







Emotional distress and adherence to self-care activities in older adults with diabetes mellitus*

Sofrimento emocional e adesão às atividades de autocuidado em idosos com diabetes mellitus

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ABSTRACT

Objective: to assess emotional distress and adherence to self-care activities in older adults with diabetes mellitus. **Methods:** cross-sectional study conducted with 75 elderly diabetics and using the instruments Problem Areas in Diabetes (Brazilian version) and Diabetes Self-Care Activity Questionnaire. For data analysis, descriptive statistics and the calculation of mean differences between groups using the Mann-Whitney test were used. **Results:** the elderly showed low emotional distress (mean score=29.86). Regarding self-care, lower adherence to blood glucose assessment and higher adherence to medication use according to recommendations. When comparing the groups, the elderly with severe emotional distress showed less adherence to the dimensions specific food ($p=0.008$) and foot care ($p=0.014$). **Conclusion:** most of the elderly showed low emotional distress and unsatisfactory adherence to diabetes self-care related to the dimensions specific diet, and foot care stood out among the elderly with severe emotional distress. **Contributions to practice:** to foster the process of comprehensive care to the elderly with diabetes mellitus, contributing to the clinical management and promotion of their emotional well-being, therapeutic adherence, self-care - especially - of specific feeding, foot care and quality of life. **Descriptors:** Aged; Diabetes Mellitus; Psychological Distress; Self Care; Treatment Adherence and Compliance.

RESUMO

Objetivo: avaliar o sofrimento emocional e a adesão às atividades de autocuidado em idosos com diabetes mellitus. **Métodos:** estudo transversal realizado com 75 idosos diabéticos com base nos instrumentos *Problem Areas in Diabetes* (versão brasileira) e Questionário de Atividades de Autocuidado com o Diabetes. Para a análise dos dados, empregaram-se a estatística descritiva e o cálculo de diferença de médias entre grupos por meio do Teste de *Mann-Whitney*. **Resultados:** os idosos demonstraram baixo sofrimento emocional (escore médio=29,86). Sobre o autocuidado, menor adesão para avaliação da glicemia e maior para uso da medicação conforme recomendação. Na comparação dos grupos, idosos com sofrimento emocional grave apresentaram menor adesão às dimensões alimentação específica ($p=0,008$) e cuidado com os pés ($p=0,014$). **Conclusão:** a maioria dos idosos demonstrou baixo sofrimento emocional e adesão insatisfatória ao autocuidado com o diabetes relativo às dimensões alimentação específica, e cuidado com os pés sobressaiu entre idosos com sofrimento emocional grave. **Contribuições para a prática:** fomentar o processo de cuidado integral ao idoso com diabetes mellitus, contribuindo para o manejo clínico e a promoção do seu bem-estar emocional, da adesão terapêutica, do autocuidado - especialmente - da alimentação específica, do cuidado com os pés e da qualidade de vida. **Descritores:** Idoso; Diabetes Mellitus; Angústia Psicológica; Autocuidado; Cooperação e Adesão ao Tratamento.

Introduction

In recent years, Brazil has been experiencing a demographic transition due to the intense growth of the elderly population and to epidemiological changes, such as reduced morbidity and mortality rates from infectious diseases and the progressive increase in the prevalence of chronic non-communicable diseases⁽¹⁾.

Regarding noncommunicable chronic diseases, diabetes mellitus is one of the most frequent metabolic disorders in the world. It is estimated that the world population is around 425 million people affected, and may reach a projection of 693 million in 2045⁽¹⁾. In Brazil, data indicate a number of approximately 13.4 million individuals with diabetes in the country, with the elderly population being the most affected, with a variation of 18.3-26.5% of prevalence among age groups⁽²⁻³⁾.

Besides the high degree of incidence, diabetes mellitus represents one of the chronic diseases with a high morbidity and mortality rate among the elderly, in which symptoms, complications, and therapeutic management trigger changes in the individual's personal and social-familiar context, which can have a direct impact on his or her quality of life⁽³⁾.

One of the elements of quality of life is emotional well-being, which in its polysemic concept portrays a state of subjective satisfaction that uses the association between personal relationships and the support mediated by them, helping to regulate feelings related to life satisfaction and personal growth⁽⁴⁾.

In this logic, satisfaction or emotional well-being is a primordial condition for healthy aging, allowing the elderly to live as best as possible with the inevitable losses and functional/cognitive declines resulting from old age and its associated clinical pictures. Changes in the emotional state of the individual with diabetes mellitus can directly influence his clinical course as well as his therapeutic decisions and adoption of control measures for the disease⁽⁵⁾.

The satisfactory clinical management of diabetes mellitus and the prevention of its complications are directly related to therapeutic adherence, especially the activities that support self-care. Thus, self-care is understood as the autonomous and determinant ability of the individual to perform actions directed to himself for his own benefit, in order to maintain his health and well-being^(2,6). Therefore, it is important to promote the adherence of the elderly to self-care activities and treatment for proper disease management, and the competence of health professionals in identifying possible factors that lead to their impairment⁽⁷⁾.

Chronic diseases such as diabetes mellitus require a clinical approach and specialized assistance that involves all the biological, social and emotional needs of these individuals, and that allows the promotion of skills that assist self-care and disease management⁽⁴⁾. The elderly with diabetes mellitus who manage their self-care efficiently show the best results in disease control, although difficulties are experienced for its implementation, such as physical limitations, financial inadequacy, social vulnerability and emotional state^(1,6). In this scenario, the relationship between adherence to self-care activities and the condition of emotional distress in the elderly with diabetes mellitus requires a better understanding, given the lack of scientific evidence on this approach.

From this perspective, this research proposes an investigation that articulates the aging process with diabetes, emotional distress, and adherence to self-care activities in elderly people monitored in the field of Primary Health Care in order to bring answers that help this population segment in the qualification and effectiveness of health care, contributing to the creation and implementation of interventionist programs that maximize the potential quality of life of the elderly with diabetes mellitus.

Given the above, the research question is: is there a difference in the adherence to self-care activities of elderly people with diabetes mellitus with different levels of emotional distress? To answer the re-

search question, this study aimed to assess emotional distress and adherence to self-care activities in older adults with diabetes mellitus.

Methods

Cross-sectional and descriptive study conducted in the municipality of Cuité, Paraíba, Brazil, following the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines. To identify the study participants, we used as reference the total of five Basic Health Units in the urban area. The choice of setting is justified by the high flow of users in these services and the longitudinal follow-up with the public of interest.

The population (N) estimated for the study was 297 elderly people with diabetes mellitus and assisted in Basic Health Units, identified through the individual/family registration in the interface of e-SUS (Brazilian Unified Health System). The calculation to estimate the sample was performed using the public domain program OpenEpi, version 3.01 and considered a confidence level of 95%, margin of error of 5% and an estimated prevalence of 50% for severe emotional distress among older adults with diabetes with an additional 5% for losses/refusals, resulting in a sample set (n) composed of 176 older adults. During data collection, direct access to the elderly was interrupted due to the COVID-19 pandemic, which generated relative compromise in obtaining the sample whose final n reached 75 elderly.

The selection of participants occurred in a systematic randomized manner based on the alphabetical listing and proportional to each Basic Health Unit. For the eligibility of participants, a sampling interval ($k=4$) was calculated using the formula " $k=N/n$ ", in which the first element of the sample was selected and the others successively in a systematic way. The following inclusion criteria were met: living in the area covered by the Basic Health Units where they are monitored and registered; and presenting a clinical diagnosis of

diabetes mellitus for at least 2 years according to the records in the medical chart. The study excluded the elderly who presented some cognitive impairment, measured by the items temporal orientation (interview date) and spatial orientation (report of address) of the Mini Mental State Examination (MMSE), as well as speech or hearing impairment that could compromise communication during data collection.

For the operationalization of data collection, three instruments were used: Sociodemographic questionnaire (containing the variables: gender, age, income, education, functional literacy, marital status, and color/race); in addition to the validated versions in the Portuguese language of the Problem Areas in Diabetes (B-PAID) and Diabetes Self-Care Activities Questionnaire (DSCAQ) instruments.

The B-PAID is a multidimensional instrument composed of 20 questions distributed in four sub-dimensions [problems with eating (03 items), problems with social support (02 items), problems with treatment (03 items) and emotional problems (12 items)], which focus on aspects related to the emotional problems associated with living with diabetes mellitus. The scale was translated and analyzed regarding validity, reliability and sensitivity in Brazil, obtaining good internal consistency (Cronbach's Alpha = 0.93) and significant correlations with other instruments. Its total score ranges from 0-100 points, obtained by adding up the responses to the 20 items multiplied by 1.25 at the end. The possible response options are established by means of a 5-point Likert-type scale, ranging from: "Not a problem = 0", "Minor problem = 1", "Moderate problem = 2", "Almost serious problem = 3" and "Serious problem = 4". The results are interpreted adopting a cut-off point ≥ 40 that indicates severe emotional distress, where the higher the score, the greater the degree of distress⁽⁸⁻⁹⁾.

The DSCAQ includes diabetes self-care activities and is composed of 15 evaluative items divided into six dimensions (general feeding, specific feeding, physical activity, blood glucose monitoring, foot care,

and medication use). It is a culturally adapted instrument, whose psychometric properties were tested, showing inter-item correlation of $\alpha = 0.09$ to $\alpha = 0.86$ and inter-rater correlation of $\alpha = 0.29$ to $\alpha = 1.00$. Its evaluation items are arranged in days per week, from 0 to 7 where zero means the least desired situation and seven the most desired. Adherence is considered high/satisfactory when self-care activity scores are greater than or equal to five, and low/unsatisfactory when they are lower than five. In items related to foods rich in fat and sugars (items 4 and 5), values are interpreted with inverted scores (if 7=0, 6=1, 5=2, 4=3, 3=4, 2=5, 1=6, 0=7 and vice-versa), as suggested in its validation⁽¹⁰⁾.

Data collection occurred in the homes of the elderly according to the address identified in their medical records between the months of November 2019 and March 2020. The stage that corresponded to the survey counted with the participation of the responsible researcher, the participant researcher, and four students linked to the Center for Studies and Research in Aging and Quality of Life. Sequentially, the data were typed and processed with the help of IBM SPSS software, version 20.0, using simple descriptive statistics measures. The processing of the B-PAID and DSCAQ results followed all the recommendations described for the validation of the instruments^(8,10).

In the bivariate analysis, the comparison between the groups of the outcome variable (emotional distress) and the exposure variables (adherence to diabetes self-care activities according to the DSCAQ) was analyzed using the nonparametric Mann-Whitney test, since the Kolmogorov-Smirnov test showed that the exposure variables did not have a normal distribution. Statistical significance was considered when $p < 0.05$. All study procedures were guided based on Resolution No. 466/2012 of the National Health Council and Resolution No. 564/2017 of the Federal Council of Nursing. And, only after approval by the Research Ethics Committee (Opinion no. 3,541,595/2019), the study could begin.

Results

Seventy-five elderly individuals participated in the study, with a predominance of females (74.7%), young elderly (60-74 years) (60.0%) with a median age of 72 years (minimum of 61 and maximum of 89 years), brown (53.3%), with a partner (married/consensual union) (52, 0%), non-literate (50.7%), median of one year of study per participant (minimum of 0 and maximum of 12 years), and median income similar to a minimum wage that was in effect at the time of collection (R\$998.00) (ranging from R\$95.00-2.994,00).

According to the results obtained through the application of the B-PAID questionnaire, in the evaluation of the emotional state of the elderly with diabetes, a total mean score of 30.8 was indicated (based on the sum of the means of the subdimensions: problems with eating = 5.46; problems with social support = 2.26; problems with treatment = 3.0; and emotional problems = 20.08), indicating low emotional distress consequent to the disease and with a greater effect proportionally caused by problems related to eating. According to the B-PAID stratification, the categorized results of the emotional state of the participants ratified that the majority shows low emotional distress (69.3%) and 30.7% show severe emotional distress.

To evaluate the adherence to diabetes mellitus self-care activities among the elderly participating in the study, each of the items of the DSCAQ were considered individually. We observed a higher adherence to the items "taking medication as recommended" (6.25 days/week) and "eating foods rich in sugars" (0.84 days/week - inverse score). The items "perform specific physical activities" (1.4 days/week) and "assess blood sugar the recommended number of times" (1.25 days/week) had the worst mean adherence scores. The overall DSCAQ mean was 3.6 days/week for adherence to self-care activities.

Table 1 – Adherence to self-care activities according to the Diabetes Self-Care Activities Questionnaire by elderly with diabetes mellitus followed-up in Basic Health Units (n=75). Cuité, PB, Brazil, 2020

Diabetes Self-Care Activity Questionnaire Items	Adherence*
1. Follow a healthy diet	4.75 (2.89)
2. Follow a dietary guidance	2.84 (3.13)
3. Eat five or more servings of fruits and/or vegetables	4.41 (2.66)
4. Eat foods high in fat [†]	2.52 (2.78)
5. Eat foods high in sugars [†]	0.84 (1.50)
6. Get at least 30 minutes of physical activity	2.41 (2.91)
7. Engage in specific physical activities	1.40 (2.34)
8. Evaluate blood sugar	1.57 (2.53)
9. Evaluate blood sugar according to the recommended number of times	1.25 (2.60)
10. Examine your feet	4.20 (3.04)
11. Examine inside the shoes before putting them on	3.61 (3.16)
12. Dry the spaces between your toes after washing them	3.67 (3.09)
13. Take medication as recommended	6.25 (2.01)
14. Take insulin injections as recommended	1.77 (3.06)
15. Take the indicated number of diabetes pills	5.43 (2.84)

*Calculation of the mean number of days per week (and standard deviation) of elderly adherence to self-care activities in the previous seven days. The higher the mean, the more favorable the situation; [†]Items with reverse score and reverse evaluation

As for the evaluation of the relationship between emotional distress (outcome variable) and adherence to self-care activities (exposure variables) to compare the existence of difference between the groups studied (elderly with low or severe emotional distress), the results pointed out that there was a statistically significant difference regarding adherence to the dimensions “specific diet” (p=0.008) and “foot care” (p=0.014), in which the elderly with diabetes with severe emotional distress showed less adherence to these self-care activities (mean Ranks = 27.96 and 28.87 respectively). As for the total DSCAQ score, there was no significant difference in the comparison between the groups.

Table 2 – Emotional state of older adults with diabetes mellitus according to adherence to self-care activities obtained using the Diabetes Self-Care Activities Questionnaire (n=75). Cuité, PB, Brazil, 2020

Dimensions of the QAD*	Emotional state		p-value [‡]
	Low emotional distress [†]	Severe emotional distress [†]	
General nutrition	37.79	38.48	0.897
Specific food	42.44	27.96	0.008 [‡]
Physical activity	39.07	35.59	0.494
Blood glucose monitoring	36.93	40.41	0.484
Foot care	42.04	28.87	0.014 [‡]
Medication	37.21	39.78	0.536
Total DSCAQ score	40.38	32.63	0.156

*Mann-Whitney test (nonparametric test for two independent samples); Independent variables “ADL dimensions” and “Total ADL score” without normal distribution identified by Kolmogorov-Smirnov test; [†]Middle ranks; [‡]Statistical significance: p<0.05; ADLF: Diabetes Self-Care Activities Questionnaire

Discussion

The evidence of a majority of elderly with low emotional distress corroborates the results identified in another research in which there was a predominance of participants with total scores below 40 points⁽³⁾. In this perspective, a similar research developed with diabetic patients in primary care, in Germany, related the low scores of emotional distress to the periodic attendance to health services and to the adequate treatment of diabetes in all its spheres⁽¹¹⁾.

The identification of low emotional distress among most elderly with diabetes mellitus is a satisfactory finding of the study, since the severity of emotional distress is a negative determinant to affect the quality of life of the individual. This can be characterized as a psychological stressor, impairing social aspects related to family life and relationships, in addition to physiological aspects such as dietary changes and interference in sleep pattern⁽³⁾.

Muitos são os fatores que podem comprometer o bem-estar emocional de idosos com diabetes, podendo ser desencadeados por um estado de sofrimento psíquico, tais como: idade, tempo de diag-

nóstico, terapias polimedicamentosas, baixo grau de escolaridade e ausência do apoio social⁽⁵⁾. De modo complementar, pesquisa realizada com pacientes diabéticos no estado de Santa Catarina, Brasil, ao observar altos níveis de sofrimento emocional entre idosos com diabetes evidenciou a associação do aumento desses escores ao baixo conhecimento sobre a doença, atitudes negativas no tratamento e a presença de multimorbidades⁽³⁾. Neste estudo, observou-se que a dimensão dos problemas relacionados à alimentação exibiu maior efeito proporcional para a determinação de sofrimento dos idosos com diabetes.

Many are the factors that can compromise the emotional well-being of the elderly with diabetes, which can be triggered by a state of psychological distress, such as age, time of diagnosis, polymedicated therapies, low level of education and lack of social support⁽⁵⁾. In a complementary manner, a research conducted with diabetic patients in the state of Santa Catarina, Brazil, when observing high levels of emotional distress among elderly people with diabetes evidenced the association of increased scores with low knowledge about the disease, negative attitudes towards treatment and the presence of multimorbidities⁽³⁾. In this study, it was observed that the dimension of problems related to food exhibited greater proportional effect for the determination of suffering of the elderly with diabetes.

When assessing the inter-item mean of the QAD, we obtained a range of values from 1.25 to 6.25 days a week (considering also the reverse-scored items). The highest mean was observed in relation to the dimension “take medication as recommended”, with 6.25 days a week, representing a satisfactory finding for adherence to diabetes self-care activities. Similar data were identified in other national studies, in which participants showed greater adherence to drug therapies compared to non-drug and preventive measures⁽¹⁻²⁾.

Satisfactory drug adherence may be related to the conception of health professionals in a curative and traditional model, based on the hegemony of the

biomedical model in health, in which drugs and procedures are attributed a higher or absolute value over the care provided to the patient⁽¹²⁾. This attitude is not restricted only to health professionals, as shown by a study conducted in primary care in the state of Paraná, Brazil, which, when assessing elderly people with diabetes, observed a supremacy in the valorization of medication as the most effective treatment modality for diabetes mellitus control⁽¹³⁾.

For many elderly people, following a drug treatment is an easier therapeutic condition than changing lifestyle habits, especially regarding the incorporation of healthy behaviors related to diet and physical exercise, and factors reported by them as hindering the process are: economic conditions, time, routine, and lack of family support⁽⁶⁾.

Among the diabetes mellitus self-care activities, the worst condition of adherence was observed in the activity “assessing blood sugar according to the recommended number of times”. Corroborating this finding, a national study conducted with elderly people with diabetes showed unsatisfactory behaviors related to blood glucose monitoring, resulting from the absence of professional guidance on the frequency and performance of this practice as well as the unavailability of glucometer or other supplies needed for self-monitoring⁽¹⁴⁾. Furthermore, due to the long life with diabetes and the fact that many times they do not present any symptoms or complaints, the elderly feel self-confident enough to interrupt the routine verification of their blood glucose, performing a mistaken and inappropriate self-management regarding their treatment⁽¹⁵⁾.

Factors such as low economic conditions, low education and difficulty in accessing health services are also related to low adherence to glycemic monitoring⁽⁶⁾. It is up to health professionals, especially nurses, to add to the care plan of the elderly person with diabetes mellitus, interventions that promote the increase of self-care, guiding them about the correct and appropriate periodicity of glycemic monitoring, contributing to a greater autonomy, coping with the

disease and self-efficacy in its control⁽⁷⁾. The supply of supplies by the health system is essential to ensure the continuity of care (and self-care) and the achievement of therapeutic outcomes by patients.

In the evaluation of the item “specific physical activity practice”, it was observed a mean equivalent to 1.40, indicating that the elderly performed this practice on less than two days a week, representing a potential risk to health and quality of life of these individuals, and confirming another study that showed averages below the standards recommended by health entities, and found in the literature⁽¹⁴⁾. Physical inactivity among the elderly is a serious risk factor for mortality, and multiple factors contribute to sedentaryness, such as low socioeconomic status, functional decline, comorbidities, fear of falls or even the lack of infrastructure⁽¹⁶⁾.

The result of the item “eating foods rich in sugars” (average of less than one day) indicates a strong adherence to diabetes self-care activities, corroborating the findings of other national studies in which the consumption of sweets was within the desirable standard for the elderly with diabetes^(1,14). The low weekly consumption of foods rich in sugars indicates an effective understanding by the elderly about the guidelines and the need for a healthier lifestyle for diabetes control⁽⁷⁾.

In the comparison of the groups, the elderly with diabetes in severe emotional distress demonstrate lower adherence to the specific eating dimension. Emotional distress may decrease the individual’s motivation to adopt healthy lifestyle behaviors, such as careful food intake and physical training. In parallel, feelings of sadness and anger, commonly present in the therapeutic management of diabetes, especially by the obligation to follow a specific eating pattern, interfere with the daily and social activities of these individuals. This condition weakens therapeutic adherence⁽¹⁷⁾. However, its adoption is decisive in the development of diabetes mellitus and covers aspects related to self-care, adherence to the therapeutic regimen and complications associated with the disease⁽¹⁵⁾.

Another evidence found was regarding adherence to the foot care dimension, in which the elderly with diabetes in severe emotional distress showed less adherence to this self-care activity. It is alleged that emotional distress, when not taken care of, can predispose to the decrease of aspects on the individual’s resilience, leading to the increase of negative feelings such as discouragement, hopelessness in treatment and lack of interest in daily activities and self-care, which include preventive foot care⁽¹⁸⁾. Corroborating this finding, an epidemiological study evidenced that patients with diabetes and with some mental suffering have a risk of developing vascular problems, such as the diabetic foot, twice as high as that of individuals who do not suffer, which frequently increases the risk of hospitalizations, amputations and deaths⁽¹⁹⁾.

Recurrent diabetes injuries represent one of the most reported complications resulting from the disease, varying in degree and extent, and may result in functional loss, single, multiple and subsequent amputations^(9,20). The prevention of this morbidity depends on a good clinical control of the disease and on the adoption of simple self-care measures, such as daily self-examination of feet and footwear, including proper foot hygiene, associated with healthy lifestyle habits and satisfactory therapeutic adherence⁽²⁰⁾.

The relationships confirmed in the comparison between groups signal that there is a need to study other variables influencing emotional distress, such as those of a sociodemographic, clinical, and behavioral nature, especially to identify confounding factors, mediators, and moderators.

Study limitations

Limitations of the study are: the use of the cross-sectional method which, besides not allowing the establishment of a cause and effect association between the variables, is prone to reverse causality bias between the outcome and exposure elements; and the reduced sample size due to the interruption of data collection due to the determination of the pandemic

state of COVID-19, which made it impossible to contact the elderly with diabetes mellitus because they are considered a double risk group for the disease.

Contributions to practice

The results obtained constitute an important tool to foster the process of comprehensive care to the elderly with diabetes mellitus, contributing to their clinical management and promotion of their emotional well-being, therapeutic adherence, self-care - especially specific diet and foot care - and quality of life. The findings may sensitize the multiprofessional team in health practices, especially the nurse during nursing consultations, directing effective and efficient interventions that allow a holistic and appropriate assistance to the elderly with diabetes. In addition to providing subsidies for the development of new investigations and evidence in health.

Conclusion

We observed a predominance of low disease-related emotional distress and unsatisfactory adherence to non-drug treatment among older adults with diabetes. The elderly in severe emotional distress, significantly, exhibited lower adherence to self-care activities related to the dimensions specific diet and foot care.

Authors' contribution

Project conception, data analysis and interpretation, article writing, relevant critical review of the intellectual content, and final approval of the version to be published: Costa PA, Nogueira MF.

Data collection and analysis, and article writing: Oliveira Neta MA, Azevedo TF, Cavalcanti LT, Rocha SRS. Agreement to be responsible for all aspects of the manuscript related to the accuracy or completeness of any part of the work to be properly investigated and resolved: Costa PA, Nogueira MF, Oliveira Neta MA, Azevedo TF, Cavalcanti LT, Rocha SRS.

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