

Original Research

Measuring the specific care management experience of patients with type 2 diabetes mellitus in the Amazon region of Brazil

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Abstract

Introduction: The present study aimed to determine whether there is an association between individual characteristics, including sociodemographic, clinical, behavioral, and functional performance variables, and the Patient Assessment of Chronic Illness Therapy (PACIC) score in the primary care setting in remote municipalities of the Brazilian Amazon.

Methods: The study was conducted between October 2020 and December 2022 in 10 rural cities in the Brazilian state of Amazonas and involved 965 participants.

Results and discussion: A generalized linear model was used to verify the association between the investigated variables. Sociodemographic, clinical, and behavioral variables were associated with PACIC scores. The evaluation of the instrument's domains demonstrated that, in addition to these variables, participants' functional performance variables were associated with their perceived level of type 2 diabetes mellitus management.

Conclusion: The study found that sociodemographic, clinical, and behavioral variables were linked to the total PACIC score.

Keywords

Brazil, chronic disease, diagnosis of health situation, primary health care, quality of health care, self-care, type 2 diabetes mellitus.

Introduction

Chronic non-communicable diseases pose a significant threat to human health due to their high potential for causing death and disability¹. Among these diseases, diabetes mellitus is particularly concerning due to its rapidly increasing incidence and substantial impact on global public health²⁻⁴. In 2021, the prevalence of diabetes in adults aged 20–79 years reached 10.5% (536.6 million people)². Projections suggest this figure will rise to 12.2% (783.2 million people) by 2045^{2,5}. Type 2 diabetes is the most common form, accounting for 90–95% of cases^{2,6}. Effective management of type 2 diabetes and other chronic conditions requires a proactive, integrated, continuous healthcare system focused on the patient⁷. However, the current system tends to prioritize acute exacerbations of these conditions and operates in a fragmented, episodic manner^{7,8}. This approach has led to negative consequences, including an increased burden on health systems and economic strain⁹. This issue is particularly pressing in low- and middle-income countries, like Brazil, where the capacity of health services to manage chronic conditions is even more limited⁹⁻¹².

The Chronic Conditions Care Model appears to be a promising strategy for implementation in Brazil¹³. Based on the principles of the Chronic Care Model, the Chronic Conditions Care Model seeks to rethink and redesign care by adopting new strategies for patients in health services^{13,14}. Its goal is to broaden the scope of care and foster dialog between informed, active patients and well-prepared, proactive health teams¹⁴. Implementing this model can enhance institutional capacity to manage chronic conditions, defined as the ability and effectiveness of health institutions to provide adequate care and services to patients^{13,14}. Evaluating this capacity provides objective data that can guide service improvements^{15,16}.

The Patient Assessment of Chronic Illness Care (PACIC) is an instrument designed to measure the perceived level of chronic illness management. It considers the service user's perspective and can be used across various levels of health care, including primary health care, which is crucial in managing patients with chronic conditions¹⁵⁻¹⁸. In diabetes, higher PACIC scores are associated with improved glycemic control markers, self-management activities, physical activity, and reduced distress^{19,20}. Actions of primary healthcare providers involve regular and systematic monitoring of chronic diseases, aiming to control and prevent complications while providing adequate support to patients²¹⁻²³. However, certain regions like Amazonas, Brazil's largest state by area, face unique geographic challenges that hinder these efforts^{24,25}. Remote municipalities face barriers such as limited access, a shortage of health services, and a shortage of medical professionals, which directly affect the health of the population^{26,27}. An integrative review revealed that few studies in Brazil have examined the care provided by health institutions for chronic conditions from the service user's perspective^{16,28-30}. In the northern region, no studies have been identified that address this topic.

The present study aimed to determine whether there is an association between individual characteristics, including sociodemographic, clinical, behavioral, and functional performance variables, and the PACIC score in the primary care setting in remote municipalities of the Brazilian Amazon.

Methods

Study design

This cross-sectional quantitative study is part of the Health in Primary Care for the Amazonas Population project³¹. Conducted between October 2020 and December 2022, the study covered 10 cities in the remote municipalities of Amazonas: Alvarães, Coari, Iranduba, Itacoatiara, Itapiranga, Manacapuru, Novo Airão,

Presidente Figueiredo, Rio Preto da Eva, and Silves (Fig1). Amazonas, with 62 cities, faces unique geographical and socioeconomic challenges that hinder the development of primary healthcare initiatives^{25,32}. Over half the population resides in Manaus, the state capital. The state has one of the lowest road

network percentages in Brazil, due to both inadequate public management and the prevalence of rivers, which facilitate river navigation but limit road travel. Most cities rely on slow river transport, hindering regional development and complicating the provision of adequate healthcare support^{25,26,33}.

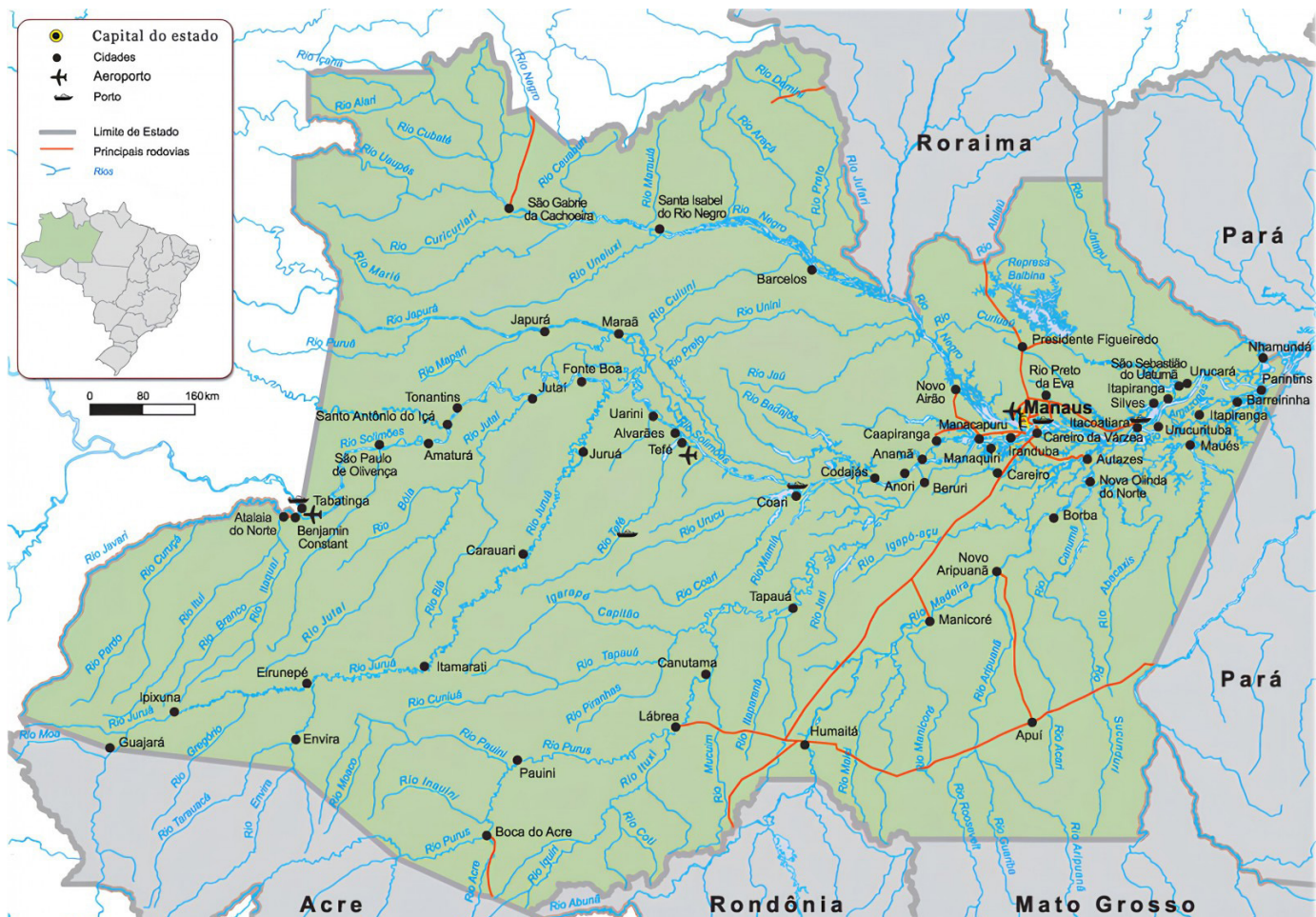


Figure 1: The state of Amazonas and its cities, Brazil³⁴.

Participants and sampling technique

Participants in this study were patients diagnosed with type 2 diabetes who had been registered with a primary healthcare provider for at least 6 months. Exclusion criteria included patients who refused to participate or had communication disorders that hindered participation. The estimated number of type 2 diabetes patients required for the research was based on a diabetes prevalence of 5.2%³⁵. Using G*Power software v3.1 (Heinrich-Heine-Universität Düsseldorf; <https://www.psychologie.hhu.de/arbeitsgruppen/allgemeine-psychologie-und-arbeitspsychologie/gpower>), a sample size of 955 participants was estimated³¹. Participants were randomly selected from the primary healthcare provider's registration lists.

Data collection instruments

Dependent variable

The dependent variable was the perceived level of type 2 diabetes management (measured by the PACIC). These scores were analyzed across the five PACIC domains and the instrument's total score. The study utilized the PACIC questionnaire, validated for use in Brazil, to collect data^{16,36}. Additional information on participants, including sociodemographic, clinical, behavioral, and functional performance variables, was also gathered. The PACIC consists of 20 questions divided into five domains, with responses on a 5-point Likert scale: (1) never, (2) rarely, (3) sometimes, (5) always.

To calculate the total PACIC score, responses are summed and divided by 20. Each domain score is calculated by averaging the responses within that domain^{8,15}. The domains provide insights into the care offered to patients with chronic conditions, reflecting essential elements of health care (Fig2).

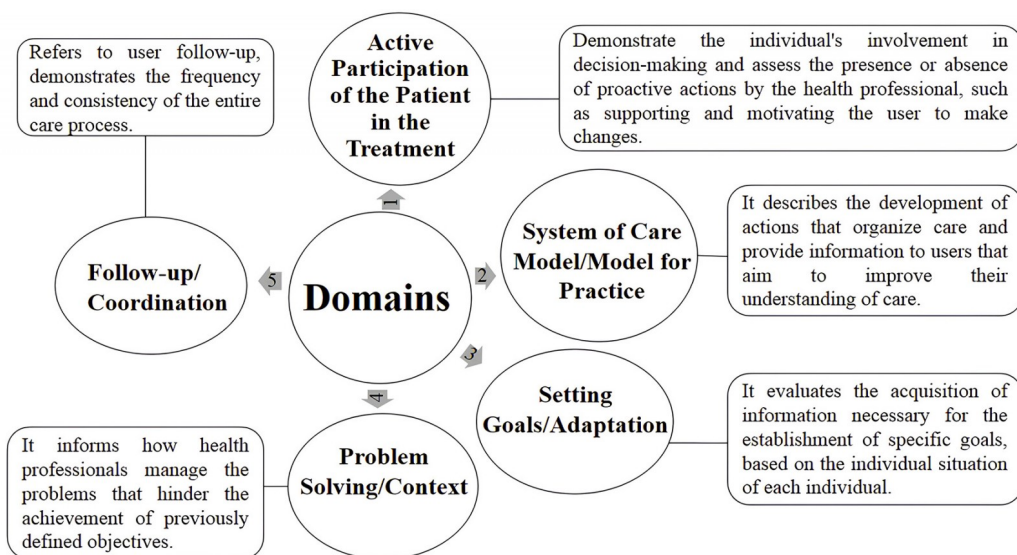


Figure 2: Description of Patient Assessment of Chronic Illness Therapy domains and their inherent aspects.

The PACIC domains are:

1. active participation of the patient in the treatment (questions 1–3)
2. system of care model/model for practice (questions 4–6)
3. goal-setting/adaptation (questions 7–11)
4. problem-solving/context (questions 12–15)
5. follow-up/coordination (questions 16–20).

Higher scores represent better ratings^{8,15}.

Independent variables

The independent variables were organized into four blocks: sociodemographic, clinical, behavioral, and functional performance. Sociodemographic variables were gender (female/male), age (years), race/ethnicity (yellow, white, indigenous, brown, black), marital status (single, married/common-law marriage, divorced, widowed), years of education, monthly income (categorized in minimum wage effective March 2023), retirement (yes, no), and current employment (yes/no). Clinical variables were self-perceived health (very bad, bad, fair, good, very good)³⁷, duration of diabetes (years), memory difficulty (yes, no), number of self-reported diseases, number of medications taken, BMI (kg/m²)^{38,39}, hospitalization in the year before the interview (yes, no), presence of chronic pain in the year before the interview (yes, no), raw score of the Patient Activation Measure 13 and patient activity level classification (level 1, no engagement and overwhelmed; level 2, becoming aware but still struggling, level 3: taking action; level 4, maintaining behavior and progressing)⁴⁰.

Behavioral variables were need for travel to receive treatment (yes, no); participation in primary healthcare provider activities (yes, no), smoking status (yes, no), frequency of alcohol consumption (never, two or three times a week, four or more times a week, once a month or less, two to four times a month), level of physical activity according to the International Physical Activity Questionnaire (very active, active, irregularly active a, irregularly active b, sedentary)³⁹, and intrinsic religiosity (Intrinsic Religiosity Inventory score)⁴¹.

Functional performance-related variables were raw score and classification in the Brazilian Older American Resources and Services Multidimensional Functional Assessment Questionnaire (no impairment, mild impairment, moderate impairment, severe impairment)⁴², and fall in the year before the interview (yes, no).

Data collection procedures

The researchers contacted the State Health Department of Amazonas and then the municipal health departments of each city. After receiving initial project approval from the state health department, they sought consent from the municipal health departments to conduct the research. Next, primary healthcare unit coordinators were identified to facilitate contact with patients and other professionals. Community health workers escorted researchers to the participants' homes.

Data analysis

After data collection, the data were tabulated and analyzed using Microsoft Office Excel for tabulation and R software v4.2.1 (R Project; <https://www.r-project.org>) [<https://www.r-project.org>] for analysis. Normality was assessed with the Kolmogorov–Smirnov test. Descriptive and inferential statistics were used to present results: percentages were used for categorical variables and means and standard deviations for continuous variables. The association between PACIC scores and independent variables was analyzed using a generalized linear model with a gamma distribution and a log-link function. Six models were adjusted, one for each dependent variable (each PACIC domain score and the total score). A significance level of 5% was used to reject null hypotheses when the *p*-value was less than 0.05. The model's linear predictor provides raw coefficient estimates, which are interpreted using the exponential function to return to the original scale of the dependent variable. For categorical variables, the lowest level served as the reference category, and 0 was used for numerical variables, applying this pattern across all models.

Ethics approval

The Health in Primary Care for the Amazon Population research study was approved by the ethics and research council of the Universidade Federal do Amazonas (registration 4.318.325 and

4.994.196). All participants sign the informed consent form before the interviews.

Results

The sample included 965 participants, predominantly female (67.7%), with an average age of 61.6 ± 13.4 years. Most participants identified as brown (74.4%). Just over half were married (57.5%) and retired (51.0%). Length of education varied from 0 to 22 years, with a mean of 5.1 ± 5.2 years. In terms of income, 47.5% earned below one minimum wage, while 36.3% reported earning one minimum wage, and approximately 64.5% of respondents were unemployed.

In terms of clinical variables, 46.0% of respondents rated their self-perceived health as fair. Poor and very poor health perceptions were reported by 22.6%. The average duration of type 2 diabetes was 7.8 ± 7.2 years, and 55.0% reported memory difficulties. Participants reported an average of 3.0 ± 1.7 self-reported diseases, with medication use ranging from 0 to 12 medications and a mean of 2.3 ± 1.8 medications. The average BMI was 28.6 ± 5.8 kg/m². More than half (58.7%) reported no chronic pain episodes, and 83.3% had no hospitalizations in the year before the interview. In terms of activity levels on the Patient Activation Measure 13, only 12.0% were classified as level 4 (high activity), while the largest group (32.8%) was level 3 (moderate activity).

There were 64.2% of participants who reported needing to travel for treatment, and many (91.0%) stated they did not participate in primary healthcare activities. The majority (95.0%) reported not

being smokers, while 84.8% indicated they never consumed alcohol, and 8.1% drank once a month or less. According to the International Physical Activity Questionnaire classification, 62.2% were sedentary, and 26.1% were active. The mean score on the Intrinsic Religiosity Inventory was 43.7 ± 14.1 . The mean raw score on the Brazilian Older American Resources and Services Multidimensional Functional Assessment Questionnaire was 4.1 ± 4.3 points. In terms of functional impairment, 33.4% were classified with mild impairment, 26.3% with severe impairment, and 25.4% with no impairment. Additionally, 64.5% reported experiencing falls in the year prior to the interview.

The PACIC findings indicate that patients rated the quality of care received as low, based on the instrument's total score (Table 1). Notably, the goal-setting/adaptation domain received the highest score, while the active participation of the patient in treatment domain had the lowest.

The regression models for each domain and the total score are summarized in Table 2. Only significant independent variables are included for each model.

Sociodemographic, clinical, and behavioral variables influenced the total PACIC score. Notably, higher age and more years of education were associated with lower scores. Specifically, for each additional year of age, the PACIC score decreased by 0.33%, and for each additional year of education the score declined by 0.74%. The effects of these variables on each domain are detailed in Table 2.

Table 1: Description of total score and five domains of the Patient Assessment of Chronic Illness Care applied to people diagnosed with type 2 diabetes in remote municipalities of Amazonas, Brazil between 2020 and 2022 (n=965)

Domain	Mean score ($\pm$ SD) (points)
1. Active participation of the patient in treatment	5.7 ± 2.9
2. System of care model/model for practice	6.9 ± 3.3
3. Goal-setting/adaptation	10.6 ± 5.1
4. Problem-solving/context	8.2 ± 4.5
5. Follow-up/coordination	9.9 ± 3.9
Total Patient Assessment of Chronic Illness Care score	2.1 ± 0.8

SD, standard deviation

Table 2: Estimates of the effect of independent variables associated with the scores of PACIC domains and total score

Domain	Characteristic/effect	Variable	Estimate	Exp (estimate)	%
1. Active participation of the patient in the treatment	Intercept		2.0717	7.9380	— [§]
	Age (years)		-0.0043	0.9957	0.43
	Years of education		-0.0099	0.9902	0.98
	Retirement	No [†]	0.0000	1.0000	
		Yes	0.1185	1.1258	12.58
	BMI		-0.0072	0.9928	0.72
	Patient activity level	Level 1 [†]	0.0000	1.0000	
		Level 3	0.1458	1.1569	15.69
	Participation in primary healthcare provider activities	No [†]	0.0000	1.0000	
		Yes	0.3636	1.4385	43.85
	Falls	No [†]	0.0000	1.0000	
		Yes	-0.0746	0.9281	7.19

2. System of care model/model for practice	Intercept		1.5016	4.4887	— [†]
		Very poor	0.0000	1.0000	
	Self-perception of health	Poor	0.1556	1.1684	16.84
		Good	0.2016	1.2233	22.33
		Very good [†]	0.3323	1.3942	39.42
	Patient activity level		0.0035	1.0035	0.35
	Need to travel for treatment	No [†]	0.0000	1.0000	
		Yes	0.0836	1.0871	8.71
	Participation in primary healthcare provider activities	No	0.0000	1.0000	
		Yes [†]	0.3625	1.4369	43.69
3. Goal-setting/adaptation	Intercept		2.3448	10.4308	— [†]
	Years of education		−0.0071	0.9929	0.71
	Duration of diabetes (years)		0.0043	1.0043	0.43
	Number of diseases		−0.0208	0.9794	8.06
	Need to travel for treatment	No	0.0000	1.0000	
		Yes [†]	0.0839	1.0875	8.75
	Participation in primary healthcare provider activities	No	0.0000	1.0000	
		Yes [†]	0.3695	1.4470	44.70
4. Troubleshooting/context	Intercept		2.2312	9.3107	— [†]
	Age (years)		−0.0046	0.9954	0.46
	Years of education		−0.0094	0.9907	0.94
	Retirement	No	0.0000	1.0000	
		Yes [†]	0.0830	1.0866	8.66
	Duration of diabetes (years)		0.0065	1.0066	0.65
	Number of diseases		−0.0247	0.9756	2.40
	Hospitalization	No	0.0000	1.0000	
		Yes [†]	−0.0947	0.9096	9.04
		Level 1	0.0000	1.0000	
	Patient activity level	Level 2	0.1213	1.1290	12.90
		Level 3 [†]	0.1518	1.1639	16.39
	Need to travel for treatment	No	0.0000	1.0000	
		Yes [†]	0.1263	1.1347	13.47
	Participation in primary healthcare provider activities	No	0.0000	1.0000	
		Yes [†]	0.3772	1.4583	45.83
5. Follow-up/coordination	Intercept		1.9596	7.0966	— [†]
	Study time (years)		−0.0062	0.9938	0.62
	Duration of diabetes (years)		0.0074	1.0075	0.75
	Chronic pain in past year	No	0.0000	1.0000	
		Yes [†]	0.0719	1.0745	7.45
	Patient activity level		0.0040	1.0040	0.4
	Need to travel for treatment	No	0.0000	1.0000	
		Yes [†]	0.2499	1.2839	28.39
		Sedentary	0.0000	1.0000	
	International Physical Activity Questionnaire	Active [†]	0.0834	1.0870	8.70
		Very active	0.1537	1.1661	16.61

Total Patient Assessment of Chronic Illness Therapy score	Intercept		0.7385	2.0927	— [†]
	Age (years)		−0.0033	0.9967	0.33
	Study time (years)		−0.0074	0.9926	0.74
	Retirement	No	0.0000	1.0000	
		Yes [‡]	0.0680	1.0703	7.03
	Duration of diabetes (years)		0.0055	1.0055	5.50
		Level 1	0.0000	1.0000	
	Patient activity level	Level 2	0.0815	1.0849	8.49
		Level 3 [‡]	0.1296	1.1384	13.84
		Level 4 [‡]	0.1033	1.1088	10.88
	Need to travel for treatment	No	0.0000	1.0000	
		Yes [‡]	0.0705	1.0730	7.30
	Participation in primary healthcare provider activities	No	0.0000	1.0000	
		Yes [‡]	0.3390	1.4035	40.35

[†] Reference category of the explanatory variables in the model.

[‡] No percentages are associated with reference values for the model.

Exp (estimates), exponential of raw estimates.

Discussion

This study assessed primary healthcare providers' ability to serve adults with type 2 diabetes in remote municipalities of Amazonas from the perspective of service patients. It explored how sociodemographic, clinical, behavioral, and functional performance variables affect perceived level of chronic illness management, analyzing both the overall PACIC score and individual domain scores. The study found a mean PACIC score of 2.1±0.8 on a scale of 1 to 5 points, indicating that care provided by primary healthcare providers in remote municipalities of Amazonas was infrequent and inadequate, reflecting weakened support. Although this value is within the range reported by other Brazilian studies (1.55 to 2.92 points), it is closer to the lower end of this variation, which may indicate specific weaknesses in the Amazonian context^{8,29,30,36}. Sociodemographic and structural differences between regions, as well as the exclusive focus on people with type 2 diabetes, may explain this result. Analyzing each domain of the PACIC questionnaire provides detailed insights into the factors affecting care quality. By examining the data from each domain, researchers can identify specific aspects of care that contributed to the low overall score, revealing unique factors that impact the quality of assistance provided.

Domain 1: Active participation of the patient in treatment

The first PACIC domain, which measures patient involvement in decision-making about their care, received the lowest score in this study, consistent with other research^{8,30,36}. In the previous year, falls were a significant negative factor, with individuals who experienced falls scoring lower on this domain (Table 2). Falls can increase dependence and impact healthcare needs⁴³. Conversely, participation in primary healthcare provider activities was associated with higher scores in this domain (Table 2). However, most participants did not engage in these activities, reflecting the domain's weakness. This lack of participation may be due to limited access to primary healthcare providers, often due to economic constraints or logistical challenges in the Amazon region, where many patients must travel long distances by river in small boats³².

Domain 2: System of care model/model for practice

The chronic care model emphasizes placing the patient at the center of health care, requiring professionals to help patients develop the skills and confidence to manage their health^{7,14}. The second PACIC domain evaluates the support provided to patients and their satisfaction with the care organization. As shown in Table 1, this domain received the second lowest score, highlighting deficiencies in care organization. Participants felt that the healthcare team did not adequately promote organized care, which may have affected patient engagement, as reflected in the first domain's low score.

Although variables associated with this domain had positive effects on scores, the overall score remained low (Table 2). This could be due to low frequencies in items with high positive impact estimates. Silva et al stress that healthcare professionals need to transition from being mere prescribers to becoming active partners in patient care to improve service quality³⁰.

Domain 3: Goal-setting/adaptation

The third PACIC domain, which assesses the adaptation of guidelines and goal setting for individual needs, received the highest score in this study. This contrasts with findings from other Brazilian studies^{8,29,30,36}. Effective adaptation and goal-setting are crucial for user adherence to treatment, influenced by factors such as understanding, memory, education, and economic conditions⁴⁴.

It appears contradictory that participants reported goals and adaptations while showing low engagement and dissatisfaction with the care organization. This suggests that patients might not fully recognize or value these measures. Regular monitoring is essential to track progress toward goals and address gaps⁴⁵. Table 2 indicates that years of education and the number of diseases negatively impacted the score for this domain, while other variables had a positive effect. Although the need to travel for treatment had a significant positive effect on this domain's score, a large portion of participants reported this issue.

Domain 4: Problem-solving/context

The low scores in domains 1 and 2, despite reports that healthcare professionals set goals and adapt instructions, suggest these efforts may not be effectively enhancing care. This highlights a barrier to improving care quality.

The fourth domain, which addresses barriers in managing chronic conditions, received the third-highest score, indicating some weaknesses that need to be addressed. Factors such as age, years of education, number of diseases, and recent hospitalizations negatively impacted this domain's score (Table 2). However, some variables positively influenced the score, and exploring these could help strengthen this component. Notably, a higher level of activity (level 3) had a significant positive effect on this domain, showing that greater awareness of one's role in care can improve outcomes. Silva et al suggest that developing a collaborative care plan between professionals and patients can enhance problem-solving effectiveness³⁰.

Domain 5: Follow-up/coordination

The fifth PACIC domain focuses on continuity of care, assessing whether patients receive adequate follow-up to manage their condition. In this study, this domain received the second-highest score, suggesting that participants perceive follow-up care as generally acceptable.

This finding aligns with results from the third domain, where participants reported that healthcare professionals effectively set and follow up on individual goals. However, despite these positive aspects, domains 1 and 2 indicate that these efforts have not significantly improved patients' understanding of their care or their involvement in decision-making. Studies suggest that low levels of education can hinder patients' comprehension of instructions, reducing their confidence in participating in care decisions^{46,47}.

Total PACIC score

The study found that sociodemographic, clinical, and behavioral variables were linked to the total PACIC score (Table 2). Specifically, advancing age was associated with a lower PACIC score, as older individuals may engage less in self-management activities³⁶, which could explain the low score observed in a Brazilian study with elderly participants in Belo Horizonte³⁰. Additionally, greater years of education were associated with lower PACIC scores. Higher levels of education often lead to a more critical assessment of received care, due to increased access to health information⁴⁸.

Conversely, participation in primary healthcare provider activities positively affected the PACIC score, indicating that user involvement in these activities improved the score. However, barriers such as accessibility issues may have limited user engagement, thereby reducing the overall impact of this variable on perceived type 2 diabetes management.

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Strengths and limitations

Unlike previous Brazilian studies^{16,29,30,36}, this research used a generalized linear model with a gamma distribution and a log-link function for regression analysis. This method enabled a detailed examination of how various independent variables influenced both the overall PACIC score and the scores for each of its five domains. This approach provided more profound insights into the factors contributing to weaker care provision. Additionally, the study benefited from a randomized, population-based sample and employed a translated and adapted Portuguese instrument, which improved response accuracy among patients with type 2 diabetes.

However, the study's cross-sectional design limited its ability to establish causal relationships between outcomes and independent variables. Furthermore, the inclusion of other chronic conditions in some comparative studies may have introduced discrepancies. The number of refusals and losses during data collection was not systematically documented, which restricts the ability to assess sampling losses. This aspect will be addressed in future studies with improved tracking procedures.

Conclusion

From the perspective of patients with type 2 diabetes, the perceived level of type 2 diabetes management (measured by the PACIC) of primary health care in the interior of Amazonas appears to be insufficient. Various sociodemographic, clinical, and behavioral factors were associated with PACIC scores. Specific associations were found between these factors and the scores of domains 3, 4, and 5. Domain 2 showed associations with specific clinical and behavioral variables, while domain 1 was associated with sociodemographic, clinical, behavioral, and functional performance factors.

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Conflicts of interest

The authors have no conflict of interest.

Data availability

Data will be made available on request.

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