage my condition. | Set a goal together with their team for what they could do to manage their condition? |
| 26 | Given a book or monitoring log in which to record the progress I am making. | Give them a book or monitoring log in which to record the progress they are making? |

Appendix 1: PACIC-5A (patients) and modified PACIC-5A (healthcare professionals) items