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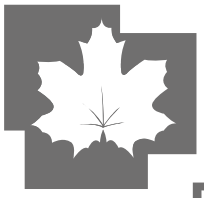

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Transparency and integrity in research: from problems to potential solutions

Integrity embodies, above all, a commitment to intellectual honesty and personal responsibility for one's actions and to a range of practices that characterize responsible research conduct. In general, integrity can be characterized both at an individual level (i.e. researchers and others interested scholars) and a collective level (i.e. institutions engaged in research)[1].

On an individual level, having a commitment to honesty and responsibility is fundamental, where these practices include: intellectual honesty in proposing, performing and reporting research; accuracy in representing contributions to research proposals and reports; clarity and fairness in the peer-review process; collegiality in scientific interactions; including communications and sharing of resources (e.g. physical materials, data sharing etc.); transparency in conflicts (or potential conflicts) of interest; protection of humans subjects and humane care of animals in the conduct of clinical trials; and adherence to the mutual responsibilities between investigators and their research team[1].

On a group or institutional level, institutions should seek to create an environment that promotes responsible conduct by individuals and that fosters integrity by establishing and continuously monitoring structures, processes, policies, and procedures. To this end, it is important to: encourage respect for everyone involved in the research enterprise; promote productive interactions between trainees and mentors; advocate adherence to the rules regarding all aspects of the conduct of research, especially research involving human subjects and animals; reveal and manage individual and institutional conflicts of interest; arrange timely and thorough inquiries and investigations of allegations of scientific misconduct and apply appropriate administrative sanctions; offer educational opportunities pertaining to integrity and transparency in the conduct of research; and lastly, to monitor and evaluate the institutional environment supporting integrity in the conduct of research and use this knowledge for continuous improvement in research quality[1].

Why is a lack of transparency and integrity problematic?

As outlined above, scientific transparency and integrity, at both the individual and group/institutional level, are scientific aspects which seek, through a variety of tools, to improve the way projects are developed, data are collected and reporting is done[2]. Today, unfortunately, scientific output (e.g. scientific articles, particularly) is used for career promotion[3,4], leading to a sharp rise in the number of articles produced, potentially causing a decline in quality[5]. In this respect, there appears to be a negative correlation between

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scientific output and both transparency and integrity, where the higher the volume, the lower the scientific rigor. In other words, many researchers are more worried about increasing the quantity of publications, while increasingly eroding the quality of studies produced.

In a famous editorial written by Douglas Altman, in the British Medical Journal (BMJ*)* in 1994[6], he discusses the problems underlying poor biomedical research and cites some of the reasons for low quality scientific research. He also questions, reflectively, the scientific community on an important issue: Why are errors so common? He then answers by stating:

> "Put simply, much poor research arises because researchers feel compelled for career reasons to carry out research that they are ill equipped to perform, and nobody stops them." (1994; pg. 283)[6].

Exemplifying this situation is the classic case of Tamiflu (Oseltamivir)[7,8], in which a lack of transparency and integrity in science led to wasteful research, not only in terms of human resources, but also financially. Since the mid-2000s, governments have spent billions of pounds stockpiling two anti-influenza drugs, the neuraminidase inhibitors oseltamivir (Tamiflu) and zanamivir (Relenza). When the so-called "swine flu" H1N1 influenza emerged in 2009, the UK and Australian governments commissioned a rapid update of an existing Cochrane review of the drugs. Following this, the BMJ began one of the first campaigns on open data and pressured some companies to release data on several anti-influenza drugs, one of which was Tamiflu.

After reanalysis of data from around 107 studies conducted by numerous renowned institutions, the reviewers concluded that: "there was no convincing trial evidence that Tamiflu affected influenza complications (in treatment) or influenza infections (in prophylaxis)." Finally, the authors raised new questions about the drug´s harms profile. The campaign lasted nearly 4 years and was considered a success, not least because it helped galvanize a movement toward increased transparency of clinical trial data.

In conclusion, the reviewers reported that the BMJ campaign: (a) facilitated the first ever Cochrane review based entirely on clinical study reports and regulatory data; led to changes in transparency by pharmaceutical companies and triggered inquiries at the national and international level; heightened awareness of the importance of independent access to underlying trial data, in particular highlighting important discrepancies between journal publications and underlying clinical study reports.

With the aim of improving the process of transparency and integrity in science, there are a number of key initiatives both in Brazil and internationally. The medical literature has historically played a leading role towards achieving this goal, most notably the ICMJE (International Committee of Medical Journal Editors) and ClinicalTrials.gov. As early as 2004, the ICMJE required pre-registration of clinical trials[9,10], along with the other initiatives described below.

The ICMJE is a group of medical journal editors and stakeholders whose objective is to improve the quality of scientific publication and reporting of their manuscripts. Journals involved include the JAMA, BMJ, Annals of Internal Medicine and the Bulletin of the World Health Organization. With regard to reporting, the EQUATOR Network strives to enhance the trustworthiness and value of medical research bibliography, disclosing transparent reports on health research. To facilitate this goal, the network provides various reporting guidelines for different study designs[11].

Reproducibility networks are being set up all over the world, the most pioneering of which is the United Kingdom Reproducibility Network (UKRN)[12]. This consists of a multi-disciplinary national consortium promoting reproducibility and transparency training initiatives, meta-research activities and disseminating best practices in research. Brazil has the Iniciativa Brasileira de Reprodutibilidade (Brazilian Reproducibility Initiative)[13] comprising the ReproducibiliTea-Brasil[14] and the No-Budget Science Hackweek[15], together

making up a network of researchers engaged in research reproducibility. The Reproducibili-Teas hold regular regional meetings that bring together researchers of different levels to discuss articles related to transparency and integrity, both key elements of the Hong Kong Principles[4] .

One of the leading precursors of the open science movement is the Open Science Framework (OSF), a platform offering a range of functions fostering greater transparency and integrity, through a platform allowing pre-registration of study protocols, sharing of databases, and a host of related functions[16]. This can be defined as an open source software project which facilitates transparent collaboration in scientific research. This is associated with the Centre for Open Science (COS), a not-for-profit technology organization with the goal of increasing openness, integrity and reproducibility of scientific research. The organization started out with reproducibility of research in psychology and later included the biology of cancer, subsequently expanding its objectives, function and scope.

It is important to point out that some initiatives for improving these aspects of research are not exactly new, such as the ClinicalTrials.gov[10], allowing registration of clinical trials. In parallel, a number of meta-research projects have emerged for monitoring the compliance of researchers with the platform, such as European Union Trials Tracker[17] and the SEES (Strengthening the Evidence in Exercise Sciences) initiative[18].

Transparency and integrity are widely considered the cornerstones of science, while transparent robust practices are invariably associated with quality. Therefore, it is fundamental that researchers (on an individual level) and institutions (on a collective level) endorse and practice responsible research conduct. Lastly, the creation of fresh initiatives, beyond those in place, is paramount in order to strengthen the movement of transparent, robust, open and reproducible science.

Charles Phillipe de Lucena Alves[1]

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Home palliative care reduces emergency room visits and deaths in health centers at a lower cost

José Ernesto Picado Ovares[1]

Abstract

Objectives: To compare the types of geriatric and palliative home care to determine which has better outcomes in patients with advanced dementia. Methods: This is a retrospective cohort study. Patients with advanced dementia admitted to the Geriatric Community Care program of a public geriatric hospital in Costa Rica in the period between January 2018 and June 2019 were included. They were divided into two groups depending on the specialized team that performed the home care, and their sociodemographic and clinical characteristics were analyzed. Subsequently, data generated from medical records on emergency consultations, hospitalization, place of death and cost of the visit generated by each patient between June 2018 and December 2019 were analyzed. A comparison was made between 192 patients with advanced Global Dementia Scale 7 dementia visited by the specialized geriatric home care team and 19 patients visited by the specialized palliative home care team of the National Geriatric Hospital. *Results:* We analyzed 226 data generated (192 by the geriatric program and 34 by the palliative program). Those receiving home care by a palliative team were less likely to go to the emergency room and die in a health center compared to those receiving home care by a geriatric team, at a lower cost. *Conclusions:* The specialized palliative home care program reduces emergency room visits, death at home, and costs of care in patients with advanced dementia compared with the geriatric program.

Keywords: Palliative Care; Geriatrics; Dementia; Home Care Services; Terminal Care; Cost-Benefit Analysis; Health Services.

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The authors declare that there is no conflict in the conception of this work.

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INTRODUCTION

Population changes related to aging will affect both the prevalence and incidence of age-related non-oncologic diseases such as dementia, mainly in Latin American countries[1,2].

Palliative care aims to alleviate the suffering of individuals and families facing a terminal illness. Dementias share certain aspects with other palliative diseases[3] but have their own characteristics[4,5] that make the approach to them different and extremely complex[6,7]. Although there is consensus on the need to provide dignified palliative care for these patients[8], it is widely recognized that the current structure of most health services is inadequate to meet the needs of this particular population[9].

It is unclear which model represents the best alternative care for this population group as it is highly dependent on the social context in which it is provided[10]. Patients generally do not receive the necessary support, which manifests itself in unsatisfactory care[11] with a poorer quality of death and an unfavorable cost/benefit ratio[12-14].

One area of palliative care is home-based palliative care, which has been previously defined in other publications[15]. Compared to usual care,[16] palliative home care has demonstrated favorable outcomes in symptom management, decreased emergency room visits or hospitalizations, and increased satisfaction with care; however, the evidence is inconclusive regarding home deaths, quality of life, caregiver burden, and functional impairment. Home palliative care may even be associated with more difficulty in caregiver bereavement management, especially in patients with dementia who are generally not included in these analyses[16-20].

Currently, information related to the costs of palliative care programs is insufficient. Generally, studies are small, use different methods of analysis and are directed at cancer patients[9,20-25]. In one review[16], lower costs were reported, with differences between 18 and 35%; however, only one of the studies analyzed reported statistically significant differences[9]. It is worth mentioning that none of the studies were conducted in Latin American countries, and therefore the scientific evidence of the impact of these programs in Latin America is minimal.

The Geriatric Community Care Unit (ACG) of the National Hospital of Geriatrics of Costa Rica offers care in the home setting by an interdisciplinary team to patients with terminal chronic degenerative diseases. Chart 1 summarizes the current status of the ACG unit and the services it offers, highlighting two visiting programs according to the model implemented, a geriatric and a palliative model[26]. Previous studies have shown that the palliative model offers good quality of death[27]; however, whether this is also accompanied by savings for the country's health system or other outcomes has not been investigated.

Chart 1. Modalities of care provided by the Geriatric Community Care service of the National Hospital of Geriatrics of Costa Rica (January 2018 to December 2019). San José, Costa Rica.

Modality of care	Patients visited	Description of program and services offered
Specialized geriatric home care	Non-oncologic terminal illness	**Visits by a multidisciplinary team a that includes** [a] **geriatric specialist** [b] **Visits every 2 to 3 months.** **Teleconsultation available during office hours.** Caregiver training group. Bereavement group.
Specialized palliative home care	Terminal oncologic and non-oncologic illness	**Visits by a multidisciplinary team including a specialist in geriatrics and palliative care.** **Visits every month or as needed.** **Teleconsultation available 24/7.** Caregiver training group. Bereavement group.

[a] The multidisciplinary teams consist of a physician, nurse, and professionals in social work, psychology, nutrition, speech therapy, occupational therapy, pharmacy, mental health, dentistry and psychiatry; [b] The main differences between the programs are highlighted in bold.

Source: Prepared by the authors.

Thus, the objective of this research is to compare, in patients with advanced dementia, care in the home setting by specialized palliative care teams with home care by specialized geriatric teams to determine which model has better outcomes (fewer visits to the emergency room or hospitalizations and a higher number of deaths at home) and a lower cost ratio to provide a replicable option to meet the needs of this particular population in the Latin American context.

MATERIALS AND METHODS

To carry out the investigation, a retrospective cohort study was performed. The data used were taken from the medical records of the patients assessed by the weekly multidisciplinary sessions of the ACG, in which all admissions to the program are reviewed. In these sessions, a decision is also made as to which specialized team will follow up the patient (the geriatric or the palliative team). This decision is based on the criteria of the multidisciplinary team (which includes a geriatrician, a licensed nurse and a social worker with 10 years of experience in these cases) which considers the sociodemographic and clinical variables of each particular case.

In February 2020, clinical and sociodemographic data that were retrospectively obtained from the medical records of patients admitted to the ACG program between January 2018 and June 2019 were analyzed (see Figure 1). Data obtained included date of admission to the program, age, marital status, gender, caregiver, and the presence of pressure ulcers, use of an enteral nutrition device, presence of a bladder catheter. Of the total number of patients assessed, patients aged 60 years or older were included, with a diagnosis of dementia syndrome at program entry and with a Global Dementia Scale (GDS) classification adequately recorded, with dementia syndrome as the program entry diagnosis, and with a classification of GDS 7.

Subsequently, the population was divided into two groups according to the team that visited the patient during the study period (the specialized palliative care team and the specialized geriatric team). It should be noted that if, during the follow-up period, a patient moved from one program to the other, his or her data were analyzed again; that is, the patient was analyzed for the time spent in one program and then again for the time spent in the other program.

To contrast and compare certain criteria of interest according to program, exploratory descriptive analyses were performed. To determine if there were differences between the variables in each program, a more detailed study was performed, and 95% confidence intervals were determined using the Wald method for multinomial distribution. For the mean values, intervals were created so that the means approached a normal distribution and the unknown standard deviation for the population was estimated using the observed data. It should be noted that, for the variables of interest, length of stay included the duration a patient remained in one program before switching to another or dying.

To assess the risk of emergency department visits and/or hospitalizations and the costs per patient of emergency department visits and hospitalizations according to group, the Costa Rican national health system's Digital Record that records national information for the entire country was used to analyze emergency department visits and hospitalizations for each patient from June 2018 to December 2019 (see Figure 1).

To analyze whether there were significant differences in emergency department visits, hospitalizations, and place of death between the two groups of patients, a logistic regression model was developed. The data were analyzed using the binomial probability distribution. Finally, the statistical significance of the OR obtained was obtained at a 5% significance level.

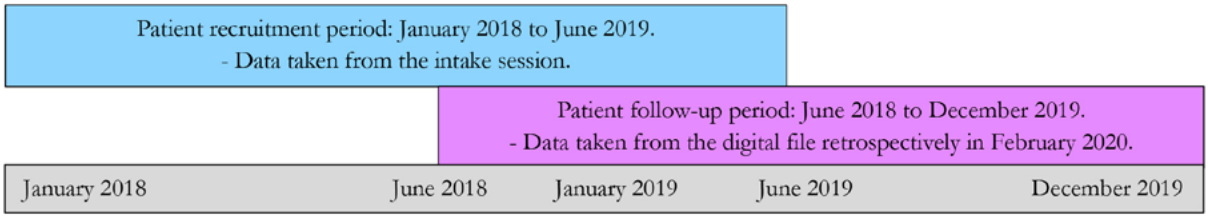

Figure 1. Time between recruitment and follow-up period (January 2018 to December 2019). San José, Costa Rica.

To compare the costs of each home program, the following formula was used:

- **Total cost per patient of the geriatric home program=** Cost of home care per patient in the geriatric program + cost of emergency room visits per patient in the geriatric program + cost per day of hospitalization per patient in the geriatric program + cost per day of hospitalization per patient in the geriatric program.

- **Total cost per patient of the palliative home program=** Cost of home care per patient in the palliative programs + cost of emergency visits per patient in the palliative program + cost per day of hospitalizations per patient in the palliative program + cost of teleconsultation.

The cost of visits per patient for each program, is derived from the ACG service cost study of the Hospital General Management, 2018. The aforementioned study used the variables of salaries, per diem, mileage used by each vehicle, and the costs of nursing and medical procedures performed. To estimate these costs, the salary category for each work team (geriatric versus palliative) was determined. To identify the actual cost of salaries, overtime, vacation, and other salary categories, the study used information from the 2018 Hospital Staff Salary Update prepared by the Department of Human Resource Management. Data regarding the distance traveled by the ACG for visits during 2018 were obtained from the Monthly Report of the Surveillance and Transportation Service. The cost per kilometer traveled was obtained from the Institutional Tariff Model. Data on the different procedures performed, both medical and nursing, were obtained from the ACG Annual Report, 2018. Once the annual costs of geriatric and palliative care were determined, the ratio of cost per patient, as mentioned above, was used to allow an appropriate comparison between programs.

For emergency department visits and hospitalizations, the duration of each visit (in hours) and the duration of hospitalization (in days) were quantified retrospectively using information from the institutional digital record for each patient, as described above. Subsequently, the costs per hour in the emergency room and per day of hospitalization were calculated for each group and finally per patient. The costs per hour in the emergency room and per day of hospitalization were obtained from the information provided by the Cost Accounting Area, 2019. Finally, once the variables necessary for the final calculation were obtained, the total costs per patient for the two programs were determined to allow comparisons between the programs.

Both the geriatric and palliative care programs offer the possibility of teleconsultation during office hours; however, only the palliative program offers the possibility of after-hours care (24 hours a day, 7 days a week). Although the cost of this teleconsultation is free, since it is donated by the Partir con Dignidad Foundation, this research calculated the cost of this care in order to determine the total cost of the palliative model in the context that this donation does not exist. Considering data from the 2018 and 2019 ACG Final Report, it is estimated that each patient in the palliative program makes an average of 5.3 calls. Each call has an approximate cost for the study year at $22.7. Of these calls, an estimated 42.5% were made outside of office hours. Taking these variables into account, the total cost in the study period for palliative care patients was $51.13 per patient.

The protocol for this study was approved by the Ethics Bioethics Committee of the Hospital Nacional de Geriatría y Gerontología Doctor Raúl Blanco Cervantes. Ordinary Session Number 12, November 5, 2019. Agreement No. 3. (protocol number CEC 14-2019).

RESULTS

Of the 443 patients seen in the Admission Session, 211 had the diagnosis of advanced dementia GDS 7 who were followed up. 192 were admitted to the geriatric program and 19 to the palliative program. The mean age of all participants was 85.3 years (SD= 8.6 years). At a general level it can be said that the ages of both groups have very similar distributions in their mean and standard deviation. The general characteristics of these patients are shown in Table 1. A total of 15 of these patients started follow-up in the specialized geriatric program and were subsequently transferred to the palliative care program. The data for these 15 patients were analyzed separately, first at the time they belonged to the geriatric program and then upon transfer to the palliative program. This generated a total of 226 cases that were followed up. A more detailed description of the study population can be found in other publications[28]. No significant differences were found in the demographic and clinical characteristics of the two groups.

As shown in Table 2 patients in the palliative care program had a lower risk of hospitalization, emergency department visits and death in the health center compared to those in the geriatric care program. This difference was statistically significant only for emergency visits and death in the health center.

It is important to note that the cost of home care per patient is higher for palliative care when considering the visit itself. However, considering the results over time, this becomes less expensive when considering that it leads to fewer emergency visits and hospitalizations, as shown in Table 3.

Table 1. Percentage distribution, mean age, and sociodemographic and health variables of patients by program, San José, Costa Rica (January 2018 to December 2019).

Variable	Geriatric Program n=192 (100%)	CI	Palliative program n=34 (100%)	CI
Average length of stay (days)	407.4	377.5; 436.5	426.1	286.9; 565.1
Average age	85.2 (SD=7,9)	84.1; 86.3	86.9 (SD=7,8)	82.7; 91.2
Marital status				
Widowed	93 (48.2%)	41.1; 55.3	16 (47.4%)	24.9; 64.8
Married	60 (30.9%)	24.3; 37.4	14 (42.1%)	19.9; 64.3
Single	26 (13.6%)	8.7; 18.5	2 (5.3%)	0.0; 15.3
Other	14 (7.3%)	3.6; 11.0	2 (5.3%)	0.0; 15.3
Gender				
Female	141 (73.4%)	67.2; 79.7	25 (73.7%)	53.9; 93.5
Male	51 (26.6%)	20.3; 32.8	9 (26.3%)	6.5; 46.1
Primary Caregiver				
Family	154 (80.2%)	74.5; 85.9	28 (83.3%)	66.1; 100.0
Hired personnel	38 (19.8%)	14.1; 25.5	6 (16.7%)	0.0; 33.9
Pressure ulcers grade 3 or 4				
Yes	27 (14.2%)	9.2; 19.2	2 (5.3%)	0.0; 15.3
Nasogastric tube or PEG[a]				
Yes	42 (22.1%)	16.2; 28.0	14 (42.1%)	19.9; 64.3
Bladder catheter				
Yes	11 (5.8%)	2.5; 9.1	5 (15.8%)	0.0; 32.2

[a] PEG: Percutaneous endoscopic gastrostomy.

Table 2. Risk model results for emergency department visits, hospitalization, and place of death by program. palliative care, San José, Costa Rica (January 2018 to December 2019).

Variable	Palliative program	
	OR1/	CI
Consultations to the emergency service		
Yes	0,18	0,09; 0,35 *.
Hospitalization		
Yes	0,46	0,07; 1,56
Place of death		
Health center	0,16	0,01; 0,93 *

CI: 95% confidence interval. OR: Odds ratio;

*: p<0.05. 1/Reference category: Geriatric.

Source: Prepared by the authors.

Table 3. Comparison of geriatric and specialized palliative program costs in the home setting. San José, Costa Rica (January 2018 to December 2019).

Variables	Program	
	Geriatric	Palliative
General variables		
Total patients at the beginning of the study	192	19
Total patients at the end of the study	192	34
Data evaluated	419	46
Cost of home care per patient	$ 368,4[a]	$ 680
Variables of emergency department visits		
Patients who visited the emergency department	106	4
Total number of emergency department visits	295	14
Time (in hours) of emergency department visits	1630	153,4
Total cost of care in the emergency department	$ 76858,4	$ 5607,7
Cost of emergency care per patient	$ 400	$ 165
Hospitalization variables		
Hospitalized patients	32	2
Total hospitalizations	38	2
Total days of hospitalization	574	26
Cost of one day of hospitalization (average)[a]	$ 802	$ 802
Cost per hospitalized patient	$ 1759	$ 485
Other variables		
Cost of 24/7 teleconsultation	n/a[b]	$ 51,13
Total cost per patient [c]	$ 2527,4	$ 1381,1

[a] Cost depends on the hospital where the patient was hospitalized; [b] Not applicable; [c] Total cost per patient in the geriatric home program= Cost of home care per patient in the geriatric program + cost of emergency room visits per patient in the geriatric program + cost per day of hospitalization per patient in the geriatric program; Total cost per patient of palliative home program= Cost of home care per patient in palliative program + cost of ER visits per patient in palliative program + cost per day of hospitalizations per patient in palliative program + cost of 24/7 teleconsultation.

Source: Prepared by the authors.

DISCUSSION

The results of this publication demonstrate the positive impact of the specialized palliative home care program on emergency visits, place of death and cost, even when compared to the geriatric program. The impact of palliative care on emergency visits, hospitalizations, and home deaths is greater than presented in previous publications [9,16,29].

Chiang J-K et al conducted a study with a similar population and methodological approach. The investigators sought to compare the impact of palliative care in the home setting on quality of life. They compared 164 patients from two different programs (one with a palliative approach and one without a palliative approach). This research showed only a significant difference in the variable related to death in hospitals and failed to document differences in emergency room visits or hospitalizations. It is worth mentioning that the research did not focus specifically on patients with dementia, nor did it perform any economic analysis[9].

Seow H et al. calculated relative risks by comparing two types of home interventions in two groups of 3109 patients each in Ontario Canada. This research demonstrated a decrease in emergency department visits and deaths in the hospital setting in patients visited by a palliative care team. However, the research did not specifically include patients with dementia nor was an economic analysis performed[15]. Similar findings were obtained from a systematized review of 4 studies analyzing interventions in the home setting of patients at the end of life, which only demonstrated a lower probability of dying in the hospital in the interventional groups[29].

Having control over the place of death is considered central to achieving an adequate quality of death. Evidence suggests that most terminally ill patients want to die at home[30]. Deaths in the hospital setting are accompanied by costly hospitalizations and aggressive treatment at the end of life, compromising the quality of death of patients and increasing the costs of care[30,31]. This explains why a death in the home setting is considered an important indicator of the quality of end-of-life care[31] , especially if the patient is cared for during this process by a home palliative care team with the characteristics presented in this study, as it ensures continuous and timely monitoring.

The cost/benefit ratio of home programs is not clear[29]; this is especially true in the Latin American context, where there is inadequate scientific evidence to guide health systems, which differ in each country and have little coverage of care in the home setting, especially for patients with dementia.

Although the frequency of care by the palliative team generates higher costs (see Table 2), this care provides high quality care[27] that allows the patient to die at home at a lower cost by avoiding emergency department visits and hospitalizations; therefore, when the total impact of this care is evaluated, the final result is a lower cost of care. This reduction is even greater than that reported in international publications[9, 16].

As shown in Table 1, the palliative care program differs from the geriatric program in three aspects. The most relevant difference is the availability of 24/7 teleconsultation and the frequency of visits 27. Virtual teleconsultation in palliative care has shown some positive results in oncology[32] and pediatric populations[33]. In addition, the increased frequency of visits allows greater contact between the team and families, thus providing more opportunities for education and awareness. These two distinctive elements of the model sensitize and empower family members, favoring decision making aimed at more conservative care[21].

The main limitation of this study refers to the unbalanced data, specifically in the target variable analyzed (program). Within the category "Geriatric Program" the great majority of the weight of the data is found, which means that it becomes complex to make inferences due to unequal counts. This explains the range of confidence intervals evidenced in the variables related to the palliative program. Another limitation of this study is that it is a nonrandomized study. Therefore, there may be a risk of selection risk in the population of each group. However, as evidenced in Table 1, the two groups did not differ significantly in their characteristics at the beginning of the study.

The study has some strengths. The control group (geriatric program) represents a highly specialized model of care, and because of the characteristics of the patients included and the similarity of the two models, conclusions can be drawn about the aspects that make the palliative model successful. This allows us to justify the investment needed to reproduce the model and offer a successful alternative in the Latin American context. Finally, the patients who were followed had a diagnosis of dementia, and the findings of this study generate scientific evidence that, to the authors' knowledge, did not previously exist for the Latin American setting in this particular population.

It is clear that more research is needed regarding home care models that can respond to the complex needs of patients with different non-oncologic diseases. Ideally, this research should use similar methods so that its results are comparable since needs vary greatly according to the social and cultural setting[33]. However, the results of the present study are sufficient to support home palliative care programs for patients with advanced dementia that are similar to those analyzed in this study.

CONCLUSION

Palliative home care has a positive impact on emergency visits, home death, and care costs for patients with advanced dementia, even when compared with similar geriatric care programs. This model of care represents an attractive alternative to the few care options currently available for this particular population.

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Dietary guidelines for the elderly in Primary Health Care: development and validation of a protocol based on the Food Guide for the Brazilian Population

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Abstract

Objective: Develop and validate a protocol for the use of the Food Guide for the Brazilian Population (FGBP) in the dietary guidelines for elderly people during individual clinic appointments in Primary Health Care (PHC). *Methods:* The elaboration followed six methodological steps, namely: (1) protocol format definition; (2) definition of the instrument for assessing food consumption; (3) extracting applicable Food Guide recommendations for individual dietary guidelines; (4) evidence systematization on dietary and nutrition needs of the elderly; (5) development of nutritional guidelines messages for the elderly; (6) content and apparent validation and data analysis. *Results:* As products of the steps, the protocol structure was defined and dietary guidelines were elaborated based on the nutritional and health needs of the elderly population, considering the functional capacity and physiological and social changes of this life cycle. The protocol was well assessed by experts and health professionals as to clarity, relevance (content validity index > 0.8) and applicability. In addition, the participants made some suggestions to improve the clarity of the messages and to expand the applicability of the instrument with elderly Brazilians. *Conclusion:* The protocol can contribute to the qualification of dietary guidelines in PHC, dissemination of information from the Food Guide and promotion of comprehensive care and healthy aging of the population.

Keywords: Primary Health Care. Dietary Guidelines. Practice Guidelines. Aged. Validation Study.

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INTRODUCTION

Primary Health Care (PHC), responsible for the longitudinal monitoring of people, plays a major role in comprehensive health care for the elderly[1,2]. Recent studies show an increase in the body weight of this population[3] and indicate that approximately 70% have at least one chronic non-communicable disease (NCD)[4].

Food and nutrition actions in PHC are associated with the promotion of healthy eating and the prevention of diseases resulting from NCDs, with dietary guidelines being an interdisciplinary health practice[5]. However, dietary guidelines finds barriers to be incorporated into the practice of services, being carried out with low frequency and, mostly, attributed to doctors or nutritionists. In addition, the low training of professionals, the difficulty in managing the time of appointments and the lack of instruments that facilitate dietary guidelines also pose challenges for the promotion of healthy eating.[6,7,8]

The existing tools to guide the practice of professionals about food are usually disease-centered, leading to a health practice focused on their recovery, disregarding the expanded aspect of healthy eating[9]. Among the elderly, the focus on the treatment of diseases can pose stigma about aging and limit comprehensive care for these individuals[10].

The Food Guide for the Brazilian Population (hereinafter called Food Guide), outlines recommendations on healthy eating for the entire population,and is a material based on scientific evidence that provides support for the qualification of dietary guidelines in the Unified Health System (SUS)[11]. Its elaboration derived from a holistic perspective, comprising biological, cultural, social and environmental dimensions of food. Updated in 2014, the Food Guide reestablishes the healthy eating paradigm basing its recommendations on the level and purpose of food processing, which can be summarized in the rule of thumb: "always prefer in natura or minimally processed foods and cooking preparations to ultra-processed foods"[12]. Therefore, the Food Guide should be used as a technical reference for dietary guidelines. However, the use of this material by PHC professionals in clinical routine with different life cycles or phases is not yet established.

Considering the importance of promoting healthy eating in favor of healthy aging and the need for instruments that facilitate and qualify dietary guidelines in PHC, the objective of this study was to develop and validate a protocol for the use of the Food Guide for the Brazilian Population in Brazil in dietary guidelines for the elderly during individual clinical appointments in PHC.

METHODS

This is a methodological study on development and validation of a protocol for the use of the Food Guide for dietary guidelines for the elderly at PHC.

Food Guide for the Brazilian Population

Published in 2014, the Food Guide is an official document that presents recommendations on healthy diet, based on evidence on the rapport between diet and health, systematized in five chapters. The first chapter presents the principles that guided its elaboration; the second one presents recommendations for the choice of food based on classification according to level and purpose of industrial processing; the third one addresses how to combine food in meals and provides recommendations on variety and ways of preparing food based on the traditional Brazilian diet; the fourth one discusses the ways of eating and how time, attention, the environment and the sharing of meals influence the quality of the diet and the pleasure in eating; and the fifth shows potential obstacles to adherence to the recommendations and suggests ways to overcome them[11].

Assuming the Food Guide as a technical reference for guidance and promotion of healthy eating, the development of this protocol is part of a matrix project that developed a series of individual dietary guideline protocols to apply the Food Guide in different life cycles/events. The methodological basis that guided the development of the series was described in a previous publication[12].

Development of the protocol to use the Food Guide for dietary guidelines for elderly people

To elaborate the series of protocols, a team of seven researchers free of conflicts of interest and experts in dietary guidelines based on the Food Guide and on PHC was formed.

The elaboration of the protocol to use the Food Guide for the elderly was carried out following six steps.

(1) protocol format definition; (2) definition of the instrument for assessing food consumption; (3) extracting applicable Food Guide recommendations for individual dietary guidelines; (4) evidence systematization on food and nutrition needs of the elderly; (5) development of dietary guidelines messages for the elderly; (6) content and apparent validation.

Step 1. Format definition: documents on the elaboration of guidelines for clinical practice were analyzed, as well as PHC protocols effective in Brazil[13]. The objective was to investigate the possible formats, analyze their characteristics and identify the most appropriate to guide dietary guidelines in individual appointments in PHC.

Step 2. Definition of the instrument to assess food consumption: To support decision-making for dietary guidelines, a search was carried out on existing instruments for assessing food consumption. The objective was to identify an assessment instrument of the main recommendations from the Food Guide that could be used by any PHC professional during individual appointments.

Step 3. Extracting the recommendations: Two researchers carried out a systematic reading of chapters 2, 3, 4 and 5 of the Food Guide in order to identify appropriate and relevant recommendations that were in line with the indicators of the food consumption assessment instrument identified in Step 2.

Furthermore, additional recommendations considered relevant to be included in the guidelines were identified, even if they were not addressed by the food consumption assessment instrument. The other five researchers on the expert team reviewed the recommendations to elaborate the final list.

Step 4. Evidence systematization on the food and nutrition needs of the elderly: a literature review was carried out by searching the Lilacs, PubMed and gray literature databases (academic Google) for original articles published in English, Portuguese or Spanish, using the terms: elderly, epidemiological surveys, food consumption and eating behavior. Based on scientific evidence produced in dietary surveys, the year 2000 was used as a starting point, considering the year in which the SABE (Health, Well-being and Aging) study began, which is of great relevance in the elaboration of population data on the elderly. The reading was done by a researcher and the entire process of searching, extracting and synthesizing data was discussed as a team. Additionally, it was carried out a search for technical materials from the Ministry of Health[2,14] on the health of the elderly and diet as well as a consultation on the report on food consumption data from the Family Budget Survey (POF) 2017-2018.

Step 5. Development of dietary guidelines messages for the elderly: dietary guidelines messages were elaborated based on the recommendations of the Food Guide extracted in Step 3 to direct dietary guidelines to the specificity of the elderly diet systematized in Step 4, considering obstacles to healthy eating in this life cycle.

Step 6. Content and apparent validation: As a result of the previous steps, version 1 of the protocol was elaborated, divided into subsections. At this step, the validity evidence of the protocol version 1 was assessed.

6.1- Content validation: consisted of assessing the clarity and relevance of the content, as well as collecting suggestions for version 1, through a panel of experts in the following knowledge areas: health of the elderly, food guide and nutritional care in PHC. The experts received support materials by email explaining the validation process, the systematization of life cycle evidence (result of Step 4) and an online form to evaluate each component of the protocol using a 4-point scale ('the item is unclear/relevant (1); 'major revisions are needed to make the item clear/ relevant' (2); 'minor revisions are needed to make

the item clear/relevant' (3); and, 'the item is clear / relevant' (4). Additionally, experts were asked to justify the need for modifications. The protocol components are identified in Table 1 and the numbers presented correspond to the minimum and maximum scores obtained in the assessment of clarity and relevance using the 4-point scale. After completing the form, the experts were invited to participate in an online focus group to collect general impressions about the protocol. Upon the experts collaboration, changes were made to the protocol, thus leading to version 2.

6.2 - Apparent validation: Subsequently, the apparent validation of version 2 of the protocol was carried out, which aimed to identify the content understanding and the protocol applicability by its potential users - health professionals. Online focus groups were held with health professionals with higher education who work in PHC in the five regions of the country. The collaboration from health professionals was taken into account to elaborate the final version of the protocol.

All focus groups were conducted by the researchers on the team, playing the roles of moderator and observer. All focus groups were recorded and later transcribed.

Data analysis of the validation step

For the analysis of the answers filled in the online form, the Content Validity Index (CVI) was used, which measures the proportion of experts who expressed agreement regarding the clarity and relevance of each protocol component. The CVI was calculated by the proportion of grades (3) and (4) divided by the total number of specialists, separately for clarity and relevance. The average CVI was also calculated considering a simple average of the CVI values for clarity and relevance. Components with CVI > 0.80 were considered adequate, that is, they did not need to be modified[15].

The reasons indicated in the online form were analyzed according to Bardin[16] in order to identify suggestions and comments related to the specificity of elderly people. After spotting the most recurrent suggestions made by the specialists, researchers defined themes for suggestions and selected demonstrative examples. Suggestions considered relevant were incorporated into version 2 of the protocol.

The transcripts of the focus groups with professionals were also evaluated with thematic content analysis[16]. Two team members read the transcripts, pre-defined the analysis categories and extracted the related statements. The pre-definition of categories and extraction of the statements were monitored and verified by a third member of the team.

The focus groups were recorded and transcribed, upon permission of the participants. All participants signed the Free and Informed Consent Form. This study was approved by the ethics committee of the Universidade de São Paulo (4,232,862) and conducted in partnership with the Ministry of Health.

RESULTS

The results of the steps described in the methodology will be presented in the items: Protocol structuring (Steps 1 to 3), Evidence on the dietary and nutrition needs of the elderly (Steps 3 and 4) and Protocol validation (Step 6).

Protocol structuring

The adopted methodology culminated in a Usage Protocol, defined according to the Comissão Nacional de Incorporação de Tecnologias (CONITEC) as "documents that set criteria, parameters and standards for the use of a specific technology in a given disease or condition". The Food Guide is understood as the technology to be used for dietary guidelines for elderly people. The protocol was divided into the following subsections:

a. Introduction: contains brief information about the Food Guide, characteristics of the life cycle and outline of the guidelines target audience, the purpose of the protocol and general instructions on conduct, time and number of dietary guidelines for the elderly;

b. Instructions on how the protocol should be used: step-by-step on how to use the protocol (for example: fill in the instrument to assess food consumption, follow the decision-making flowchart and the dietary recommendations);

c. Instrument for assessing food consumption: the Food Consumption Markers form of the Sistema de Vigilância Alimentar e Nutricional (SISVAN)[17], was chosen because it is a concise instrument, already used in the service routine of PHC professionals and that effectively addresses the main recommendations of the Food Guide through nine indicators on healthy and unhealthy eating.

d. Decision flowchart: the flowchart directs the health professional to dietary guidelines according to the questions on the SISVAN form, priority recommendations and the Food Guide rule of thumb. The flowchart is shown in Figure 1.

e. Recommendations: dietary guidelines messages related to each consumption marker on the SISVAN form. Six recommendations were elaborated: "Recommendation 1 - Encourage the daily consumption of beans", "Recommendation 2 - Advise the avoidance of sweetened beverages", "Recommendation 3 - Advise the avoidance of ultra-processed foods", "Recommendation 4 - Advise the daily consumption of vegetables", "Recommendation 5 - Encourage the daily consumption of fruits", "Recommendation 6 - Encourage the person to eat in appropriate environments and with attention".

f. Valuing eating habits: messages to encourage the continuity of healthy eating practices.

g. Additional messages: messages that were not covered by the SISVAN markers, but are relevant in the dietary guidelines for the elderly.

Evidence on the dietary and nutrition needs of the elderly

The search in the Lilacs, Pubmed and gray literature databases found eight, 738 and 70 articles respectively. Seven scientific papers18-24 were included in the evidence synthesis with analysis of the databases of the Health, Well-being and Aging (SABE) study, of the Longitudinal Study on Health and Well-being of Brazilian Elderly (ELSI-Brasil), on the National Health Survey 2013/2014 and VIGITEL (Surveillance of Risk and Protection Factors for Chronic Diseases by Telephone Survey) (Chart 1).

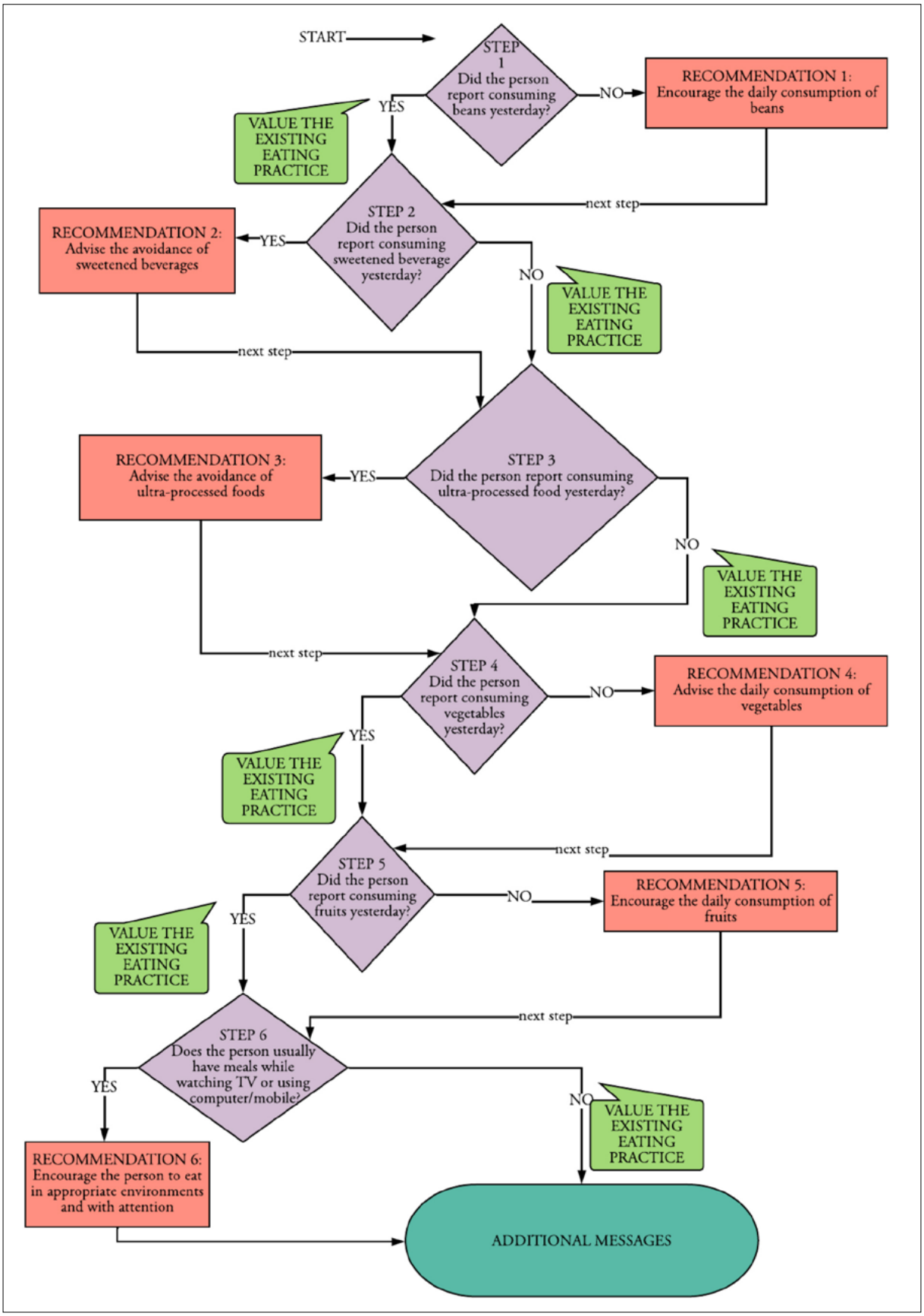

Figure 1. Directional flowchart of conduct for dietary guidelines for the elderly. São Paulo, 2020.

Chart 1. Summary of the main studies included in the literature review on food consumption and associated factors in the elderly. São Paulo, 2020.

Author, year, type of study and survey	Objective and Population	Main results of interest
Almeida MGN, Nascimento-Souza MA, Lima-Costa MF, Peixoto SV. 2020. Transversal. Longitudinal Study on Health and Welfare of Brazilian Elderly (ELSI-Brasil).	To assess associations between unhealthy lifestyle factors (individual and combined) and sex-stratified multimorbidity in Brazilians aged 50 or over.	More than 80% of the elderly had insufficient intake of fruits and vegetables, in both sexes, with or without multimorbidity.
Bezerra I, Gurgel AOC, Barbosa RGB, Junior GBS. 2018. Transversal. National Health Survey - 2013/2014	To describe healthy and unhealthy eating behaviors among Brazilian young and old adults.	Elderly people had higher habitual intake of fruits and fruits and/or juices compared to young adults (18 to 39 years old) and middle-aged adults (40 to 59 years old), in both sexes.
Costa MFFL, Peixoto SV, César CC, Malta DC, Moura EC. 2009. Transversal. VIGITEL (Surveillance of Risk and Protection Factors for Chronic Diseases by Telephone Survey)	To estimate the prevalence of harmful health behaviors and other cardiovascular risk factors among elderly people with self-reported hypertension and comparing them with non-hypertensive individuals.	Prevalence of insufficient intake of fruits and vegetables, addition of salt to meals and consumption of meat with excess fat did not differ significantly between hypertensive and non-hypertensive individuals, even when analyzed separately by sex.
Firmo JOA, Peixoto SV, Loyola Filho AI, Souza-Júnior PRB, Andrade FB, Lima-Costa MF, Mambrini JVM. 2019. Transversal. Longitudinal Study on Health and Welfare of Brazilian Elderly (ELSI-Brasil).	To quantify the contribution of selected health behaviors (physical activity, dieting and smoking habits) to the control of blood pressure levels in a national sample representative of the population aged 50 and over.	17% of individuals indicated eating vegetables and fruits regularly. When analyzing the prevalence of hypertension control according to the adoption of health behaviors, it was observed that this control was greater among the men who reported regular intake of vegetables and fruits (57%).
Dourado DAQS. 2015. Transversal. Health, Wellness and Aging Study (SABE)	To verify the association between metabolic syndrome and eating patterns in elderly people from the city of São Paulo participating in the SABE study, in 2010.	The inadequate pattern was significantly associated with male sex, schooling years greater than 8, alcohol consumption, physical inactivity and absence of NCDs. The modified pattern was significantly associated with female sex, aged between 64 and 69 (cohort B), schooling years greater than 8, never having smoked and having 3 or more NCDs. The traditional Brazilian pattern was significantly associated with age between 60 and 64 years old (cohort C). The beneficial pattern was significantly associated with education and never having smoked.

to be continued

Continuation of Chart 1

Author, year, type of study and survey	Objective and Population	Main results of interest
Marucci MFN. 2018. Transversal. Health, Wellness and Aging Study (SABE)	To compare the nutritional status and food intake of two cohorts (2000 and 2010) of the elderly (60 to 64 years old) participating in the SABE study, according to gender.	Elderly people in the 2010 cohort had a higher prevalence ratio for consuming 3 or more meals/day and 5 or more glasses of liquids/day; and lower prevalence ratio for dairy products, meat and fruits and vegetables. Among women, the prevalence ratio was higher for consumption of 3 or more meals/day and lower for meat consumption; among men, the prevalence ratio was higher among those in the 2010 cohort for consumption of 3 or more meals/day and 5 or more glasses of liquids/day and lower for consumption of dairy products and fruits and vegetables (p<0, 05).
Moura CSS. 2012. Transversal. SABE study: Health, Wellness and Aging Study	To verify the association between the eating behavior of elderly people living in the city of São Paulo and sociodemographic and cultural variables.	82% of the elderly reported intake of dairy products at least 1x/day. 94% reported intake of eggs, beans or lentils at least 1x/week. 92% reported intake of meat, fish or poultry at least 3x/week. 83% reported intake of fruits or vegetables at least twice a day. 58% reported drinking liquids in amounts less than or equal to 5 glasses/day. 68% reported not drinking alcohol in the last 3 months. 67% of the elderly reported having 3 or more meals/day. 82% reported the habit of preparing a hot meal. 85% reported the habit of buying food.

Source: Own elaboration, 2020.

Additionally, information from technical materials published by the Ministry of Health[2-14], and the 2017-2018 POF report, also supported the preparation of the protocol.

The literature review showed that the triple burden of diseases characteristic of this phase of life influences the eating habits of the elderly. The included studies showed insufficient intake of fruits and vegetables and habits of adding salt to ready-to-eat foods and consumption of meat with excess fat. On the other hand, the influence of reduced functional capacity was also identified, such as difficulties in locomotion, chewing and swallowing, changes in taste, smell, vision and cognition, in addition to social changes with a possible reduction in family income and support network for care, in the elderly eating habits and practices.

According to the 2017-2018 POF, the elderly eating pattern was mainly characterized by the consumption of *in natura* or minimally processed foods (56.9% of total energy), mainly rice (11.1%), meat (7.1%) and beans (6.7%). However, there was an insufficient intake of fruits and vegetables, which represented, respectively, 5.0% and 2.2% of the total energy consumed. Ultra-processed foods, in turn, contributed with about 15% of the calories consumed, especially margarine (2.6%), industrialized bread (2.4%) and cookies and "package" snacks (2.2%), followed by cold cuts and sausages (1.2%), sweet biscuits (1.1%) and sweets (1.0%)[25].

Based on these results, the dietary guidelines messages were elaborated considering the needs of the elderly and the possible difficulties found in this cycle to adhere to the recommendations.

Protocol validation

Version 1 of the protocol, submitted to content validation by a panel of experts, in June 2020, had 17 participants, all women, with complete higher education in nutrition (12), medicine (3), nursing (1) or physiotherapy (1) and working in teaching and research, public management or health care.

All protocol components had an average CVI above the cut-off point (0.80). Even so, all contributions from experts in each component were analyzed individually. Out of the 29 components evaluated, 21 obtained total agreement (CVI = 1.0) for clarity and 17 for relevance (Table 1). According to the evaluators, the components that most needed changes were: "Introductory text", "How to use the protocol?", "Assessment of food consumption", "Flowchart", "Recommendation 1" and "Recommendation 6".

Table 1. Description of the content validity index by the protocol component to use the Food Guide for the Brazilian Population in the dietary guidelines for elderly people, São Paulo, 2020.

	Content Validity Index (CVI)		
Component	Clarity (min-max)	Relevance (min-max)	Average CVI
Introductory Text	0.82 (2-4)	0.94 (2-4)	0.88
How to use the protocol?	0.88 (2-4)	1.00 (3-4)	0.94
Food consumption assessment	1.00 (3-4)	0.94 (2-4)	0.97
Flowchart	1.00 (3-4)	0.94 (2-4)	0.97
Recommendation 1- Guideline	1.00 (3-4)	0.94 (2-4)	0.97
Recommendation 1 - Suggestions for variations	1.00 (3-4)	0.94 (2-4)	0.97
Recommendation 1 - Reason	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 1- Obstacles	1.00 (3-4)	0.94 (2-4)	0.97
Recommendation 2 - Guideline	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 2 - Suggestions for variations	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 2 - Reason	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 2- Obstacles	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 3 - Guideline	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 3 - Suggestions for variations	1.00 (3-4)	0.94 (2-4)	0.97
Recommendation 3 - Reason	0.94 (2-4)	1.00 (3-4)	0.97
Recommendation 3 - Obstacles	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 4 - Guideline	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 4 - Suggestions for variations	0.94 (2-4)	0.94 (2-4)	0.94
Recommendation 4 - Reason	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 4 - Obstacles	0.94 (2-4)	0.94 (2-4)	0.94
Recommendation 5 - Guideline	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 5 - Suggestions for variations	0.94 (2-4)	0.94 (2-4)	0.94
Recommendation 5 - Reason	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 5 - Obstacles	1.00 (3-4)	1.00 (3-4)	1.00
Recommendation 6 - Guideline	1.00 (3-4)	0.88 (2-4)	0.94
Recommendation 6 - Suggestions for changing habits	1.00 (3-4)	0.94 (2-4)	0.97
Recommendation 6 - Reason	1.00 (3-4)	1.00 (3-4)	1.00
Additional Guidelines	0.88 (2-4)	1.00 (3-4)	0.94
Practice Appreciation	1.00 (3-4)	1.00 (3-4)	1.00

Source: Own elaboration, 2020.

Some suggestions made by the experts and which were incorporated into the protocol are shown in Chart 2. In addition to suggestions for changes and comments on the relevance, clarity and applicability of the protocol, the experts brought elements about functionality, nutritional needs and eating habits of the elderly, support network and conditions of access to food.

Chart 2. Theme of suggestion and its definition, example of suggestion and example of protocol change, São Paulo, 2020.

Suggestion theme and definition	Suggestion example	Example of change made to the protocol
Clarity: Suggestions for adapting the technical terms used, improving phrases and defining the profile of the elderly to direct the guidelines.	"We know that the audience for this protocol of use is the elderly, but we suggest including the reference in years (individuals above 60 years old or over), at the beginning of the material".	"This group of individuals includes those aged 60 and over."
Functionality: Suggestions related to physiological changes in the elderly (smell, vision, taste, chewing, swallowing, intestinal function, appetite, loss of muscle mass), comorbidity, cognitive condition of the elderly and autonomy to buy, prepare food, as well as to feed themselves.	"Include something about oral hygiene care - related to taste loss and guidelines for taste preservation in the elderly".	"Remember that oral hygiene care, including brushing the tongue, helps to better feel the taste of food, avoiding excess use of salt and processed seasonings".
Nutritional needs: Suggestions related to specific nutritional needs and for the elderly.	"I believe it will be valid to add how many glasses of water per day, as dehydration is common in the elderly".	"Encourage water intake even not being thirsty. Drinking water is essential to prevent dehydration and constipation, common in this stage".
Support network: Suggestions related to the support network for the elderly, including, in addition to family members and caregivers, health care and health professionals.	"Reinforce that elderly and family caregivers at a time of loss of autonomy can offer an opportunity to raise awareness, discuss solutions and search for healthy choices that meet the elderly particularities and needs ".	"In cases of greater clinical complexity and functional fragility, it is necessary to involve a multidisciplinary team, such as the NASF team or specialized secondary care teams, so that the diagnosis and choice of the most appropriate conduct are carried out from the perspective of comprehensive care".
Access and income: Suggestions on access to food and income for the elderly to buy it.	"Consider the socioeconomic issue of the vast majority of elderly PHC users".	"For the elderly person who has difficulty in obtaining financial access to buy food, seek help from social service or other support in the country to face food and nutritional insecurity".
Eating habits and method of preparation: Suggestions related to eating habits and how to prepare food.	"It is important to discuss with the elderly how they prepare beans (addition of sausages)".	"Attention to the amount of salt, salted meat and sausage meats, such as pork sausage, used when preparing beans. Encourage the use of natural seasonings (such as parsley, garlic, onion, basil, black pepper, cumin, bay leaf, mint, jambu, oregano, coriander, rosemary, pepper, tomato, among others) to add flavor to the preparations and reduce the excessive use of salt".

Source: Own elaboration, 2020.

The apparent validation with health professionals, carried out with version 2 of the protocol, had the participation of 9 professionals working in PHC in different regions of the country, including nurses (3), doctors (3), psychologists (2) and dentists (1) and took place in August 2020. Thematic analysis of the focus group transcripts identified two analysis categories: (1) applicability of the protocol in the life stage and (2) applicability of the protocol in the work routine in PHC. In general, the professionals considered the protocol applicable in individual appointments with the elderly assisted in the Brazilian PHC.

One professional recognized the protocol as an educational tool and reinforced that, as challenging as it may seem to promote changes in eating habits in the elderly, he can already see its application in this life stage.

> "It's about valuing the food practice and guiding what he needs to reeducate. [...] Reeducating is not something common in the plans of an elderly person, right? It's hard for us to have that kind of approach with them, but yes, I can already see people using it. I think it will be really welcome on a day to day basis." P1

Another professional expressed satisfaction with the protocol structuring and argued that the use of justification to explain and reinforce the recommendation given in the protocol is essential to help change behaviors in this period.

> "I'm going to tell this old man not to eat the sweets he has eaten his whole life and he's never done him any harm. He's going to leave and he didn't see the point of it. So, when you explain the reasons, how beneficial this food is, how much it impacts the body, how much it reverberates across the general context of health, he feels part of this conversation [...]. So justifying it makes sense. Then we can do, eat things that maybe we don't like, don't want, but because we saw meaning in that and that will have an impact in the future. So I really like the justification part." P2

Regarding the protocol application in the work routine, a professional pointed out that the protocol can be used in the appointment as long as there is enough time.

> "When [the professional] manages to access an elderly person in an appointment or in a spontaneous demand with a little more time to apply the markers on Sisvan, I think we have to get that time with him. So, I don't think it's bad for us to be able to apply [the protocol] as a whole, because it's saving time with this person. Because, perhaps, the professional can no longer have him in the appointment schedule with as much time as there is for other health conditions in the unit." P3

At the end of this step, the final version of the protocol for the use of the Food Guide for the elderly was elaborated, published by the Ministry of Health[26].

DISCUSSION

The protocol development and validation process demonstrated the relevance of an instrument to support the individual clinical practice of PHC health professionals at SUS. The protocol was well assessed as to clarity and relevance by experts, justifying its purpose. In addition, the experts indicated that the instrument achieved its objective by synthesizing the recommendations from the Food Guide, contemplating the specificities of the elderly, such as functionality, nutritional needs and support network. The panel with health professionals indicated the feasibility of using the protocol and its potential to be applied in the work routine in different regions of the country, qualifying the dietary guidelines for the elderly in PHC.

This is the first study in the country to date that seeks to develop and validate a protocol for dietary guidelines for the elderly in the PHC context. Previous efforts in the perspective of promoting healthy eating were invested from the incorporation of the Food Guide messages in the 10 steps for healthy eating for the elderly, contained in the "Elderly Card" [14]. However, the 10 steps are configured as an educational instrument, not meeting the need for a protocol for dietary guidelines based on the assessment of individual food consumption.

It is also noteworthy that most of the protocols related to the elderly diet are related to a specific disease, or yet designed to the bedridden or hospitalized elderly [6,27,28]. In this sense, the protocol described in this study is innovative as it proposes to support guidance for a health practice that promotes healthy aging, healthy eating and comprehensive care based on food diagnosis and provides technical support to health professionals, which can contribute to the use of the Food Guide recommendations in clinical practice in PHC.

In addition, the protocol contributes to giving value to the SISVAN food consumption markers form, which still has incipient use coverage in all life stages[29]. Furthermore, the protocol advances the discussion on the need to think about the dialogic elaboration of clinical-nutritional protocols, to legitimize interdisciplinarity and comprehensive care to promote healthy eating, from the perspective of an expanded clinical practice[30,31].

Another innovation of this protocol is the target audience. The protocol seeks to serve as an instrument of dietary guidelines that can be applied by all health professionals with higher education in PHC to promote the health of the elderly. The evaluation of the protocol applicability with health professionals from different categories demonstrated its potential to be used in the service context, contributing to the comprehensive care of the elderly, ceasing the fragmentation of health care at this stage of life[31,32,33].

However, although the protocol was well assessed in all aspects investigated, the dense work routine with little time for individual consultation, the lack of permanent education activities that strengthen the incorporation of tools in the work routine and the insufficient induction of management to carry out food and nutrition actions in the teams[34] make it difficult to incorporate new tools into the services. In this sense, although the protocol has proven to be relevant and viable for use, continuing education strategies for professional training and support from the three management levels are required to legitimize the implementation of the protocol developed[35]. As well as new studies to evaluate the implementation of protocols in Brazilian PHC.

As limitations of the study, we highlight that due to the lack of participation of representatives from all Brazilian states in the focus groups, there may be an insufficient representation of all food regionalities found in the country. On the other hand, the participation of representatives from the five Brazilian regions and the extraction of recommendations from the Food Guide (Step 3) contributed to incorporating the food characteristics from different regions around the country. Another aspect is linked to the online format for data collection. The contribution, especially from professionals who participated in the groups after a work day, may have been influenced by the participants tiredness.

Finally, it is noteworthy that the instrument elaborated is not intended to replace the individualized dietary prescription, does not comprise frail elderly people, with a marked decrease in their functional capacity or those with special dietary needs. However, the recommendations for promoting adequate and healthy eating contained in the Food Guide are applicable and benefit all individuals, including the prevention and management of CNCDs, not excluding its use in the dietary guidelines of individuals with associated pathologies.

CONCLUSION

The article presents the protocol elaborating process for the use of the Food Guide for Brazilian Population in dietary guidelines for the elderly. The protocol has the potential to expand the practice of promoting healthy eating and quality of life among SUS elderly people. In addition, it provides clinical support to the different areas of knowledge of PHC health professionals, including geriatrics and gerontology, expanding comprehensive health care, qualifying guidelines on healthy eating and knowledge about the information in the Food Guide. It is noteworthy that for its implementation throughout the country, broad dissemination among managers and health professionals as well as investment in continuing education activities are required.

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Relationship between functional capacity, nutritional status and sociodemographic variables of institutionalized older adults

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Abstract

Objective: To analyze the relationship between functional capacity, nutritional status, and sociodemographic variables of older adults living in long-term care facilities. *Method:* This is a cross-sectional study conducted with 82 institutionalized older adults. For data collection, we used the Barthel Index to assess the degree of independence in the performance of basic activities of daily living and the Mini Nutritional Assessment (MNA) to assess the nutritional status of older adults. Data were collected in five geriatric long-term care facilities located in southern Brazil. Ordinal regression analyses were performed to identify associations between contextual social factors, and nutritional status with the functional capacity of institutionalized older adults. *Results:* Most participants showed complete independence in performing activities of daily living (39.0%) and poor nutritional status (59.8%). The multivariate ordinal regression analysis showed that older adults with higher scores in the nutritional assessment are associated with better indicators of functional capacity (OR=1.33; 95% CI=1.15 to 1.54; p<0.001). We did not find an association between educational level, pressure injuries, body mass index, and functionality. *Conclusion:* Nutritional status is a significant predictor for dependency in institutionalized older adults.

Keywords: Functional Status; Elderly Nutrition; Activities of Daily Living; Homes for the Aged.

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INTRODUCTION

The aging process is characterized by a global and progressive decline in physiological functions. Therefore, the maintenance of functional capacity has to be essential in the health and quality of life of older adults, as it is related to the ability to perform daily activities necessary for an independent life. The characterization of the functional capacity of older adults has great relevance since it is an indicator of the health status of this population and essential for choosing the best intervention and monitoring the clinical status of older adults[1].

Sarcopenia and decreased muscle strength can limit the functional capacity of older adults. The loss of muscle mass, around 1 to 2% per year after the age of 50, occurs mainly due to a decline in protein synthesis, causing the replacement of muscle tissue by adipose and fibrotic tissue[2,3]. Studies have shown a significant increase in malnourished older adults, with prevalence ranging from 15 to 60%, depending on the older adult's place of residence[4–7].

Many families increasingly tend to share the responsibilities of older adult care with the geriatric long-term care facilities, as they need help with health conditions and day-to-day care. Long-term care institutions are a strong trend in health care and are becoming increasingly necessary[5,6,8]. Studies have identified that functional disability is related to multidimensional factors that reduce the well-being and quality of life of the older adults[9,10]. However, few studies in Brazil have carried out investigations on functionality, specifically with institutionalized older adults[10–12].

Considering that institutionalized older adults have a higher prevalence of malnutrition and dependence for activities of daily living (ADLs) than community-dwelling[2,13], it is essential to identify the factors associated with the decline in functional capacity to support strategies for promotion and health care for this population. In this context, this study aimed to analyze the relationship between functional capacity with sociodemographic variables and the nutritional status of a group of older adults living in long-term care facilities in Curitiba (PR).

METHODS

This cross-sectional study was conducted with 82 older adults in five geriatric long-term care facilities (LTCF) in Curitiba (PR) from 2015 to 2016. The participants, selected for convenience, consisted of institutionalized older adults aged over 60 years. Older adults who presented severe cognitive alterations that affected their perceptive, discernment, and language skills were excluded.

The researchers followed the ethical research aspects set out in the Brazilian Resolution 466/12 of the National Health Council. The study was approved by the Research Ethics Committee of the Pontifical Catholic University of Paraná (no. 80.215.901) and formally authorized by those responsible for the institutions involved. All participants were informed about the research objectives and data confidentiality and signed the Informed Consent Form (ICF).

Initially, the participants' sociodemographic data were collected: age (in years), sex, marital status, education (in years of formal education), institutionalization time (length in LTCF in months), presence of pressure injury, number of medications, and polypharmacy, defined in the present study as more than five medications per patient[14].

The assessment of the functional status of the older adults was performed by the Barthel Index (BI)[15]. The level of independence for ten basic activities of daily living was evaluated: feeding, personal hygiene, use of toilets, bathing, dressing, bladder control, walking, transferring from chair to bed, and going up and down the stairs. The total scale score ranges from 0 (complete dependence) to 100 (complete independence). In the present study, the BI was analyzed as a continuous variable and categorized as: totally dependent (0-20), severely dependent (21-60), moderately dependent (61-90), mildly dependent (91-99), and independent (100)[15].

For the nutritional assessment of the older adults, the translated version into Brazilian Portuguese of the Mini Nutritional Assessment (MNA®) (*Société des Produits Nestlé SA, Trademark Owners*) was used. The MNA is a validated, sensitive, and appropriate

instrument for identifying malnourished older adults or those at risk of malnutrition and is widely used with older adult populations in different contexts[4,16,17]. It consists of 18 items of anthropometric aspects, global clinical assessment, dietary assessment, and nutritional status. The final score is the sum of all items, which allows for identifying the nutritional status and the risks for the older adults. The assumed scores to classify the nutritional status of the participants were: malnutrition (<17), risk of malnutrition (17-23.5), and normal nutritional status (24-30)[16].

Anthropometric measurements of weight, height, and waist, hip, arm, and calf circumferences were collected according to procedures recommended by the Brazilian Ministry of Health[18] and the World Health Organization[19]. The classification of the body mass index (BMI) was based on specific cutoff points for the older adults established by the Food and Nutritional Surveillance System, as follows: underweight (≤22 kg/m2), eutrophic (> 22 and < 27), and overweight (≥ 27)[18]. Interviews and data collection were conducted in a standardized manner by the first author. These data were collected in a single moment, in reserved places in the LTCF, to preserve participants' privacy.

Descriptive statistical analyses were performed to present and summarize the collected data. Absolute and relative frequencies presented categorical variables. Continuous variables were presented as mean and standard deviation (SD) when normally distributed and as median and interquartile range (IQR) when not normally distributed. The variables were tested for normality using the Kolmogorov-Smirnov test. To verify the association between the independent variables and the functional capacity of institutionalized older adults, considering the IB categories as a dependent variable, Fisher's exact test, unidirectional analysis of variance, and Kruskal-Wallis were applied. All independent variables that showed a significant association in the univariate analysis (p≤0.25) were included in the multivariate model. For the multivariate analysis, the proportional odds ordinal logistic regression model was used[20], estimating the odds ratios and the respective 95% confidence intervals (95% CI). The assumptions for ordinal regression of absence of multicollinearity between independent variables and proportional odds were met. Multicollinearity was assessed using variance inflation factors (VIF) that remained between 1.05 to 1.10. The assumption of proportional probabilities was verified by the parallel line test for the fitted model (p=0.065). Pearson's and deviance tests were used to analyze the goodness of fit of the model. Residuals for each covariate included in the model were calculated using binary logistic regression for all cutoff points of the dependent variable. The significance level of 5% was adopted in all analyses.

RESULTS

Eighty-two older adults participated in the study, with a median age of 74.5 years, ranging from 64 to 92 years old, and a median length of institutionalization of 42.88 months. Most participants were men, single, illiterate, eutrophic, and had no pressure injuries. Polypharmacy was observed in 57.3% of the older adults, with a median consumption of 5.0 medications. The sociodemographic characteristics of the participants are shown in Table 1.

As for the functional capacity of institutionalized older adults, the median BI was 95.0. Most showed complete independence (39.0%) in performing basic ADLs. About 46.0% showed a degree of mild to moderate dependence, and only 14.6% showed a degree of severe to total dependence. Regarding the nutritional assessment of the older adults, the mean MNA score was 22.5 (±3.19), and most were classified as at risk of malnutrition.

Only MNA was statistically associated with the BI score in univariate analyses (Table 3). Four variables were included in the multivariate model (p<0.25): education, pressure injuries, BMI and MNA.

The multivariate analysis between functional capacity and the variables education, pressure injuries, BMI, and MNA resulted in a statistically significant model (Table 4). After model adjustment, the results indicate that MNA remained significantly associated with functional capacity (p<0.001). The parallel line assumption test was not violated (p=0.065). Institutionalized older adults with higher scores on the MAN are 33.4% more likely to present better functional capacity indicators.

Table 1. Sociodemographic characteristics of institutionalized older adults. (N=82). Curitiba, PR, 2015-2016.

Variables	Frequencies
Sex*	
Male	51 (62.20)
Female	31 (37.80)
Age (years)**	74.50 (70.00 – 80.20)
Age (categories in years)*	
60-69	19 (23.20)
70-79	39 (47.60)
80-89	22 (26.80)
>90	2 (2.40)
Marital status*	
Single	33 (40.30)
Married/living with a partner	2 (2.40)
Separated/divorced	20 (24.40)
Widowed	27 (32.90)
Education*	
Illiterate	49 (59.80)
Elementary School	21 (25.60)
High school	12 (14.60)
Length of institutionalization** (months)	42.90 (2.00 – 96.00)
Length of institutionalization* (categories in months)	
0-11	10 (12.20)
12-59	39 (47.60)
60-119	19 (23.20)
>120	14 (17.10)
Pressure injuries*	
No	61 (74.40)
Yes	21 (25.60)
Number of drugs**	5.00 (3.00 – 8.00)
Polypharmacy*	
No	35 (42.70)
Yes	47 (57.30)
Body Mass Index** (kg/m^2)	23.50 (21.00 – 26.40)
Body Mass Index (categorized)*	
Underweight	27 (32.90)
Eutrophic	36 (43.90)
Overweight	19 (23.20)

*****Categorical data are presented with numerical values and percentages.

****** Continuous variables are reported with median and 1st and 3rd quartiles.

Table 2. Classification of institutionalized older adults according to Barthel Index and Mini Nutritional Assessment. (N=82). Curitiba, PR, 2015-2016.

Variables	Frequencies
Barthel Index (continuous)	95.00 (80.00 – 100.00)
Barthel Index (categorized)	
Totallly dependent	4 (4.80)
Severely dependent	8 (9.80)
Moderately dependent	24 (29.30)
Mildly dependent	14 (17.10)
Independent	32 (39.00)
Mini Nutritional Assessment (continuous)	22.50 ±3.19
Mini Nutritional Assessment (categorized)	
Malnourished	3 (3.70)
At risk of malnutrition	46 (56.10)
Normal nutritional status	33 (40.20)

Note: BI is presented as median and 1st and 3rd quartiles and MNA as mean and standard deviation.

Table 3. Univariate analyses between functional and sociodemographic variables and mini nutritional assessment in institutionalized older adults. (N=82). Curitiba, PR, 2015-2016.

	Barthel Index					
Independent variables	Total (n=4)	Severe (n=8)	Moderate (n=24)	Low (n=14)	Independent (n=32)	p-value
Sex						0.708*
Male	3 (5.9)	5 (9.8)	12 (23.5)	9 (17.6)	22 (43.1)	
Female	1 (3.2)	3 (9.7)	12 (38.7)	5 (16.1)	10 (32.3)	
Age (years)	76.00 (71.0-79.0)	79.50 (72.0-85.0)	75.00 (72.5-79.5)	72.00 (68.0-83.0)	74.00 (68.0-80.0)	0.666**
Marital status						0.496*
Single	0 (0.0)	3 (9.1)	12 (36.4)	4 (12.1)	14 (42.4)	
Married/living with a partner	1 (50.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (50.0)	
Separated/divorced	1 (5.0)	1 (5.0)	6 (30.0)	4 (20.0)	8 (40.0)	
Widowed	2 (7.4)	4 (14.8)	6 (22.2)	6 (22.2)	9 (33.3)	
Education						0.089*
Illiterate	4 (8.2)	4 (8.2)	17 (34.7)	7 (14.3)	17 (34.7)	
Elementary School	0 (0.0)	1 (4.8)	7 (33.3)	3 (14.3)	10 (47.6)	
High school	0 (0.0)	3 (25.0)	0 (0.0)	4 (33.3)	5 (41.7)	
Length of institutionalization	54.0 (24.5-72.0)	36.0 (12.0-36.0)	42.0 (15.0-96.0)	44 (24.0-96.0)	50.0 (24.0-96.0)	0.544**
Pressure injuries						0.130*
No	3 (14.3)	1 (4.8)	8 (38.1)	2 (9.5)	7 (33.3)	
Yes	1 (1.6)	7 (11.5)	16 (26.2)	12 (19.7)	25 (41.0)	
Number of medications	8.00 (6.00-9.00)	6.50 (3.50-8.00)	6.00 (3.50-9.00)	5.00 (2.00-8.00)	4.00 (1.50-6.50)	0.385**

to be continued

Continuation of Table 3

	Barthel Index					
Independent variables	Total (n=4)	Severe (n=8)	Moderate (n=24)	Low (n=14)	Independent (n=32)	p-value
Polypharmacy*						0.569*
No	1 (2.9)	2 (5.7)	9 (25.7)	6 (17.1)	17 (48.6)	
Yes	3 (6.4)	6 (12.8)	15 (31.9)	8 (17.0)	15 (31.9)	
Body Mass Index	19.8 (17.74-22.12)	22.56 (20.80-26.71)	25.55 (21.50-29.86)	23.11 (19.90-28.70)	23.66 (22.04-25.75)	0.139**
Mini Nutritional Assessment	17.37 ± 4.76	21.50 ± 1.75	21.52 ± 3.22	23.32±2.99	23.81±2.43	<0.001***

Categorical values presented as absolute numbers and percentages; continuous variables presented as medians and 1st and 3rd quartiles or mean and standard deviation; *Fisher's exact test; **Kruskal Wallis test; *** One-way ANOVA.

Table 4. Multivariate ordinal regression model between functional capacity as a dependent variable and education, pressure injuries, body mass index, and nutritional assessment in institutionalized older adults. (N=82). Curitiba, PR, 2015-2016.

	Barthel Index		
Independent variables	OR	I95% CI	p-value
Education			
Illiterate	1.18	0.34 to 4.10	0.792
Elementary School	2.15	0.52 to 8.89	0.290
High school	1.00		
Pressure injuries			
No	0.75	0.28 to 1.99	0.569
Yes	1.00		
Body Mass Index	0.97	0.90 to 1.05	0.537
Mini Nutritional Assessment	1.33	1.15 to 1.54	<0.001*

OR, odds ratios; 95% CI, 95% confidence interval adjusted for the other variables included in the ordinal logistic regression model.

Model summary: F(5)=19.42, p=0.002; Pseudo R^2 Nagelkerke = 0.225; Pearson's test p=0.660; Deviance test p=1,000.

*Statistically significant variables (p≤0.05).

DISCUSSION

The present study demonstrated that nutritional status is a significant predictor for dependency in institutionalized older adults. The multivariate ordinal regression model results indicated that older adults with higher scores in the nutritional assessment are 1.33 times more likely to have higher scores in the IB (low dependence and independence). Deficient nutritional status was identified in 59.8% of institutionalized older adults. Malnutrition is a frequent condition among older adults, but health professionals often underestimate it in diagnostic and therapeutic investigations[20,21]. The high prevalence of nutritional risk in older adults was also identified in LTCF in different regions of Brazil, with proportions ranging from 39.6 to 76.2%[8,22–24].

Deficient nutritional status decreases muscle strength and increases fatigue, negatively impacting physical capacity and quality of life[3,7]. Sousa et al.[8] found that low weight is an important factor associated with functional disability in institutionalized older adults, with a prevalence ratio of 1.2 times compared to eutrophic individuals. In this study, 33.0% of older adults were independent in their ADL, and 67.0% had some degree of dependence. Moreira and Boas[12] evaluated the functional capacity of

54 institutionalized older adults by applying the scales of basic activities of daily living (BADL) and instrumental activities of daily living (IADL). The authors found that the reduced ability for BADL was directly related to low weight, with a prevalence ratio of 2.35.

Our study found no association between the number of medications and functional capacity. Several medications of continuous use can increase the absorption of nutrients, increasing the risk of malnutrition in older adults[25].Several studies have shown an association between functional capacity decline and polypharmacy in older adults, with a consequent increase in the risk of adverse clinical outcomes[14,25–28]. However, most of these studies were carried out with community-dwelling older adults. There was no association between polypharmacy and functional status in two longitudinal studies carried out precisely with institutionalized older adults[29,30]. A possible explanation may be that the variable "number of medications" used in the study was measured by self-report. We cannot exclude the possibility that more refined measures for medication use and studies with longitudinal designs may help identify the association between polypharmacy and functionality. Furthermore, we consider that factors related to the health systems and medicine conditions of access may be investigated in greater depth.

In the multivariate ordinal regression analysis, we found no association between length of institutionalization and functional capacity. The majority of the older adults (47.6%) lived in the LTCF between one and five years. Oliveira and Mattos[13] also did not find this association when assessing the functional capacity of institutionalized older adults in Cuiabá (MT), most of them with a length of stay of less than five years. Likewise, an association between length of stay and nutritional status of institutionalized older adults was not identified in the study conducted in Rio de Janeiro (RJ)[22]. Lacerda et al.[31] found that the degree of dependence can vary according to the host institution. The institution starts to assume all the responsibilities that would originally belong to the older adults, increasing their dependence and, consequently, decreasing their functional capacity.

Different instruments are applied to assess the nutritional and functional status of older adults. The lack of standardization in the classification of dependence and different cutoff points for the same instrument make it difficult to compare the results between studies carried out with the older adults[13]. In the present study, we used the Barthel Index and the MNA to diagnose the functional and nutritional status of older adults. The MNA is an essential nutritional screening tool for the early identification of nutritional risk in groups of older adults, and it can be used both in LTCF and in the community in a family environment[16]. On the other hand, the BI is an instrument developed to evaluate the degree of independence in the performance of BADL, with consistent reliability and validity and previously applied to older adult populations in LTCF[1,28,32,33].

We found that most older adults were independent, with a median BI of 95.0. A study carried out in three LTCFs in Presidente Prudente (SP) evaluated the functional capacity of 115 older adults and found that 75.6% presented independence for ADLs, with an average of 80 points in the BI[3]. Functional capacity is related to primary, instrumental, and advanced activities of daily living. The effects of aging, added to conditions that cause dependence, reduce the ability of older adults to overcome environmental challenges[1]. Physical inactivity can enhance the functional disability of older adults. Consequently, the decline in aspects related to their health can result in an even greater reduction in the level of physical activity and an increase in the risk of falls[9,35].

The results of this study must be interpreted with caution. The convenience sample limits the generalization and extrapolation of data, and causal inferences between the functional capacity and the analyzed variables cannot be made due to the cross-sectional design. Therefore, we highlight the need to conduct longitudinal and multicenter studies that assess the risk factors for functional dependence in the context of LTCF, especially to guide strategies for health promotion, reduction of nutritional risk, and independence of the institutionalized older adults.

Institutionalization can be a factor in the functional decline of the older adults[9]. It is noteworthy that the progressive character of functional disability

among older adults concerning increasing age is not only due to chronological factors and is not an inevitable result of aging itself. Instead, what defines the autonomy in the daily life of older adults is the quality of care provided, encouragement and support to carry out tasks, and respect for their eating habits and preferences, especially in an institutional context.

CONCLUSION

This study showed that the nutritional status might be associated with the functional decline of older adults living in long-term care facilities in Curitiba (PR). The largest proportion of older adults participating in this research presented deficient nutritional status, which denotes attention to the nutritional care of this population. Identifying variables associated with the reduction of functional capacity contributes to understanding this phenomenon and allowing for the guidance of the practices developed in the LTCF that prevent health problems of institutionalized older adults. Based on the results, we highlight the need to invest in actions that promote the functional independence of the institutionalized older adults, giving close attention to the stimulation of levels of functionality and reduction of nutritional risks.

Functionality requires a look beyond chronic diseases; one must seek to understand all the functional aspects of the aging individual. Therefore, a multidisciplinary team in the care of institutionalized older adults is essential to carry out an early diagnosis of nutritional deficiency and working on maintaining autonomy and reducing functional disability, which is essential to guarantee the improvement of the quality of life of this population.

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Nutritional risk and associated factors in older people with HIV / AIDS and use of antiretroviral therapy in reference centers

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Abstract

Objective: To identify the nutritional risk of older people with HIV / AIDS and the associated factors. *Method*: It is a cross-sectional and analytical study. 241 older people from the Reference Services in Recife/PE, Brazil participated. The dependent variable was Nutritional risk, assessed by the Mini Nutritional Assessment and the independent ones, the sociodemographic, lifestyle and health conditions. *Results:* 44% of participants with nutritional risk were identified. There was an association between nutritional risk and female gender, education between 1-4 years of study and symptoms of depression. *Conclusion:* It is suggested to include screening measures for early intervention of nutritional status, such as Mini Nutritional Assessment in the care routine, with a view to enabling greater comprehensiveness in care in Gerontology and reducing the risk of morbidity and mortality associated with the disease, and promoting longevity of better quality for those living with HIV.

Keywords: Older people. HIV. Nutritional status. Nutritional assessment.

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INTRODUCTION

The occurrence of HIV/AIDS in older people is a public health problem. Between 1996 and 2019, the incidence in the Brazilian population aged 60 and over increased from 5.9 to 12.2 in men and from 1.8 to 5.9 in women, per 100,000[1]. Older people living with HIV are more vulnerable to premature death, since, with the epidemiological transition, it is in this population group that chronic diseases[2] related to an inadequate lifestyle, such as a sedentary lifestyle, consumption of alcohol, smoking and unhealthy eating[3] prevail.

On the one hand, the introduction of antiretroviral therapy (ARVT), from 1996 onwards, reduced the morbidity and mortality rates associated with the infection, improved the quality of life and enabled the longevity of people living with HIV. On the other hand, it favored the occurrence of metabolic alterations and changes in body composition, such as: accumulation of visceral fat, weight loss or overweight and obesity.

From a nutritional point of view, the magnitude of malnutrition in HIV-infected individuals has negative health impacts. The weakening of the immune system caused by the disease is aggravated by malnutrition, increasing susceptibility to opportunistic diseases. As the disease progresses, there is a reduction in the response to antiretrovirals and an increase in mortality rates[4].

Studies that address nutritional assessment in older people with HIV, as an exclusive case series, are still insufficient. The vast majority of manuscripts include assessments with the adult population, including older people in this group. In this context, the metabolic and body composition changes caused by the disease and its treatment are being considered, devaluing the knowledge about the particularities related to the aging process, such as the reduction of body water, the loss of muscle and bone mass (osteopenia), and immunosenescence[5]. The detection of the risk of malnutrition in older people with HIV is important to support the establishment of strategies for early intervention, monitoring and prevention of complications. In this sense, this research aimed to investigate the nutritional status of older people with HIV/AIDS in the city of Recife and its associated factors.

METHODS

Quantitative, cross-sectional and analytical study carried out at reference services for HIV treatment in Recife/PE, Brazil. The municipality has seven reference services for specialized treatment, including the dispensing of medication to people living with HIV. Only two services were not included, due to the lack of timely release of the letter of consent for data collection at the unit. The State STI/AIDS Program, autonomous in each sphere of government, carries out actions to promote the health of the national STI/AIDS Policy; protection of the fundamental rights of people with HIV/AIDS; prevention of transmission of STIs, HIV/AIDS and drug misuse; diagnosis, treatment and assistance to people with STI/HIV/AIDS.

The participants in this study were older people aged at least 60 years, infected with HIV, of both sexes and registered to receive specialized treatment at outpatient, laboratory, drug and inpatient levels, when necessary, in these health services.

To determine the sample size, the number of older people using ARVT was used, according to data from the Health Department of the State of Pernambuco, according to the Medication Logistic Control System (SICLOM), corresponding to a total of 1,032 older people. The Correction Factor for finite population was used, estimating the expected prevalence of 50% for the outcome (nutritional risk), considering the lack of consensus on its magnitude in older people. After establishing a confidence level of 95% and a maximum acceptable error of 5%, the sample size was determined in 241 older people, selected by convenience, from March to August 2017.

The sample was determined by convenience, since the individuals eligible for the research were a minority in the care services, given the predominance of young people. The capture of the older people for the interviews took place in one of three situations: by the presence of the participants for a medical consultation identified on the previous day, in the collection of laboratory tests by appointment and in

the Pharmacy sector, on the occasion of dispensing medications. The older people were identified by the Nursing team and invited to participate by the responsible researcher. The research objectives and all data collection procedures were duly clarified. Those who agreed to participate registered their consent in the Free and Informed Consent Form (ICF). There was only 1.6% of refusals. The interviews were carried out in the morning, during every day of the week until completing the sample, due to the greater demand for attendance of older users to be concentrated in this period.

Older people registered in HIV reference units and using antiretroviral therapy for at least 30 days were included. Individuals with cognitive impairment, assessed using the Mini Mental State Examination – MMSE[6] and unable to have their anthropometric measurements measured (bedridden and wheelchair users) were excluded.

For the dependent variable, the Mini Nutritional Assessment - MNA short form was used, consisting of six questions that classified the older people according to the scores in: normal nutritional status (≥12 points), risk of malnutrition (8 to 11 points) and malnutrition (≤7 points)[7]. The independent variables corresponded to sociodemographic data, health conditions and lifestyle. Sociodemographic data included: sex, age, marital status, education, individual monthly income, condition of living alone, source of financial resources and contribution to family income.

Regarding lifestyle, three modifiable factors were evaluated[8]: physical activity, considered physically active, one whose practice was performed for at least 30 minutes a day, five days a week (150 minutes), including the daily routine walking or by bicycle to work, climbing stairs, if possible every day, continuously or cumulatively.

For smoking, the classification was: non-smoker, ex-smoker and smoker. Current smoking or quitting within a period of less than six months was considered as a Smoker[8]. For alcohol consumption (habit and frequency), the classification was: "no consumption", occasional or rare (less than four times a month), 1-6x/week or daily.

With regard to health conditions, comorbidities were observed from the entries in the medical records. Functional impairment was assessed using the Barthel Index (0-20 total dependence; 21-60, severe dependence; 61-90, moderate dependence; 91-99, very mild dependence and 100, independence)[9]. To screen for depressive symptoms, the Yesavage Geriatric Depression Scale (GDS–15) was used, which considers a result of five or more points as positive for depression[10].

To measure the circumference measurements, a 2 meters long and 1 mm graduation Cescorf® inelastic measuring tape was used. Waist circumference was measured with the older person standing upright, with relaxed abdomen, arms extended along the body and legs closed, measuring the midpoint between the last rib and the iliac crest, with no clothes on the region. The hip circumference was obtained at the level of maximum gluteal extension. Then, the ratio was calculated by dividing the waist measurement by the hip measurement, in centimeters[11,12].

The cut-off point for high risk for waist circumference corresponded to ≥94 for men and ≥80 for women. Measures ≥102 and ≥88 for men and women, respectively, were indicative of very high risk in terms of abdominal adiposity[13]. Values resulting from a waist-to-hip ratio ≥0.85 cm for women and ≥0.95 cm for men were considered as risks for coronary artery disease, hypertension and diabetes. In relation to HIV, viral load was evaluated, based on secondary data of up to 90 days and classified as detectable (>40 copies) or undetectable (≤40 copies)[14].

The association between explanatory variables (sociodemographic and health conditions) and nutritional status (outcome) was performed through bivariate and multivariate analyses. For the outcome, MNA was recategorized as "present" (malnutrition or risk of malnutrition) or "absent" nutritional risk. To determine the factors associated with nutritional risk, in the bivariate analysis, the explanatory variables were observed individually, a contingency table was constructed and the chi-square test for independence was applied. In cases where the assumptions of the chi-square test were not satisfied, Fisher's exact test was applied. All conclusions were made considering a 5% significance level. In the multivariate analysis,

Poisson regression was used. The prevalence ratio was adopted as a measure of association with their respective confidence intervals.

Variables in which the association test showed significance of up to 20% ($p \leq 0.20$) in the bivariate analysis were included in the multivariate model. To assess which factors jointly influence nutritional risk, the Poisson multivariate model was adjusted with a robust covariance matrix to obtain the corresponding estimates of the prevalence ratios (PR). Initially, an individual model was adjusted for each group of variables. In the adjustment of each multivariate model, a significance level of 5% was considered for the permanence of the variable.

The present study derives from the project "Identification of the Social and Epidemiological Profile of older people infected by HIV/AIDS assisted in reference services". Approved by the Research Ethics Committee of the Health Sciences Center of the Federal University of Pernambuco, with opinion number 1,707,44. This research met the prerequisites established by resolutions 466/2012 and 510/2016 of the Ministry of Health, regarding ethical principles involving scientific research with human beings. In addition, the term of consent and free clarification was used.

RESULTS

The sample consisted of 241 older people with a predominance of men, aged between 65 and 69 years, single, with up to four years of education, monthly income of up to two minimum wages, living with other people, main income from retirement and total contribution to the family income. (Table 1)

Regarding lifestyle and health conditions, older people who practiced physical activity, former smokers, who did not use alcohol, functionally independent, with negative screening for depressive symptoms, no risk for malnutrition and waist circumference and risk for waist-hip. Regarding viral load, 87.9% were classified as undetectable. (Table 1)

Regarding comorbidities, there was a higher frequency for systemic arterial hypertension, followed by diabetes mellitus, as shown in Table 2.

Table 3 shows the distribution of nutritional risk, according to sociodemographic profile, lifestyle and health conditions. There is a higher prevalence in female older people, aged 70 years or older, widowed, with up to four years of education, monthly income of one to two minimum wages, retired and with a partial contribution to the family income. Regarding lifestyle factors and health conditions, there was a higher prevalence of nutritional risk in the group of older people with severe dependence, suspected depression, who practiced physical activity, smokers, who drank alcohol from 1 to 6 times a week, no risk to waist circumference, no risk to waist-hip and detectable viral load.

The characteristics that were associated with nutritional risk were: sex ($p=0.002$), education ($p=0.003$), depressive symptoms ($p<0.001$), waist circumference ($p=0.012$), viral load classification ($p=0.047$).

The distribution of nutritional risk, according to the investigated comorbidities, is described in table 4. There is a positive association between nutritional risk and the occurrence of osteoarthrosis ($p=0.018$).

Variables with $p<0.20$ in the bivariate analysis (sex, education, source of financial resources, CVD, osteoporosis, osteoarthrosis, renal dysfunction, waist circumference, functional impairment, viral load and depressive symptoms) were included in the multivariate model.

In the adjusted model, a significance level of 5% was considered in the Wald chi-square test, with the following variables remaining: sex, education, waist circumference and depressive symptoms (Table 5).

Table 1. Distribution of the sociodemographic profile, lifestyle and health conditions in older people infected by HIV/AIDS assisted in Reference Units. Recife, PE, 2021.

Evaluated factors	n (%)	*p*-value
Sociodemographic		
Sex		
Male	151 (62.7)	<0.001
Female	90 (37.3)	
Age		
60 to 64 years	61 (25.3)	0.001
65 to 69 years	108 (44.8)	
70 or more	72 (29.9)	
Marital status		
Single	83 (34.4)	<0.001
Married/with a partner	74 (30.7)	
Widower	45 (18.7)	
Separated/Divorced	39 (16.2)	
Education		
Illiterate	25 (10.4)	<0.001
1 to 4 years	69 (28.6)	
5 to 8 years	59 (24.5)	
9 to 11 years	56 (23.2)	
Over 11 years	32 (13.3)	
Individual monthly income*		
No income	51 (6.2)	<0.001
<1 MW	27 (11.2)	
1 to 2 MW	134 (55.7)	
2 to 4 MW	36 (14.9)	
More than 4 MW	29 (12.0)	
Lives alone		
No	166 (68.9)	<0.001
Yes	75 (31.1)	
How many people do you live with?		
Only with partner	40 (16.6)	
With more people	126 (52.3)	
Origin of financial resources		
Does not have its own earnings	19 (7.9)	<0.001
Salary or informal activity	38 (15.8)	
Retired	156 (64.7)	
Pensioner	18 (7.5)	
Retired and pensioner	10 (4.1)	
Contribution to family income		
Fully	137 (56.8)	<0.001
Partially	86 (35.7)	
Does not contribute	18 (7.5)	

to be continued

Continuation of Table 1

Evaluated factors	n (%)	*p*-value
Lifestyle		
Physical activity		
No	113 (46.9)	0.334
Yes	128 (53.1)	
Smoking		
Never smoked	96 (39.8)	<0.001
Ex smoker	105 (43.6)	
Smoker	40 (16.6)	
Alcoholic beverage consumption		
Daily	3 (1.2)	<0.001
1 to 6 times a week	14 (5.8)	
Occasionally or rarely	60 (24.9)	
No consumption	164 (68.0)	
Health conditions		
Functional impairment		
Severe dependence	1 (0.4)	<0.001
Moderate dependence	15 (6.2)	
Light dependency	22 (9.1)	
Independence	203 (84.3)	
Depressive symptoms		
No suspicion of depression	161 (67.1)	<0.001
With suspected depression	79 (32.9)	
Mini nutritional assessment		
Normal	134 (55.8)	
Nutritional risk	87 (36.3)	<0.001
Malnourished	19 (7.9)	
Waist circumference		
Without risk	105 (43.6)	0.001
High risk	56 (23.2)	
Very high risk	80 (33.2)	
Waist-hip ratio		
No cardiovascular risk	115 (47.9)	0.519
With cardiovascular risk	125 (52.1)	
Viral load rating		
Detectable	24 (12.1)	<0.001
Not detectable	174 (87.9)	

p-value of the chi-square test for proportion comparison;*In minimum wage (MW), in force in Brazil in 2017, equivalent to R$ 937.00.

Table 2. Distribution of comorbidities investigated in older people infected by HIV/AIDS assisted in Reference Units. Recife - PE, 2021.

Evaluated factor	Absent	Present	No information	*p*-value
Systemic arterial hypertension (SAH)	133(55.2%)	94(39.0%)	14(5.8%)	<0.001
Diabetes Mellitus (DM)	167(69.3%)	59(24.5%)	15(6.2%)	<0.001
Cardiovascular disease (CVD)	200(83.0%)	24(10.0%)	17(7.0%)	<0.001
Osteoporosis	194(80.5%)	31(12.9%)	16(6.6%)	<0.001
Osteoarthrosis	201(83.4%)	26(10.8%)	14(5.8%)	<0.001
Neurological diseases	213(88.4%)	11(4.5%)	17(7.1%)	<0.001
Respiratory diseases	213(88.4%)	10(4.1%)	18(7.5%)	<0.001
Neoplasm	221(91.7%)	4(1.7%)	16(6.6%)	<0.001
Depression	212(88.0%)	12(4.9%)	17(7.1%)	<0.001
Chronic diseases	146(60.6%)	2(34.0%)	3(5.4%)	<0.001

p-value of the chi-square test for proportion comparison.

Table 3. Distribution of nutritional risk, according to sociodemographic profile, lifestyle and health conditions in older people infected with HIV/AIDS assisted in Reference Units. Recife - PE, 2021.

Evaluated factors	Nutritional risk		*p*-value
	Present	Absent	
Sociodemographic			
Sex			
Male	55(36.4%)	96(63.6%)	0.002[1]
Female	51(57.3%)	38(42.7%)	
Age			
60 to 64 years	25(41.0%)	36(59.0%)	0.212[1]
65 to 69 years	43(40.2%)	64(59.8%)	
70 or more	38(52.8%)	34(47.2%)	
Marital status			
Single	39(47.0%)	44(53.0%)	0.703[1]
Married/with a partner	30(40.5%)	44(59.5%)	
Widower	22(48.9%)	23(51.1%)	
Separated/Divorced	15(39.5%)	23(60.5%)	
Education (years)			
0	13(52.0%)	12(48.0%)	0.003[1]
1 to 4 years	43(62.3%)	26(37.7%)	
5 to 8 years	21(35.6%)	38(64.0%)	
9 to 11 years	19(34.5%)	36(65.5%)	
Over 11 years	10(31.2%)	22(68.8%)	
Individual monthly income*			
No income	6(40.0%)	9(60.0%)	0.667[1]
<1 MW	12(44.4%)	15(55.6%)	
1 to 2 MW	63(47.4%)	70(52.6%)	
2 to 4 MW	12(33.3%)	24(66.7%)	
More than 4 MW	13(44.8%)	16(55.2%)	

to be continued

Continuation of Table 3

Evaluated factors	Nutritional risk		*p*-value
	Present	Absent	
Lives alone			
No	74(44.6%)	92(55.4%)	0.847[1]
Yes	32(43.2%)	42(56.8%)	
How many people do you live with?			
Only with partner	16(40.0%)	24(60.0%)	
With more people	58(46.0%)	68(54.0%)	
Origin of financial resources			
Does not have its own earnings	9(47.4%)	10(52.6%)	0.111[1]
Salary or informal activity	11(28.9%)	27(71.1%)	
Retired	76(49.0%)	79(51.0%)	
Pensioner	8(44.4%)	10(55.6%)	
Retired and pensioner	2(20.0%)	8(80.0%)	
Contribution to family income			
Fully	58(42.6%)	78(57.4%)	0.852[1]
Partially	40(46.5%)	46(53.5%)	
Does not contribute	8(44.4%)	10(55.6%)	
Lifestyle			
Physical activity			
No	48(42.9%)	64(57.1%)	0.702[1]
Yes	58(45.3%)	70(54.7%)	
Smoking			
Never smoked	46(47.9%)	50(52.1%)	
Ex smoker	40(38.5%)	64(61.5%)	0.291[1]
Smoker	20(50.0%)	20(50.0%)	
Alcoholic beverage consumption			
Daily	0(0.0%)	3(100.0%)	
1 to 6 times a week	8(61.5%)	5(38.5%)	
Occasionally or rarely	27(45.0%)	33(55.0%)	0.314[2]
No consumption	71(43.3%)	93(56.7%)	
Health Conditions			
Functional impairment			
Severe dependence	1(100.0%)	0(0.0%)	
Moderate dependence	10(66.7%)	5(33.3%)	
Light dependency	11(50.0%)	11(50.0%)	0.124[2]
Independence	84(41.6%)	118(58.4%)	
Depressive symptoms			
No suspicion of depression	62(38.8%)	98(61.3%)	0.013[1]
With suspected depression	44(55.7%)	35(44.3%)	
Waist circumference			
Without risk	57(54.3%)	48(45.7%)	
High risk	23(41.8%)	32(58.2%)	0.012[1]
Very high risk	26(32.5%)	54(67.5%)	

to be continued

Continuação da Tabela 3

Evaluated factors	Nutritional risk		*p*-value
	Present	Absent	
Waist-hip ratio			
No cardiovascular risk	52(45.6%)	62(54.4%)	0.617[1]
With cardiovascular risk	53(42.4%)	72(57.6%)	
Viral load rating			
Detectable	15(62.5%)	9(37.5%)	0.047[1]
Not detectable	71(41.0%)	102(59.0%)	

[1]*p*-value of the chi-square test for independence; [2]p-value of Fisher's exact test; ;*In minimum wage (MW), in force in Brazil in 2017, equivalent to R$ 937.00.

Source: Data obtained from the survey, 2021.

Table 4. Distribution of nutritional risk, according to comorbidities in older people infected by HIV/AIDS assisted in Reference Units. Recife - PE, 2021.

Evaluated factors	Nutritional risk		*p*-value
	Present	Absent	
Systemic arterial hypertension (SAH)			
Absent	57(43.2%)	75(56.8%)	0.702[1]
Present	43(45.7%)	51(54.3%)	
Diabetes Mellitus (DM)			
Absent	71(42.8%)	95(57.2%)	0.533[1]
Present	28(47.5%)	31(52.5%)	
Cardiovascular disease (CVD)			
Absent	84(42.2%)	115(57.8%)	0.133[1]
Present	14(58.3%)	10(41.7%)	
Osteoporosis			
Absent	80(41.5%)	113(58.5%)	0.083[1]
Present	18(58.1%)	13(41.9%)	
Osteoarthrosis			
Absent	82(41.0%)	118(59.0%)	0.018[1]
Present	17(65.4%)	9(34.6%)	
Neurological diseases			
Absent	95(44.8%)	117(55.2%)	0.355[2]
Present	3(27.3%)	8(72.7%)	
Respiratory diseases			
Absent	94(44.3%)	118(55.7%)	1.000[2]
Present	4(40.0%)	6(60.0%)	
Neoplasia			
Absent	97(44.1%)	123(55.9%)	1.000[2]
Present	2(50.0%)	2(50.0%)	
Depression			
Absent	92(43.6%)	119(56.4%)	0.664[1]
Present	6(50.0%)	6(50.0%)	

to be continued

Continuation of Table 4

Evaluated factors	Nutritional risk		*p*-value
	Present	Absent	
Kidney dysfunction			
Absent	42(42.4%)	57(57.6%)	0.140[2]
Present	1(12.5%)	7(87.5%)	
Chronic diseases			
Absent	67(45.9%)	79(54.1%)	0.454[1]
Present	33(40.7%)	48(59.3%)	

[1] chi-square test value for independence; [2] Fisher's exact test value.

Source: Data obtained from the survey, 2021

Table 5. Final adjustment of the Poisson model for Nutritional risk in older people infected with HIV/AIDS assisted in Reference Units, Recife, PE, 2021

Evaluated factors	PR	CI (95%)	*p*-value*
Sex			
Male	1.00	-	-
Female	2.09	1.56 - 2.80	<0.001
Education			
Over 11 years	1.00	-	-
9 to 11 years	1.04	0.57 - 1.90	0.89
5 to 8 years	1.06	0.60 - 1.89	0.84
1 to 4 years	1.73	1.02 - 2.94	0.041
Illiterate	1.25	0.68 - 2.30	0.474
Waist circumference			
Very high risk	1.00	-	-
High risk	1.35	0.89 - 2.03	0.157
No risk	2.50	1.73 - 3.61	<0.001
Depressive symptoms*			
No suspected depression	1.00	-	-
With suspected depression	1.34	1.02 - 1.75	0.035

PR = Prevalence ratio; CI = Confidence Interval; **p*-value from the Wald test.

DISCUSSION

This study demonstrated a high prevalence of nutritional risk among older people with HIV, given that it presents itself as a "sentinel event" in situations of AIDS and co-infections. Thus, malnutrition in this group presents itself in greater magnitude, providing disadvantages such as: increased morbidity and mortality and opportunistic infections, reduced drug efficacy and reduced serum albumin levels. Nutritional care is even more important because it minimizes muscle loss and the risk of death[15], and it is crucial to identify the nutritional risk and intervene early on.

Although there are no indicators of nutritional status or specific classification for HIV carriers[14], nor a lack of studies in the recent literature that address older people as a target group for investigation related to nutritional aspects, this study contributed to Gerontology with: the importance of inserting the MNA, a reference instrument[7] for the early

identification of malnutrition, even in eutrophic and overweight individuals at risk of developing malnutrition.

A meta-analysis carried out in 2019[15] showed that malnutrition is one of the most common problems among people living with HIV, contributing to premature death and the development of comorbidities in older people with this virus. However, the biggest obstacle is related to inadequate and underdiagnosed screening of the risk of developing malnutrition, silently increasing its prevalence, often aggravated by the appearance of comorbidities, especially tuberculosis[15-18].

Regarding the factors associated with risk, although they are not dissociated from each other, they will be addressed separately. The first, related to the influence of sex, it is observed that although HIV is more prevalent in men[19], as was also demonstrated in this study, it is verified that the group of female patients presents a significant increase of 109% for the nutritional risk when compared to male patients. This situation may be related to the process of feminization of aging, because although the woman is a survivor of the disease, she brings with her the accumulation of disadvantages in aging, related to financial condition, lower income and greater food insecurity to purchase food[19-23].

Despite greater attendance at health services, women are more socially stigmatized, in the condition of "receiver of the virus", which may discourage self-care, considering that the diagnosis of the disease is seen almost as a death sentence[24]. In addition, the female age group from 20 to 59 years, which covers the period prior to aging, has a higher risk of developing opportunistic infections compared to men, using viral load as an immunological evaluation criterion[20].

The physiological process also justifies the greater vulnerability of older women to changes in nutritional status in aging[21], since the loss of muscle mass is more intense in this group, especially in the initial phase of aging, age identified in 60% of the women in this investigation. In contrast, for men, the greatest loss occurs at older age, although women are more prone to dehydration and osteopenia[25].

The second associated factor is education. It appears that the significant increase in nutritional risk was found only for the group that studied from 1 to 4 years, in which the risk is 73% higher when compared to the group of patients who studied for more than 11 years. For illiterate patients, with 5 to 8 years of schooling and 9 to 11 years of schooling, the nutritional risk was higher than the group of patients who studied more than 11 years, however, the increased risk is not significant among these groups.

The relationship between education, income and HIV impoverishment is widely discussed in the literature. The lower the level of education, the more insufficient the income and the more precarious the purchase of food, the access to health services and guidance by health professionals, the greater the damage to self-care[19]. Thus, in addition to the changes related to the natural process of aging, older people are still faced with food insecurity, when there is little financial resource for the choice and acquisition of adequate food, compromising the quality and quantity of food, impacting the nutritional condition[26,27].

The third associated factor is waist circumference. In the group with a measurement within the normal range, there was a significant increase in nutritional risk of 150%, compared to the group with very high risk in waist circumference. For the group at high risk in waist circumference, the non-significant increase in nutritional risk was 35% compared to the group at very high risk in waist circumference.

Despite being a protective factor against nutritional risk for analysis purposes, waist circumference is still a concern, as it contributes to an increase in cardiovascular risk. In this context, a subsequent assessment related to factors associated with excess weight can be carried out, considering its growth also among people with HIV, as demonstrated by other authors[28,29], increasing the risk of chronic diseases by five times[29,30]. It is assumed that these survivors experienced the success of ARVT, but on the other hand, increased risk factors related to current diseases, especially cardiovascular diseases.

And the fourth associated factor is related to depression. In this study, if symptoms were present in

the patient, a significant 34% increase in nutritional risk occurred when compared to patients without suspected depression.

Although the analysis of medical records identified only 5.9% of the older people infected with a diagnosis of depression and undergoing drug treatment, when screening for depressive symptoms using the GDS-15, the depressive prevalence increased to 46% of the sample, with the non-nutritional factor presenting the strongest association. An underreporting of depression is assumed, requiring identification to include measures such as social and psychological support and more comprehensive care for the patient[30].

Studies point to the relationship between malnutrition and depression[22,30-32]. Changes in body weight can affect mood, self-image and symptoms of depression, as well as being associated with risk factors for infection, such as non-adherence to ARVT, which further worsens nutritional status. These authors reinforce the strong effects of gender, since women have a higher prevalence, incidence and risk of morbidity from depression than men[22,31,32].

The symptoms of depression are difficult to identify, but they must be investigated carefully and attentively to the stage of the disease, because often the immunological decline resulting from HIV brings symptoms similar to those of depression, such as anorexia, fatigue, weakness and weight loss. Thus, in advanced stages of the disease, the use of these signs as a diagnostic criterion for depression is of little value[33]. However, in this study, as the disease was not at an advanced stage, the result becomes more reliable and the certainty that depression also permeates seropositive older people.

People living with HIV have poor food quality[31] and lack of appetite, which, associated with depression, further compromise their nutritional condition, especially in older women, with the aggravating factors of social isolation, lack of adherence to treatment, high viral load and worsening of lack of appetite[30,31].

With regard to the limitations of the study, some points need to be mentioned: 1) for reasons related to ensuring greater adherence to treatment and minimizing the financial cost for attending the service, the delay for most users to return for at least three months made it impossible to include laboratory tests that complemented the nutritional assessment; 2) as the profile of standardized drugs for the treatment of HIV includes 2 to 3 drugs per day, polypharmacy could not be investigated in this study; 3) the type of convenience sampling selection may have generated a selection bias, but in the case of older people, and in view of a higher prevalence of individuals under 60 years of age on ARVT at the collection sites, another way to choose the participants would make the research unfeasible since the functioning of these health services, which serve extremely stigmatized people, occurs more frequently in the form of spontaneous demand.

To minimize this bias, it was decided to use more than one collection site, sample calculation and standardization of allocation of the older people (every day of the week). The importance of this research should be highlighted because it is a target group in the ≥60 years old with HIV population segment, with a multidimensional approach, contemplating sociodemographic variables, health status, functional capacity, mental health, which can be an important result for healthcare providers who care for older people with HIV.

CONCLUSION

This study portrayed a high prevalence of nutritional risk in seropositive older people, demonstrating their degree of vulnerability, especially in women, in those with low education, and with present signs of depression. Waist circumference was strongly associated with protection, although largely associated with coronary heart disease. With regard to routine follow-up in primary care, the MNA, an instrument for early risk screening, is quick and practical, and its use in nutritional practice is recommended.

It makes a significant contribution by using an instrument to identify "nutritional risk" that, despite being recommended by the Ministry of Health

and being part of the Comprehensive Geriatric Assessment (CGA), little has been used in health services aimed at HIV, not to mention that its routine use would make it possible to plan relevant intervention measures.

There are few studies that address a more complete assessment of the health situation of older people with HIV. From this perspective, the care of the older person living with HIV has been an extension of the care of adults with HIV, which should have provided a better nutritional condition, considering that the diagnosis of the disease occurred still in the phase of life that preceded aging.

In view of this scenario, it is expected that the result of this research will contribute to the establishment or routine inclusion of specific investigations for nutritional care such as the MNA, which act both in monitoring and in therapeutic intervention, aiming, in this way, at a more comprehensive care for older people living with HIV.

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Variables associated with religious practice in Brazilian adults and older adults aged 50 and over: ELSI-Brazil

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Abstract

Objective: To identify variables associated with religious practice in Brazilian adults and older adults aged 50 and over. *Method:* In this observational and cross-sectional study, the participants included 7,171 individuals aged 50 and over from a representative national sample (N=9,412), interviewed in the first wave of the Brazilian Longitudinal Study of Aging (ELSI-Brazil), on frequency of participation in religious services, religious affiliation, self-rated health, sex, age, education, living arrangements, region of residence, and race. The Poisson regression model was used to investigate crude and adjusted associations between variables. *Results:* Fifty-seven percent of the sample was female, the mean age was 62.5±9.4 years old, the majority had 5 to 8 years of education and lived with 3 or more people, 42% resided in the Southeast region, and 48% self-declared as *Pardo* [mixed race], 66% were Catholic, 76% attended religious services once or more times a week, and 45% rated their health as fair. The most frequent participants in religious services were Black (PR=1.06, 95%CI 1.00-1.12)and mixed race (PR=1.07, 95%CI 1.03-1.11), Evangelical (PR =1.26, 95%CI 1.22-1.30), and self-rated their health as fair (PR=1.07, 95%CI 1.02-1.11). In contrast, the least frequent were male (PR=0.87, 95%CI 0.84-0.90), with 5 to 8 years of education (PR=0.92, 95%CI 0.88-0.97), residing in the Southeast (PR=0.91, 95%CI 0.86-0.95) and South (PR=0.90, 95%CI 0.82-0.99) regions. **Conclusion:** Self-declaration as Black and mixed race, Evangelical religion, and self-rated health as fair were associated with higher attendance at religious services among Brazilians aged 50 and over.

Keywords: Religion. Aging. Self-assessment. Aged.

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INTRODUCTION

Religiosity is a multidimensional phenomenon and concept that includes a person's involvement in beliefs, behaviors, rituals, and sacred and transcendent symbols shared and practiced by religious institutions and communities[1,2]. Etymologically, "religion" comes from the Latin term *religare*, which refers to religious practices through which human beings are bound to God and to a community that shares the same principles[1]. Religiosity offers an understanding of how the world and human existence works[1–3], and brings together individuals with similar behaviors and beliefs about transcendence[1,2]. It performs psychological functions, since it provides social support, optimism, purpose in life, a sense of belonging, and favors adaptation to stressful situations[1,3].

Religious practice and religious affiliation are dimensions of religiosity, together with religious commitment and coping[1]. Religious practice involves public and private religious activities, also known as organizational and non-organizational practices[4]. Public religious practice refers to a person's attendance and participation in religious services and ceremonies and in other community activities, such as groups for reading religious writings and prayer groups[4]. Private religious practice comprises religious activities that the individual carries out alone, such as praying, meditating, reading religious writings and watching religious channels on television[4]. Religious affiliation is related to the religious tradition that a person practices, publicly or privately, and with which they identify, sharing beliefs and rituals with other individuals[1].

The frequency of religious practice changes as a person ages. According to Bengtson et al.[5], participation in religious services is low in early adulthood, increases during middle age, reaches its peak in early old age, remains stable for a period and then declines due to losses associated with senescence, multimorbidity, and physical and cognitive disabilities. This trajectory is also affected by generational and context variables, including the secularization of societies[6,7].

The frequency of attendance at churches and temples for religious practices varies according to sex, education, and race. Women tend to participate more assiduously in public religious activities than men because they value the social aspects of religiosity more than men[8–10]. In addition, public practices offer opportunities for deriving a sense of belonging, valuing oneself[1,3], social involvement[1,8], volunteer services[10], giving and receiving support[1,2] which are activities valued more by women than by men[8,10]. Older adults with formal education of eight or more years tend to be less assiduous practitioners of religious ceremonies than less educated older adults[9,10]. In research conducted among Europeans[10,11], Asians and White North Americans[11], the most common finding is that these groups have a low frequency of public religious practice, a fact not observed among African Americans residing in the United States[12], who show a high frequency of attendance at religious services.

The frequency of attendance at religious services may also vary according to religious affiliation. Among practitioners of Evangelical religion, frequent participation in cults is a precept that is more important to follow than among Catholics[13]. Ninety-four percent of Brazilian adults and older adults report following at least one religion that performs public and community rituals and ceremonies, including masses, cults, and meetings[14], in which the Catholic and Evangelical religions are the affiliations with the highest number of practitioners[13,14].

In addition to being a reliable indicator of general health status, self-rated health is a subjective variable capable of identifying signs of functional decline and mapping the risk of mortality[15]. Older adults who show assiduous public religious practices present better self-rated health than older adults with low or no attendance at public or organizational religious activities[15,16], because of the adoption of healthy behaviors and the emotional and social support received in churches and within congregations[17,18].

According to the literature, public religious practice among older adults can be influenced by social and health factors, and is associated with psychological well-being. There is some controversy,

but religiosity tends to be more valued by older adults than by the adult population in general, partly due to the tendency to adopt it as a coping mechanism for stressful events, the incidence of which increases in old age, in part due to generational issues.

There are few Brazilian studies with recent population-based data that investigate the characteristics of public religious practice in the older adult population. The Brazilian Longitudinal Study of Aging (ELSI-Brazil) is the first survey conducted on a representative sample of the Brazilian population aged 50 and over. The inclusion of the religiosity domain in the data collection protocol enables the investigation of public religious practice and its relation with sociodemographic and health indicators. In this study, the domain of religiosity was divided into two aspects – affiliation and religious practice. The purpose was to identify associations between public religious practice, religious affiliation, self-rated health, and sociodemographic variables (sex, age, education, living arrangement, region of residence, and race) in a national sample representative of the Brazilian population aged 50 and over, among participants of ELSI-Brazil.

METHODS

This is an observational, cross-sectional study conducted on baseline data from the *Estudo Longitudinal da Saúde dos Idosos Brasileiros* (ELSI-Brazil), collected in 2015 and 2016. The full sample of the ELSI-Brazil consisted of 9,412 individuals[19]. The size and composition of the full sample were representative of the non-institutionalized Brazilian population aged 50 and over, randomly selected by inverse sampling to avoid increasing the sample size to compensate for missing data[19]. For this study, data from 7,171 participants were used. The sample losses did not comply with any selection criteria, they included participants who declared themselves nonreligious and who therefore did not respond to the variable "public religious practice", and those who failed to respond to items from the other instruments used. Briefly, those who did not respond to all the variables of interest were excluded. The participants lived in 7,500 households in 70 small, medium and large municipalities in the five Brazilian macro-regions, selected through stratification into four categories, according to population size[19,20]. All residents of selected households aged 50 or older, who accepted the invitation to answer an individual questionnaire[19,20], were included in the study. If the participant presented any physical and/or mental limitation that prevented them from responding, a substitute informant was elected to answer the individual questionnaire on their behalf[19].

Public religious practice was examined based on an item from the Duke University Religion Index (DUREL)[4,21], which measures the frequency of participation in religious services: "In the last 12 months, how often did you participate in religious services, such as masses, services or prayer groups in temples or churches or on TV?". This was evaluated according to the responses: 1, more than once a week; 2, once a week; 3, two or three times a month; 4, one or more times a year; 5, never; which were then grouped as "once or more than once a week", "two or three times a month", and "one or more times a year/never". The first two categories represent greater regularity and religious involvement, while the last category combined the response "one or more times a year", corresponding to low regularity for participation in religious ceremonies that represents minimal religious involvement, and the response "never", which represents no involvement.

Religious affiliation was verified by means of nine items: 1, No religion; 2, Catholic; 3, Protestant; 4, Evangelical; 5, Spiritism/Kardecism; 6, Buddhism; 7, Islam; 8, religions of African origin; 9, other, which were then grouped as "Catholic"; "Protestant"; "Evangelical"; "Spiritism"; and "other religions". Participants in the "Protestant" category correspond to those affiliated with the Lutheran, Baptist, Adventist, Presbyterian and Methodist Churches, among others. Participants in the "Evangelical" category correspond to those affiliated with Pentecostal and Neo-Pentecostal churches. The other religions were grouped in the category "other religions" to enable statistical calculations.

Health self-assessment was investigated through the item: "In general, how do you rate your health?",

according to the answers: 1, very good or excellent; 2, good; 3, fair; 4, poor; 5, very poor, which were reduced to three categories: "good/very good"; "fair"; and "poor/very poor".

The sociodemographic variables measured were sex (female and male), age (50 to 59 years old, 60 to 69 years old, 70 to 79 years old, and 80 years old and over), education (none, 1 to 4 years, 5 to 8 years, and ≥9 years), living arrangements (alone, with 2 people, and with 3 or more people), region of residence (North, Northeast, Southeast, South and Midwest), and self-reported race/color (White, Black, *Pardo* [mixed race], Asian and Indigenous).

The sample responses recorded were submitted to descriptive analysis, with absolute and relative frequency measurements of all the variables. Subsamples of participants were compared according to the frequency of participation in public religious practices, using Pearson's chi-square test, for a value of $p<0.05$. To verify associations between frequency of religious practices, religious affiliation, self-rated health, and sociodemographic variables, crude and adjusted prevalence ratios and respective confidence intervals (95%) were analyzed using the Poisson regression model. All variables were included in the final model and those that presented a value of $p<0.05$ remained.

The ELSI-Brazil project was approved by the research ethics committee of the René Rachou Research Center of the FIOCRUZ, under report protocol no. 2111911. For each stage of data collection, all participants signed a term of free, informed consent.

RESULTS

Table 1 presents the descriptive results of the sample of 7,171 individuals regarding sociodemographic variables, religious affiliation, public religious practice, and self-rated health.

The results of comparisons between the frequency of participation in public religious practices, religious affiliation, self-rated health and sociodemographic variables are presented in Table 2. Among the most assiduous individuals, there were more women than men, more mixed race than White individuals, more Catholics than Evangelicals, and more individuals who rated their health as fair than good/very good or poor/very poor. Among the less assiduous participants, those with 5 to 8 years of education, who lived in the Southeast region, were White, Catholic, and self-rated their health as good/very good predominated (Table 2).

Table 3 shows the crude and adjusted prevalence ratios of all variables, according to the probability of the participant's frequency of participation of at least once a week. In the crude analysis, higher attendance was observed among Black (PR = 1.06) and mixed race participants (PR = 1.07) than among White participants, among Evangelicals (PR = 1.28) than among Catholics, and among those who rated their health as fair (PR = 1.07) than among those who rated their health as good/very good. Lower attendance was observed among men (PR = 0.85) than among women, among those with 1 to 4 (PR = 0.83) and 5 to 8 years of education (PR = 0.92) than those with no formal education, and among those residing in the Southeast (PR = 0.88) and South (PR = 0.86) regions than in the North region. Analysis of PR adjusted for sex, age, education, living arrangement, region of residence, race/color, religious affiliation, and self-rated health indicated that Evangelicals were more assiduous than Catholics (PR = 1.26) and that being a man (PR = 0.87) and living in the Southeast (PR = 0.91) and South (PR = 0.90) regions were associated with lower attendance for public religious activities (Table 3).

Table 1. Sample characterization (N=7,171). Brazilian Longitudinal Study of Aging, Brazil, 2015-2016.

Variable	n (%)	95%CI[1]	Mean (SD)	Median (Min. – Max.)
Sex				
Female	4,097 (57.1)	55.9 – 58.2		
Male	3,074 (42.9)	41.7 – 44.0		
Age (years)			62.5 (±9.4)	61.0 (50-99)
50 to 59	3,226 (45.0)	43.8 – 46.1		
60 to 69	2,264 (31.6)	30.5 – 32.6		
70 to 79	1,274 (17.7)	16.8 – 18.6		
80 and over	407 (5.7)	5.1 – 6.2		
Education (years)			6.71 (±4.3)	5.0 (0-16)
None	1,006 (14.0)	13.2 – 14.8		
1 to 4	97 (1.4)	1.1 – 1.6		
5 to 8	4,353 (60.7)	59.5 – 61.8		
≥ 9	1,715 (23.9)	22.9 – 24.9		
Living arrangements				
Alone	867 (12.1)	11.3 – 12.8		
2 people	2,228 (31.1)	30.0 – 32.1		
3 or more people	4,076 (56.8)	55.6 – 57.9		
Region of residence				
North	643 (9.0)	8.3 – 9.6		
Northeast	1,845 (25.7)	24.7 – 26.7		
Southeast	3,028 (42.2)	41.1 – 43.3		
South	923 (12.9)	12.1 – 13.6		
Midwest	732 (10.2)	9.5 – 10.9		
Race/Color				
White	2,786 (38.9)	37.7 – 39.9		
Black	704 (9.8)	9.1 – 10.5		
Pardo [mixed race]	3,429 (47.8)	46.6 – 48.9		
Asian	71 (1.0)	0.7 – 1.4		
Indigenous	181 (2.5)	2.1 – 2.9		
Religious affiliation				
Catholic	4,752 (66.3)	65.1 – 67.3		
Protestant	54 (0.7)	0.5 – 0.9		
Evangelical	1,951 (27.2)	26.1– 28.2		
Spiritism	262 (3.7)	3.2 – 4.1		
Other religions	152 (2.1)	1.8 – 2.4		
Public religious practice				
Once or more than once a week	5,458 (76.1)	75.1 – 77.1		
Two or three times a month	753 (10.5)	9.8 – 11.2		
One or more times a year/never	960 (13.4)	12.6 – 14.2		
Self-rated health			2.6 (±0.8)	3 (1-5)
Good/Very Good	3,104 (43.3)	42.1 – 44.4		
Fair	3,238 (45.1)	44.0 – 46.3		
Poor/Very poor	829 (11.6)	10.8 – 12.3		

[1] 95%CI, 95% confidence interval

Source: the authors.

Table 2. Percentage of adults and older adults according to frequency of participation in public religious practices, considering the sociodemographic variables, religious affiliation and self-rated health (N=7,171). Brazilian Longitudinal Study of Aging, Brazil, 2015-2016.

Variable	Once or more than once a week n (%)	Two or three times a month n (%)	One or more times a year/never n (%)	*p**
Sex				**<0.0001***
Female	3,320 (58.3)	385 (50.8)	392 (37.4)	
Male	2,138 (41.7)	368 (49.2)	568 (62.6)	
Age (years)				0.1907
50 to 59	2,398 (49.7)	358 (54.3)	470 (50.6)	
60 to 69	1,745 (30.4)	232 (29.5)	287 (31.0)	
70 to 79	1,016 (15.2)	115 (11.8)	143 (13.0)	
80 and over	299 (4.6)	48 (4.4)	60 (5.6)	
Education (years)				**0.0008***
None	799 (11.9)	102 (9.8)	105 (8.6)	
1 to 4	66 (1.1)	12 (1.6)	19 (1.6)	
5 to 8	3,255 (63.1)	472 (69.2)	626 (70.3)	
≥ 9	1,338 (23.8)	167 (19.5)	210 (19.4)	
Living arrangements				0.3685
Alone	663 (8.7)	89 (8.5)	115 (8.5)	
2 people	1,755 (32.4)	209 (29.7)	264 (29.6)	
3 or more people	3,040 (58.9)	455 (61.8)	581 (61.8)	
Region of residence				**0.0014***
North	526 (6.9)	65 (6.3)	52 (3.5)	
Northeast	1,468 (24.1)	177 (19.2)	200 (17.7)	
Southeast	2,203 (46.8)	329 (48.5)	496 (56.7)	
South	683 (14.6)	116 (20.7)	124 (16.4)	
Midwest	578 (7.5)	66 (5.7)	88 (5.5)	
Race/Color				**0.0035***
White	2,063 (40.1)	305 (45.0)	418 (48.1)	
Black	549 (10.1)	60 (7.5)	95 (9.9)	
Pardo [mixed race]	2,657 (46.7)	360 (44.5)	412 (38.6)	
Asian	49 (1.0)	13 (1.6)	9 (0.8)	
Indigenous	140 (1.9)	15 (1.4)	26 (2.4)	
Religious affiliation				**<0.0001***
Catholic	3,366 (63.3)	580 (77.6)	806 (83.7)	
Protestant	43 (0.7)	5 (0.5)	6 (0.7)	
Evangelical	1,762 (30.5)	111 (13.8)	78 (8.4)	
Spiritism	176 (3.3)	40 (5.6)	46 (4.9)	
Other religions	111 (2.1)	17 (2.3)	24 (2.4)	
Self-rated health				**0.0195***
Good/Very Good	2,317 (43.2)	337 (49.6)	450 (49.1)	
Fair	2,519 (45.6)	325 (40.6)	394 (40.0)	
Poor/Very poor	622 (11.2)	91 (9.8)	116 (10.9)	

* Pearson's Chi-square test. Statistically significant differences when $p<0.05$.

Source: the authors.

Table 3. Crude and adjusted prevalence ratios (PR) of higher attendance compared to less attendance in public religious practices, according to sociodemographic variables, religious affiliation and self-rated health (N=7,171). Brazilian Longitudinal Study of Aging, Brazil, 2015-2016.

Variable	Crude PR[1] (95%CI)[2]	*p**	Adjusted PR[3] (95%CI)	*p**
Sex				
Female	1		1	
Male	0.85 (0.82-0.89)	**<0.001***	0.87 (0.84-0.90)	**<0.001***
Age (years)				
50 to 59	1			
60 to 69	1.01 (0.97-1.04)	0.667		
70 to 79	1.05 (0.99-1.11)	0.071		
80 and over	0.98 (0.91-1.05)	0.576		
Education (years)				
None	1			
1 to 4	0.83 (0.70-0.98)	**0.029***		
5 to 8	0.92 (0.88-0.97)	**<0.001***		
≥ 9	0.98 (0.94-1.03)	0.537		
Living arrangements				
Alone	1			
2 people	1.02 (0.96-1.07)	0.457		
3 or more people	0.99 (0.94-1.03)	0.640		
Region of residence				
North	1		1	
Northeast	0.97 (0.91-1.02)	0.265	0.98 (0.92-1.03)	0.500
Southeast	0.88 (0.85-0.92)	**<0.001***	0.91 (0.86-0.95)	**<0.001***
South	0.86 (0.78-0.96)	**0.005***	0.90 (0.82-0.99)	**0.041***
Midwest	0.97 (0.90-1.05)	0.520	0.98 (0.89-1.07)	0.648
Race/Color				
White	1			
Black	1.06 (1.00-1.12)	**0.051***		
Pardo [mixed race]	1.07 (1.03-1.11)	**<0.001***		
Asian	1.00 (0.84-1.19)	0.998		
Indigenous	1.04 (0.92-1.17)	0.534		
Religious affiliation				
Catholic	1		1	
Protestant	1.11 (0.90-1.38)	0.309	1.12 (0.90-1.40)	0.283
Evangelical	1.28 (1.24-1.32)	**<0.001***	1.26 (1.22-1.30)	**<0.001***
Spiritism	0.93 (0.84-1.03)	0.169	0.94 (0.85-1.04)	0.279
Other religions	1.04 (0.93-1.16)	0.499	1.04 (0.94-1.16)	0.386
Self-rated health				
Good/Very Good	1			
Fair	1.07 (1.02-1.11)	**0.002***		
Poor/Very poor	1.05 (0.99-1.11)	0.151		

[1] PR, prevalence ratio; [2] 95%CI, 95% confidence interval; [3] Poisson regression model adjusted for sex, age, education, living arrangements, region of residence, race/color, religious affiliation, and self-rated health.

* Significant *p* value when $p<0.05$.

Source: the authors.

DISCUSSION

Self-declared Black and mixed race adults and older adults aged 50 and over, Evangelicals and individuals who self-rated their health as fair were the most assiduous participants in ceremonies and other public religious activities. In contrast, men, participants with 1 to 8 years of formal education, and those resident in the Southeast and South regions were the least assiduous in public religious practices.

The majority of the study participants were Catholics, most likely because the current generation of older adults and Brazilians of advanced age were socialized in this religion as children and adolescents, since Catholicism was highly widespread from the early to mid-twentieth century[13,22,23]. Catholicism has been losing ground in Brazil in recent years[13,22,23] due to the occurrence of social changes that determined a reduction in family influence in the transmission of Catholic precepts and traditions[13,23]. The prevalence of Evangelicals in this study is important, since there has been a diffusion of Evangelical churches on the outskirts of Brazilian metropolises, with more believers engaging this religion[13,22]. The realization of social programs by Evangelical communities and the use of different means of communication in the propagation of the Evangelical doctrine have also facilitated the affiliation of new adherents, particularly among persons of low income and with less education[22].

A large part of the sample consisted of assiduous practitioners. According to Idler et al.[6] and Hayward and Krause[7], participation in public religious practices is higher among older adults than among younger adults. Older adults value religious issues more and, following retirement and the decrease in family obligations, they tend to have more time to devote to religious activities[6,7]. The generational difference in public practices is also a result of the secularization process, which involves a decrease in religious practices and beliefs in societies as a whole[6,7]. Higher frequency of public religious practices is associated with positive mental health outcomes, such as increased psychological well-being[17,18] due to the social and emotional support that religious communities promote among their members[17,18,24] and the acceptance of health problems as part of life[24], lower use of antidepressants[24], lower rates of substance use[9,18], anxiety and depression[17,18], and it may reduce the risk of mortality[18]. Brenner[11] states that participation in religious ceremonies is an important part of socialization in South American countries.

Almost half of the participants rated their health as fair. This finding differs from the more recent descriptive results of studies that use methodologies similar to the ELSI-Brazil, such as the English Longitudinal Study of Aging (ELSA)[25], in which 74% of the sample rated their own health as good, very good or excellent[25]. Compared with English older adults, Brazilian middle-aged and older adults are considered to present less favorable health conditions, with the presence of multimorbidities, which explains the predominant self-rating of health as fair.

Black and mixed race participants were more assiduous than White participants. Krause[12] observed that older adult Black Americans attended more religious services than their White peers due to the fact that the social and emotional support offered by people from their religious community was greater than that offered among White people. According to Dos Santos[26], Black and mixed race people in Brazil experience social and economic difficulties caused by the particularities of racial discrimination in the Brazilian context, such as low or no formal education, unemployment, and lack of income. However, through their involvement with a community that assiduously attends religious ceremonies of any religious affiliation, they probably find a source of support that can help them face such adversities[26].

Evangelicals showed greater participation in religious practices than Catholics. Religious ceremonies are occasions when practitioners praise, give thanks, ask for divine help and guidance, and receive teachings from religious leaders. These elements are more valued by Evangelical practitioners than by Catholics[13]. Coutinho and Golgher[22] state that the Evangelical religion bases its precepts on the theology of prosperity, according to which the believer prospers by individually striving to overcome difficulties and maintain the behaviors instituted by Evangelical leaders. Thus, high attendance at services is an expected behavior of the Evangelical believer.

Evangelical churches usually provide more precise solutions for overcoming the problems that their practitioners may experience, such as low income and other socioeconomic adversities, chemical dependency, family problems, and urban violence[27], all of which are harmful to mental health. Presence at the services offers social and emotional support to cope with these problems and can strengthen the religious commitment of the practitioner regarding the Evangelical doctrine[27].

Individuals who self-rated their health as fair showed higher attendance than those who rated it as good or very good. Health self-assessment accurately represents the individual's state of health[15] and can be influenced by both sociocultural context and individual habits, such as the adoption of healthy behaviors and the use of coping strategies that reduce stress[15–18]. It is possible that the individuals in this sample rated their health as fair because they have less healthy habits and experience health problems that lead to functional limitations. Thus, attending religious services regularly can act as a social and emotional resource to deal with the difficulties caused by such functional restrictions[1,2].

Men showed less assiduous attendance than women. Schnabel[28] observed that men tend to be more dogmatic and hold more leadership positions than women and attributed these differences to gender stereotypes, which, according to the author, contribute to women being encouraged to participate in community religious activities, while men are encouraged to assume roles of leadership and authority[8,28]. According to Silva et al.[8] and Sowa et al.[10], women are socialized to express their feelings and seek support in religious communities to a greater degree than men. Men may encounter social support and ways to deal with their personal difficulties in sources other than participation in community religious services[8,10] or even in leadership positions in a church or congregation[8,28].

Participants with 1 to 8 years of education were less assiduous in their attendance at religious services than those with no formal education. Several studies[6,7,9,10,22] have observed that less participation in religious ceremonies is associated with an increase in the level of formal education and attribute this phenomenon to the secularization process. The importance given to attendance at religious services may be lower among more educated individuals[6], who dedicate themselves to other activities, such as those related to work[10].

Participants residing in the Southeast and South regions showed a lower frequency of religious practices than those in the North region. Compared with other macro-regions, the Southeast and South regions are more economically developed, their populations have higher levels of education and a higher proportion of Catholic practitioners[13,22], factors that are associated with less assiduous attendance at religious services. Considering the expansion of Evangelical religion in the North region and among the poorest Brazilians[13,22,27], and that the social support offered by religious communities helps the poorest in coping with difficulties, it seems reasonable to affirm that residents in the South and Southeast find other sources of social support and other ways of exercising religiosity, in addition to participating in public religious ceremonies.

This study presents limitations in that it did not consider the presence of comorbidities, functional disability and the participants' levels of autonomy and independence, variables that can influence participation in public religious practices. The cross-sectional design of this study means that investigating the causal relationships between the variables was not possible. However, there are advantages that should be mentioned: the use of population-based data from a longitudinal study, which has a methodology similar to other longitudinal studies on human aging, including the English Longitudinal Study of Aging (ELSA), the Health and Retirement Study (HRS), the Survey of Health, Aging and Retirement in Europe (SHARE), the Mexican Health and Aging Study (MHAS), enabling the generalization of the results obtained and transnational comparisons and meta-analysis studies; and the involvement of a panel of national experts and the use of standardized instruments that demonstrate methodological rigor. Furthermore, the support offered by government agencies and national research foundations for this study suggests the possibility of continued Brazilian research on the theme of religiosity and

its associations with social and health indicators among older adults.

CONCLUSION

This study aimed to identify associations between religious practice, religious affiliation, self-rated health and sociodemographic variables in a representative sample of Brazilian older adults and adults aged 50 and over, population segments marked by strong social inequality, which is based on important social, economic and health needs. We observed that Black and mixed race participants, Evangelicals, and those who rated their health as fair were more assiduous in public religious practices than White participants, Catholics and those who rated their health as good or very good. The main explanatory hypotheses for these results are of a socioeconomic and behavioral nature, that is, religious practices can act as a community source of social and emotional support when coping with social, economic and health difficulties.

Considering that the Brazilian older adult population is highly religious and that religious practices influence the physical and mental health of older adult practitioners, we argue that it is important to research the phenomenon of public religious practice in a population-based study, since it allows us to understand the characteristics of the Brazilian older adult population that assiduously attends religious ceremonies, taking into account their different cultural and social segments, particularly during a phase of demographic changes and religious transition, with profound sociological repercussions such as those faced today.

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Cross-cultural adaptation of functioning evaluation Routine Task Inventory - Extended (RTI-E) for use in elderly people with dementia in Brazil

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Abstract

Objective: Cross-cultural adaptation of the Routine Task Inventory-Expanded assessment for use in Brazil. Method: This cross-cultural adaptation study of the Routine Task Inventory-Expanded followed translation, back-translation, and expert committee review guidelines. The pre-test was performed with 10 elderly subjects with no cognitive impairment. The reliability study (agreement between evaluators and internal consistency) was executed with elderly subjects with and without dementia (n=26). Results: The initial translation was revised to preserve the instrument's construct. Adjustments were made to task C. Bathing, task G. Use of the telephone, and task H. Use adaptive equipment to clarify the meaning of items. The instrument showed internal consistency α= 0.813 ADL/self-report to α=0.966, ADL/caregiver, and reliability between ICC evaluators (95%IC) from 0.987 in IADL to 1.000 in communication. Conclusion: The cross-cultural adaptation of the Routine Task Inventory-Expanded was achieved, maintaining equivalency to the original instrument and providing a new instrument to assess cognitive functional abilities of elderly individuals living with dementia in routine daily living activities for use in Brazil.

Keywords: Aged. Dementia. Functional Status. Occupational Therapy.

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INTRODUCTION

Routine tasks are activities performed with defined performance and frequency standards. They are also called Activities of Daily Living (ADL) [1], which comprise Basic Activities of Daily Living (BADL), aimed at caring for the body itself (eg personal hygiene, use of the bathroom, clothing, etc.) and Instrumental Activities of Daily Living (IADL), which involve interaction with tools and with the community (eg financial management, community mobility, etc.). Routine tasks are also related to complex activities such as communication (verbal and non-verbal) and work (keeping the pace of task execution, following safety precautions, etc.). The routine in which activities are carried out gives structure to the person's daily life. The underlying elements of ADL are studied in Occupational Therapy[2] and are represented in the unified terminology of health and rehabilitation, the International Classification of Functioning and Disability (ICF)[3].

According to the ICF[3], functionality indicates the interaction between health/disease, body functions and structures, activities, participation, environmental factors and personal factors. Thus, changes in brain structure or function can result in cognitive impairments that are related to impairments in activity performance and participation. Disabilities are mitigated or worsened according to the interaction with personal and environmental factors, including the adjustment of activity demands[2]. Cognitive disabilities are found in dementia and are related to the limitations of functionality inherent to the development of the condition[4].

It is estimated that there are about 50 million people in the world with dementia and that this will reach 152 million in 2050[5]. In Brazil, it is estimated that there are about 1.5 million people living with dementia in the country, with Alzheimer's disease (AD) dementia being the most prevalent form[6]. The decline in functionality observed in AD dementia is a relevant aspect[7]. The inability to perform IADL can evolve to total dependence on BADL[8], increasing the demand for care[9], provided mainly by a family caregiver who, in general, experiences deleterious changes in their lifestyle, finances and health conditions, due to the overload for caring[9,10].

There are few specific functionality instruments for dementia, which offer dichotomous responses, do not grade performance variation and do not consider other factors involved in the outcome, such as personal factors and environmental factors. Functionality assessment can be performed by direct or indirect observation. Assessment instruments by direct observation of performance require preparation that make them less accessible for everyday clinical practice, where there is often a high demand for care and limited material resources[11]. Assessment instruments by indirect observation based on the report of a caregiver are widely used[12], considering that the lack of awareness of the deficit is a characteristic of the dementia condition[13]. Such instruments can bring information bias, underestimating or overestimating[14] the performance capacity of the person with dementia[12]. Although the combined use of instruments for direct and indirect observation of performance is recommended[13], those available in our environment do not allow observation of the same items of routine tasks, making it difficult to compare perceptions and identify discrepancies between different sources.

Routine Task Inventory- Extended (RTI-E)[15] assesses routine tasks based on self-report, caregiver report and direct observation of performance by a therapist on the same tasks. It considers the interference of other factors in the performance, such as the opportunities provided by the environment and interests in occupations. It is an instrument developed from the Cognitive Disability Model (CDM)[1], whose central concept is functional cognition, which explains the interaction between cognition and functionality in the performance of activities, within a psychosocial approach. It considers the biological aspects involved in occupations (what the person can do - represented by *can do*), the psychological aspects (what the person intends to do - *will do*) and the social aspects (opportunities and possibilities to do according to the environment - *may do*)[16]. The CDM has a six-level scale (Allen's Cognitive Levels Scale) that characterize occupational behavior according to the expected cognitive abilities within each cognitive level[4]. The score obtained on the RTI-E refers to these functional cognitive levels.

The RTI-E is used to describe the variation in the performance pattern in routine tasks and to assess functionality in different health conditions, populations and practice contexts[11]. Zimnavoda et al.[17] used the self-report on the Community Living Scale - IADL as a standard for the study of concept and criterion validity of a functionality assessment instrument in a population of older people in Israel. Bar-Yosef et al.[18] used RTI items that were parallel to the Cognitive Performance Test (CPT) tasks, to verify their correlation, in older people with dementia and in healthy older people, in the observation of tasks and in the caregiver's report. Ziv et al.[19] used the Community Life Scale - IADL to compare a group of older people with depression to healthy controls and to verify the predictive capacity of Allen's cognitive levels for performance in this domain of functionality.

Assessment instruments designed in languages, countries and cultures different from those in which they will be introduced must be adapted to the new culture in order to have semantic, idiomatic, experiential and conceptual equivalence between the original and the adapted, in order to enable the study of a phenomenon in different cultures[20].

This article presents the process of cross-cultural adaptation of the RTI-E to Brazilian Portuguese.

METHOD

Cross-cultural adaptation and psychometric properties study of the RTI-E into Brazilian Portuguese for use in the population of older people with AD dementia, carried out in the Third Age Program (PROTER) of the Instituto de Psiquiatria, Hospital das Clínicas, São Paulo School of Medicine, between 2016 and 2018. Project approved by the Ethics Committee for the Analysis of Research Projects of the Hospital das Clínicas, School of Medicine, University of São Paulo (opinion nº1,076,759). Participants were informed of the research objectives and signed the Free and Informed Consent Form.

Allen et col.[1] built items from the observations of occupational therapists on the performance of routine tasks, gathered in the original RTI, composed of BADL and IADL scales[21]. The RTI-E extended version was developed by Katz[15] who added two items (use of adaptive equipment and childcare) and two domains (Communication and Work Readiness) to the original instrument.

The RTI-E is composed of a manual and four scales in four domains of functionality: Physical Scale - ABVD (8 items: personal hygiene, clothing, bathing, functional mobility, food, use of the toilet, use of medications, use of adaptive equipment), Community Living Scale – IADL (8 items: household chores, preparing/obtaining food, financial management, washing clothes, community mobility, shopping, using the telephone, taking care of children), Communication (4 items: listening comprehension, verbal expression, reading comprehension, written expression), Work Readiness (6 items: keeps pace/follows schedule, follows instructions, performs simple/complex tasks, interacts with co-workers, follows safety precautions/reacts to emergencies, plans work/supervises others). Each scale describes routine tasks in detail so that the behavior that most closely matches the customer's current performance is identified. The application of the RTI-E is done through an interview for self-report and the caregiver's report. Therapist observation is accomplished by observing performance on tasks performed in real life. The result of each scale is independent and represents the average performance in the observed tasks. Therefore, each scale of the RTI-E can be applied separately.

The RTI-E score represents the client's Allen Scale cognitive level at the time of observation. Level 1 represents greater impairment of functionality and level 6 represents total independence[16]. The identification of the cognitive level that best describes the performance of the person makes it possible to infer the cognitive processes underlying the performance, constituting the parameter for the adaptation of activities, adapting them to the performance potential so that the person can experience their best functionality[4].

The adaptation study followed the guidelines of Beaton[20] and started after the author's authorization, following the steps shown in Figure 1.

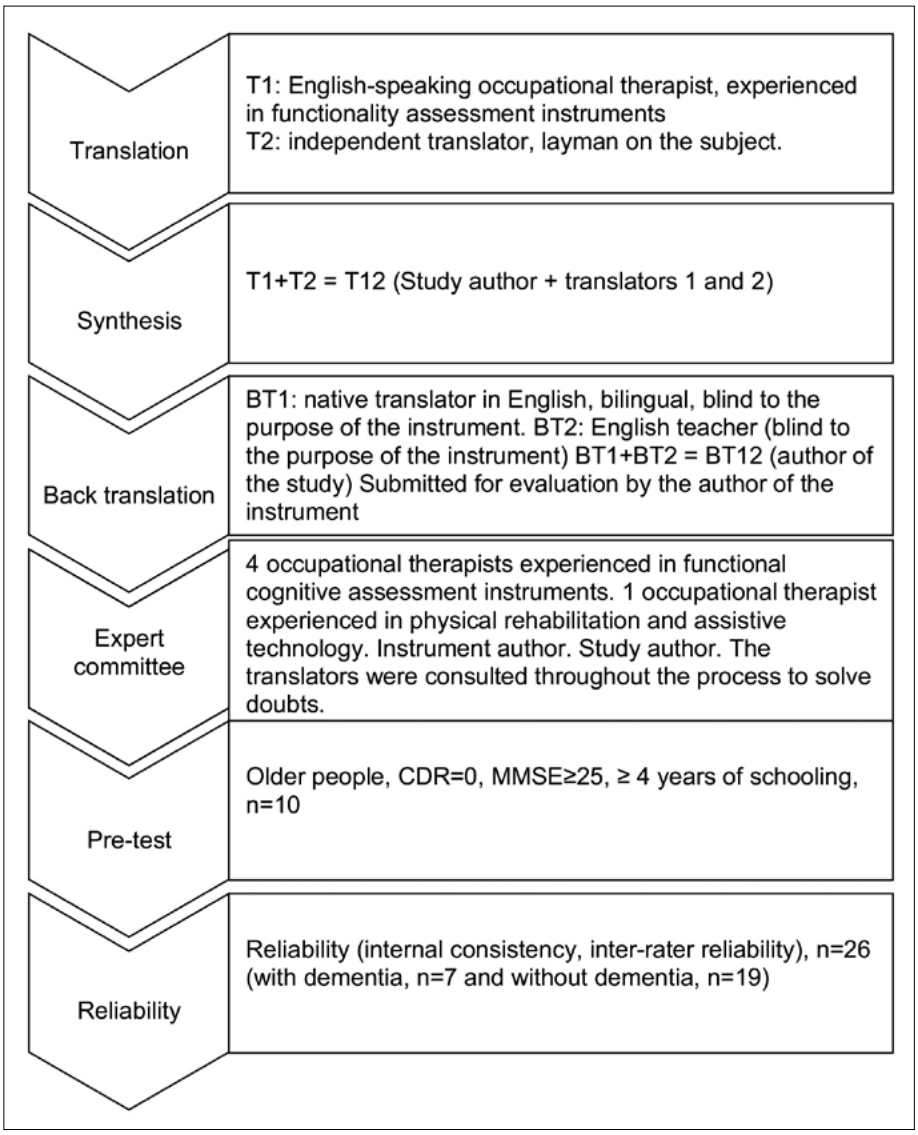

Figure 1. Cross-cultural adaptation process

Key: T1 = translator 1 (Adriane Colozzio), T2 = translator 2 (Eduardo Benaglia). T12 = synthesis of translations. BT1= back translator 1 (Nicholas J. Geboy), BT2 = back translator 2 (Ângela Nancy Pinto). BT12 = synthesis of the back translation. Expert review: 4OT = 4 occupational therapists: Natalie Torres Mattos, Adriana Dias Barbosa Vizotto, Eliyara Ikehara, Cíntia Soares. 1 OT = Tenille Aguiar. CDR = Clinical Dementia Rating. MMSE = Mini-Mental State Examination n= number of subjects.

The expert review was performed by occupational therapists experienced in functional cognitive rehabilitation and mental health. Each therapist received the instrument in its entirety, to read, apply and record their considerations in the instrument. The alteration suggestions were discussed and adopted by consensus among the experts. An occupational therapist specializing in physical rehabilitation was consulted to adjust assistive technology terms.

The pre-test was carried out with 10 older subjects without cognitive impairment, recruited through a convenience sample, among those accompanying patients at the occupational therapy service outpatient clinic, with schooling ≥4 years, age ≥ 60 years and without diagnosis of mental, neurological disorders, uncorrected sensory deficiencies that could interfere with the understanding of the questions. The application was performed by occupational

therapists trained in the instrument, in individual sessions. The subjects' difficulties in understanding the questions were noted, as well as their suggestions to improve their understanding.

The subjects of the reliability study were recruited from outpatient clinics of the Senior Citizens Program, the Reference Center for Cognitive Disorders and the Occupational Therapy Service of the Institute of Psychiatry, Hospital das Clínicas, Sao Paulo School of Medicine and the community. The reliability study was carried out in a sample of 26 subjects, schooling ≥4 years, age ≥ 60 years, diagnosed with dementia, Mini Mental State Examination (MMSE) ≤24 and Clinical Dementia Rate (CDR) = 1 or 2 or without diagnosis of AD (MMSE ≥25 and CDR=0) and no diagnosis of mental, neurological disorders, uncorrected sensory impairments that could primarily interfere with functionality. The sample size was calculated using the GPower 3.17[22] program, for α=0.05, statistical power of 95%, and effect size of 0.8 (large). For inter-rater reliability, two previously trained occupational therapists scored the instrument at the same time.

Data were entered into electronic spreadsheets and analyzed using a statistical program. Reliability was studied by internal consistency analysis and obtained by calculating Cronbach's alpha coefficient (α). The analysis of inter-rater reliability, in which two raters scored the instrument at the same time, was obtained using Intraclass correlation coefficient (ICC).

RESULTS

In the translation stage, the author requested modification of phrases beginning with "may" (Chart 1). In the synthesis translation, these sentences had been placed in a direct form, such as "does/does not do". In the final version, we accepted the author's request and the sentences beginning with "may" were translated as "*pode* + verb in the infinitive form".

The experts pointed out the need to modify the task description to meet the most current information seeking customs in G. Telephone Use (Chart 2). The original instrument uses yellow pages (telephone directory). The change was defined based on the suggestions of the pre-test subjects, asked how they usually locate an unknown phone.

The 10 older subjects in the pre-test were 9 women and 1 man, with schooling from 4 to 7 years (20%), 8 to 11 years (40%), ≥12 years (40%) and age range from 60 to 69 years (50%), 70 to 79 years (30%), ≥80 years (20%). In the pre-test, it was identified the need to add examples of adaptive equipment and text adjustment to improve understanding in three items of the Physical Scale - ABVD and in 1 item of the Life in Community Scale - IADL (Chart 2). Examples of adaptive equipment were added with advice from an occupational therapist specializing in physical rehabilitation.

Chart 1. Comparison between the versions in the different stages of translation, with revisions in the back-translation and adjustments by the specialists before the pre-test.

Original	Initial version (T1-2 synthesis)	Back translation	Final version (with cross-cultural adaptation)
A. Grooming (Care of hair, nails, teeth; cosmetics) *1. Ignores personal appearance. May change body position* for a few seconds on command.*	**A. Higiene Pessoal: (cuidados com o cabelo, unhas, dentes, uso de maquiagem)** 1. Não se importa com a própria aparência. Sob comando muda a posição corporal* por alguns segundos	***A. Personal care: (hair, nails and tooth care, makeup use)*** *1. Does not care about his/her appearance.* *Changes the body position* for a few seconds under command.*	***A. Higiene Pessoal: (cuidados com o cabelo, unhas, dentes, uso de maquiagem)*** 1. Não se importa com a própria aparência. Pode mudar a posição corporal* por alguns segundos, sob comando.

Note: *Example of the objection that the author made, in the evaluation of the back-translation, in relation to the change in the speech that would interfere with the flexibility of the instrument and adjustment.

Chart 2. Cross-cultural adaptation

Original	Synthesis Version	Back translation	Final version
G. Telephoning *5. Looks up numbers in the White Pages or in a personal address book.* *May not use the Yellow Pages or consider sub classifications such as governmental agencies, or* 6. Uses a classification system to find a number in the Yellow Pages or in the listing of governmental agencies and learns to use new options.	**G.Uso do Telefone** 5. Procura números numa lista telefônica ou numa agenda pessoal Não usa lista telefônica (Páginas Amarelas) ou não considera subclassificações, como agências governamentais ou (serviços públicos) 6. Usa um sistema de classificação para encontrar um número em uma lista telefônica (Páginas Amarelas) ou na lista de telefones úteis de serviços públicos ou aprende a usar novas opções.	***G.Using the phone*** *5. Search for numbers in a phone book or in a personal address book* *Does not use the phone book (Yellow Pages) or does not consider sub-classifications, such as government agencies or 6. Uses a classification system to find a number in a phone book (Yellow Pages) or in the list of government agencies or learns to use new options.*	**G.Uso do Telefone** 5. Procura números numa lista telefônica ou numa agenda pessoal Pode solicitar ajuda a terceiros para obter o número em meios eletrônicos.* 6. Usa o serviço de informações ou a busca na internet para obter o número, ou aprende a usar novas opções.**
C. Bathing *1. Does not try to wash self and is given a sponge or bed bath by another person or uses a mechanical lift for transfer to bathtub.*	**C. Banho** 1. Não tenta se lavar e outra pessoa lhe dá banho no leito ou usa elevador mecânico para ser transferido para a banheira.	***C. Bathing*** *1. Does not try to bathe and another person gives him/her a bed bath or uses a mechanical lift to be transferred to the bathtub.*	**C. Banho** 1. Não tenta se lavar e outra pessoa lhe dá banho no leito ou usa elevador mecânico/ cadeira higiênica para ser transferido para a banheira/ chuveiro***
D. Walking/exercising *4. Walks in familiar surrounding without getting lost and can be trained to follow an exercise program after weeks of practice.*	**D.Mobilidade Funcional** 4. Anda em ambientes familiares sem se perder e pode ser treinado para seguir um programa de exercícios depois de semanas de prática	***D. Functional Mobility*** *4. Walks in familiar surroundings without getting lost and can be trained to follow an exercise program after months of practice.*	**D. Mobilidade Funcional** 4. Anda em ambientes que lhe são familiares§ sem se perder e pode ser treinado para seguir um programa de exercícios depois de semanas de prática.
H.Use of adaptive equipment	**H.Uso de equipamento adaptativo**	***H.Using Adaptive Equipment***	**H.Uso de equipamento adaptativo** (por exemplo, andador, muleta, cadeira de roda) §§

Note:*Adaptation at level 5 involves getting help from other staff to get the new information. **Adaptation at level 6 which implies the ability to be completely independent to obtain new information and the possibility of learning to use new technologies. *** Examples have been added for experiential approximation. §Semantic adaptation for understanding that the word familiar in this context would mean something usual and not belonging to a family. §§Examples of added adaptive equipment.

The complete manual and instrument can be found in full at Mello[23].

In the reliability study, 26 subjects participated, 7 with a diagnosis of dementia and 19 without a diagnosis of dementia. All had schooling ≥4 years, age ≥60 years (42.30% up to 69 years; 70 to 79 years, 46.15%; ≥80 years, 3%), 11.5% worked, 15.4% never worked, 73% retired.

Table 1 presents the inter-rater reliability and shows high agreement between two observers.

The internal consistency analysis of the RTI-E was performed for the Physical scale (ABVD), Community Life scale (IADL) and Communication scale, regarding the caregiver's report and self-report. The Work Readiness scale could not be analyzed due to the small sample of subjects to which this dimension was applied.

Table 2 presents the analysis of total internal consistency, obtained by Cronbach's α coefficient.

Table 1. Reliability between evaluators

RTI-E scales	Intraclass correlation coefficient		
	N	ICC	95% CI.
Physical (BADL)	26	0.992	0.982-0.996
Community Life (IADL)	26	0.987	0.972-0.994
Communication	26	1.000	
Work readiness	3	1.000	

Note: RTI-E = Routine Tasks Inventory – Extended. N = sample size. ICC = Intraclass Correlation Coefficient; 95% CI =Confidence Interval 95%. BADL = Basic Activities of Daily Living. IADL = Instrumental Activities of Daily Living.

Table 2. Internal consistency analysis of the RTI-E

RTI-E scales	Self-report	Caregiver/Informant Report
Physical Scale (BADL)	0.813*	0.895*
Community Life Scale (IADL)	0.944*	0.966*
Communication Scale	0.896*	0.955*

* Cronbach's α

DISCUSSION

The cross-cultural adaptation achieved semantic, cultural and idiomatic equivalence in relation to the original. The back-translation stage was crucial in this study to achieve idiomatic and conceptual equivalence, keeping the content faithful to the original. The back-translation led to a conceptual discussion, as "can" in English means "*capacidade*" ("be able to"), "*saber*" ("know how to") and "may" refers to "possibility", "opportunity". The initial translation had modified the precision of these terms in relation to the concepts of the original. Assessment instruments developed in other countries may present linguistic and cultural differences that modify the understanding of the concepts being evaluated[24]. In the CDM, the model that underlies the RTI-E, "can do" refers to biological aspects, cognitive ability, "will do" to personal aspects (psychological, volition, motivation) and "may do" to possibilities related to the environment[4]. Only when the imprecision was corrected, guaranteeing the equivalence between the instruments, the author approved the translation.

In the evaluation by experts phase, adaptations in items C. Bath, G. Use of Telephone and H. Use of Adaptive Equipment, monitored and approved by the author, were carried out to obtain experiential equivalence[20], adding relevant examples to the Brazilian reality.

It was confirmed in this study that the knowledge and previous training in the CDM, recommended by Katz[15] and Heimann[21] is essential and was crucial to align the form of application and scoring. High inter-rater reliability was obtained, with ICC values (95%CI) from 0.987 in IADL to 1.000 in communication. In the original study, Heimann[21] also found r = 0.9872 ($p<0.001$) for inter-rater reliability. There was high internal consistency in the total analysis of the RTI-E items and one item was removed, in accordance with the results of Heimann[21] in the internal consistency analysis of the original RTI ($\alpha=0.9402$).

Thus, the RTI-E meets the proposed requirements to be considered as a reliable instrument. Inter-rater reliability demonstrates the degree of agreement between different professionals when assigning scores, and internal consistency refers to the degree to which the inventory items are theoretically related to what is proposed to be measured[24].

The RTI-E aims to translate the influence of cognition on performance in routine tasks, to predict which are the potentials and limitations in the

individual's functionality, resulting from cognitive incapacity[15]. This study showed that the RTI-E allows the analysis of performance with details not detected in dichotomous assessments, in real life situations, without requiring special preparations or materials. Thus, reliable information about the client's functional cognition can be collected to compose the therapeutic planning and safety considerations during performance in a viable way to clinical practice, as proposed by Katz[11].

When evaluating the three perspectives of information, in the same items, the RTI-E proves to be useful both to compare the discrepancies in the observations and to understand the view that the evaluated person has of their situation. Although information from a caregiver may be more reliable regarding actual performance, self-report can be useful for intervention planning, as it provides information about the person's awareness of their abilities[13].

Older subjects without cognitive impairments were selected for the pre-test to ensure that comprehension difficulties arising in the application of the instrument were related to the content of the RTI-E and not to the comprehension difficulties inherent to the subject. In the reliability study, subjects with dementia were included in order to verify the feasibility of applying the instrument in this population.

The therapist's observation was adapted for an outpatient clinic with real tasks and the use of four items, with monitoring by the author of the instrument, but this made it impossible to analyze internal consistency in the therapist's observation. It was not possible to verify the internal consistency in the Work Readiness dimension due to the greater number of participants having already retired.

CONCLUSION

Semantic, conceptual, cultural, idiomatic and experiential equivalence were achieved in relation to the original. The RTI-E is the first CDM assessment instrument adapted to our environment and has been shown to be applicable to people with dementia. It showed high internal consistency and inter-rater reliability. The RTI-E fills the gap in assessment instruments for performance in routine tasks in older people with AD dementia. It can be useful to assess the interaction between cognition and functionality in a more specific and personalized way.

This initial study is followed by the expansion of the study of psychometric properties with a greater number of subjects with dementia and further studies with different populations are suggested, including older people with cognitive impairment due to other conditions.

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Relationship between the ability to walk long distances and to climb up and down stairs with the health-related quality of life of older adults with symptomatic knee osteoarthritis

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Abstract

Objective: To investigate the relationship between physical capacity and health-related quality of life (HRQoL) in older patients with symptomatic knee osteoarthritis (KOA). Method: A cross-sectional study was carried out, in which 67 older people (55 women and 12 men) diagnosed with KOA completed the physical function tests: Timed Up and Go (TUG); 30-second Chair Stand Test (30CST); Stair Climb Test (SCT); 40m Fast-Paced Walk Test (40FPWT); and Six-Minute Walk Test (6MWT). HRQoL was measured using the Western Ontario McMaster Universities Osteoarthritis Index (WOMAC). Univariate and multivariate linear regression analyzes were used to explore the relationship between the variables. Results: Patients were predominantly female, overweight, inactive, non-depressed, with bilateral KOA and in severe pain. In HRQoL, the domains showed low performance compared to healthy individuals. An association was observed between 30CST, SCT, 40FPWT and 6MWT with pain and physical function and an association of 30CTS, 6MWT with stiffness (R^2 = 0.064 to 0.304, $p<0.05$). In the multivariate analysis, BMI, sex and bilateral impairment were also considered as independent variables, resulting in significant associations of the 6MWT and BMI with pain (ß[6MWT]=0.121, 95%CI 0.005 to 0.237; ß[BMI]=0.022, 95CI and sex (ß=10.724, 95%CI 2.985 to 18.463) with physical function. Conclusion: The results suggests positive association between TSDE and physical function and negative associations between physical capacity on 6MWT on pain and stifness.

Keywords: Older Adults. Quality of Life. Osteoarthritis, Knee. Physical Functional Performance.

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INTRODUCTION

Knee osteoarthritis (KOA) annually affects around 86.7 million individuals[1]. KOA patients often experience pain while at rest and during movement, stiffness, apparently enlarged joints, crepitation, restricted movement, muscle weakness, and atrophy[2]. In addition, individuals with KOA spend approximately ten seconds to stair descent, 12 seconds to stair descent and nine seconds to perform TUG, in comparison to five, seven and five seconds for healthy individuals to perform the same activities, respectively[3].

During the progression of KOA, individuals with an elevated falls risk, sedentary behavior, a higher number of comorbidities, higher BMI, depressive symptoms, lower handgrip strength, and females experience increases in the deterioration of health-related quality of life (HRQOL)[4]. Regarding OA physiology, pain seems to be crucial for the physical capacity of these individuals, being capable of predicting up to 60% of the capacity to walk long distances and 48% of the HRQOL[5].

Collectively, these factors suggest the potential significance of physical capacity as an indicator of the HRQOL in older adults with KOA. The evaluation of an increase in HRQOL can also be used to measure success in intervention programs since individuals with a higher HRQOL seem to be physically more active[6]. The combination of walking short and long distances, chair standing, and stair climbing has been shown to be adequate for monitoring functionality in these individuals[7].

Considering that individuals with KOA experience lower QOL compared to paired individuals, regardless of the instrument of evaluation, the inclusion of QOL as a first step towards global management of KOA[8] and the lack of studies, within the knowledge of the authors on main databases, that have concomitantly assessed the main daily transfer activities performed by this population, understood as global physical capacity, the combination of these activities was included in the current study to investigate a possible relationship between these factors. We aimed to investigate the relationship between physical capacity and health-related quality of life (HRQOL) in older adults with KOA. We hypothesized that the global physical capacity assessed through the ability to walk short and long distances, chair stand, and stair climb would be associated with the different domains of HRQOL of older adults with symptomatic KOA. We also expect to encourage other researchers to investigate this important matter.

MATERIALS AND METHOD

This is a cross-sectional study. Recruitment and data collection were carried out between August 2017 and March 2020. Recruitment was conveniently performed through waiting lists for physiotherapy and geriatric care, distribution of flyers, and information on social media and local websites. Data collection was performed at the Human Functional Performance Laboratory of the University of Brasília - Ceilândia Campus. This research project was approved by the Ethics and Research Committee of the Faculty of Health Sciences - CEP / FS of the University of Brasília - UnB (CAEE 62256516.2.0000.0030). All study participants provided a written informed consent form. Data were reported according to the recommendations of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE).

We performed a secondary analysis of data obtained from an ongoing randomized clinical trial. The protocol of this study has been previously detailed[9] and registered in the Brazilian Registry of Clinical Trials - REBEC (RBR-875ZSW). The study included older men and women living in the western and southwestern regions of Brasília. The inclusion criteria were as follows: (i) age ≥ 60 years; (ii) clinical diagnosis of uni- or bilateral KOA according to the American College of Rheumatology criteria (ACR)[10]; and (iii) average pain ≥ four on a numerical rating scale. Participants were excluded if they: (i) had any medical restrictions that prevented the evaluation procedure (cardiorespiratory, neurological, and musculoskeletal changes), (ii) previous knee or hip surgery, (iii) could not walk without assistance; (iv) had undergone physical therapy treatment in the three months prior to the investigation; (v) had experienced infiltration or intramuscular procedure with corticosteroids or other medications in the knee

(previous six months); (vi) scored less than 18 points in the Mini-Mental State Examination in the case of participants who were declared illiterate and less than 24 for those with school education[11].

Data collection was performed over two days by a single trained examiner, lasting approximately one and a half hours. On the first day, the participants responded to the clinical characteristics and the WOMAC questionnaire. Physical-functional tests were performed on the second day.

The following information was assessed: age in full years, sex (female or male), joint impairment (unilateral or bilateral KOA), physical exercise practice (Active: ≥150 minutes per week of moderate-intensity exercise; Inactive: <150 weekly minutes of moderate-intensity physical exercise[12], cognitive status (total score of the Mini-Mental State Examination - MMSE), body mass index ($BMI = \frac{weight\ (Kg)}{height\ (m)^2}$), depressive symptoms (total score of the Geriatric Depression Scale of 15 items - GDS)[13], pain perception (Numerical rating Scale - NRS), and number of prescribed medications. According to the BMI, the participants were categorized as underweight (below 22 kg / m^2), eutrophic (between 22 and 27 kg / m^2), or overweight (above 27 kg / m^2)[14]. The identification of depressive symptoms allowed us to classify participants as not depressed (0 to 5 points), with mild depressive symptoms (6 to 10 points), or a suggestion of severe depression (11 to 15 points)[15]. The perception of pain in the NRS greater than or equal to 6 was characterized as severe[16].

Health- related quality of life (*Dependent variable*) was assessed using the WOMAC (Western Ontario and McMaster Universities Osteoarthritis), translated and validated for the Brazilian population. This is a self-report questionnaire that assesses three domains of HRQOL: pain, stiffness, and physical activity. The score for the items is expressed using a Likert scale, with a rating ranging from: none = 0, low = 1, moderate = 2, severe = 3, and very severe = 4. The maximum score in each section used in this study was expressed through the sum of the items of each domain, with higher scores indicating more significant pain (0-20 points), stiffness (0-8 points), and physical dysfunction (0-68 points)[17].

Physical capacity (*Independent or explanatory variables*) was evaluated using the five tests recommended by OARSI[18]: (i) Timed Up and Go (TUG); (ii) 30 Seconds Chair Stand (30CST); (iii) Stair Climb (SCT); (iv) 40m Fast-Paced Walk (40FPWT); (v) Six-Minute Walk (6MWT).

Except for the 6MWT, all evaluations were performed in a quiet, controlled, climatized environment. Individuals were instructed not to ingest coffee on the day of the physical test and to maintain their regular activities and medications.

For the TUG evaluation, each participant was initially positioned seated in a chair placed at the end of a 3m track. At the word "go", the participant walked at a comfortable speed to the 3m mark, turned around, walked back, and sat down again. The participants were not allowed to use their hands to help them get up[18]. The mean value of a previous study for obese individuals with KOA is approximately 8,9 seconds[19].

For the 30CST evaluation, participants sat in the middle of an armless chair, with their back straight, feet shoulder-width apart, and arms crossed on their shoulders. On the word "go", the participant stood up and sat down again as fast as they could for 30 seconds[18]. A low number of repetitions (>12) implied in poor muscle power performance.

The SCT test[18] was adapted to a set of two steps. The participants began the stair climb facing forward and on the word "go", ascended two steps (height 40cm; step width 16cm), and descended the two steps facing backward, nine times while being timed. The participants were allowed to use the therapist's support if necessary. More time to complete the test implied in poor lower body strength and balance performance.

The 40FCWT test was administered in a 10m hallway with a marked beginning and end[18]. On the word "go", participants began walking fast, without running, they walked 10m, walked back, and repeated the course until they had covered 40m. More time to accomplish the test implied in poor walking speed performance.

For the 6MWT, patients walked as far as possible in 6 minutes on a 30m quiet, partially covered hallway, and the distance they covered was recorded. A one-minute warning was also provided, along with the sentence "You are doing well, keep the pace". The mean value of a previous study for obese individuals with KOA is described as approximately 299 meters[19].

The possible confounding variables (BIAS) such as age, sex, BMI, joint impairment, physical exercise, and depressive symptoms were controlled by including them as covariates in the data analysis. To ensure an accurate predictive model, the recommendation of approximately ten individuals per variable was considered in the linear regression analysis[20].

The statistical analyses were performed using descriptive statistics (mean, standard deviation, absolute frequency, and percentage) for the measurements of clinical characteristics, HRQOL, and physical capacity. No imputations were made for missing data. In the cases of participants with missing data, the data were analyzed using pairwise exclusion so that the available data could be included in the analyses and, thus, the risk of bias minimized.

Pearson's correlation was calculated considering each domain of HRQOL (WOMAC) and measures of physical capacity. Pearson or Spearman correlations were calculated between continuous covariates and HRQOL. Additionally, independent student t-tests or the Mann Whitney U test was used to compare the scores of the HRQOL domains between the groups of categorical covariates. Correlations or comparisons of measures of physical capacity and covariates with a p-value ≤ 0.05 were considered significant.

Measures of physical capacity that showed significant correlation ($p \leq 0.05$) with the domains of HRQOL were chosen for the analysis of univariate linear regression to identify a possible relationship between each of the predictors (physical capacity) and the output variable (HRQOL). Any measures of physical capacity identified as significant predictors of HRQOL in these analyses ($p \leq 0.05$) were included in the multiple regression analysis.

The remaining predictors were then placed in a multiple linear regression model to determine whether the importance of these tests in explaining possible variations in the WOMAC domains was maintained when included with the others. Four multiple linear regressions were performed between each HRQOL domain and the physical capacity measures (independent variables) that were already significant in the simple regression. The significant covariables ($p<0.05$) in the correlation or comparison analyses were included in the multiple regression analyses as adjustment variables. For each analysis, the principles of independence between residues (Durbin-Watson), normality of residues, presence of homoscedasticity, and absence of multicollinearity between variables (VIF <10 and Tolerance> 0.1) were respected and, therefore, assumptions were guaranteed to perform regression by the step-by-step method. The analyses were performed using the stepwise-forward method. The variables not identified as predictive were removed, and the model with the highest adjusted R^2 value or that explained a higher percentage of the output variable was presented. A significance level of 5% was considered.

RESULTS

Initially, 188 participants were contacted. After applying the inclusion/exclusion criteria, 67 were considered eligible to participate in the study and included in the final analyses (Figure 1). Briefly, the research participants were predominantly women, aged between 60 and 83 years, overweight, inactive, without depressive symptoms, and with bilateral knee impairment associated with severe pain. The clinical characteristics of the participants and data on HRQOL and physical capacity are summarized in Table 1. Complete data were provided by 60 participants, with partial data available for the other 7. Two individuals had no BMI information, two individuals did not have information on the level of physical activity, and seven individuals had no information on the number of medications being used.

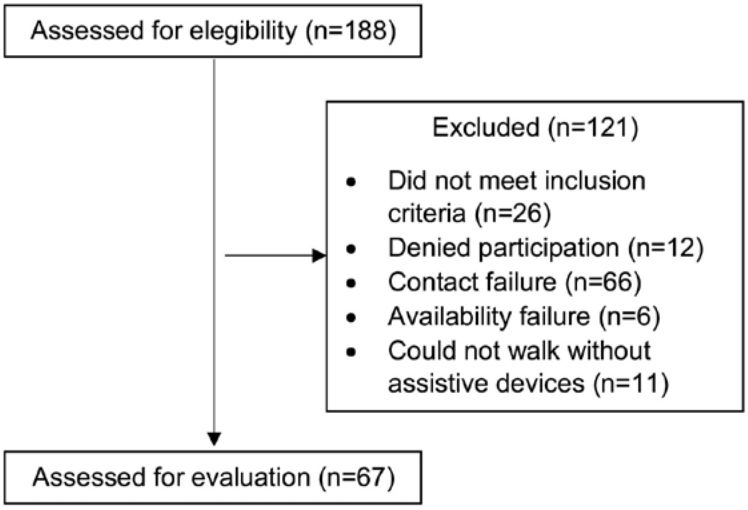

Figure 1. Study flowchart, Brasília, 2020.

Table 1. Demographic, physical, and functional performance variables of the participants (n=67), Brasília, 2020.

Variables	Total sample	Female (n=55)	Male (n=12)
Age (years)[a]	68.8 (5.8)	68.36 (5.69)	70.50 (6.028)
Sex (female)[c]	82.1 (55)	-	-
BMI (Kg/m²)[a]	30.38 (7.98)	30.60 (8.66)	29.43 (3.99)
Underweight[c]	1.5 (1)	0.0 (0)	25.0 (3)
Eutrophic[c]	16.9 (11)	15.1 (8)	25.0 (3)
Overweight[c]	81.5 (53)	84.9 (45)	66.7 (8)
Joint impairment (bilateral)[c]	73.1 (49)	78.2 (43)	50.0 (6)
Physical exercise practice (inactive)[c]	79.1 (53)	84.9 (45)	66.7 (8)
Number of medications[a]	4.07 (2.2)	4.10 (2.074)	3.91 (2.844)
MMSE (score) [a]	21.4 (5.9)	21.02 (6.317)	23.67 (3.367)
NRS (0-10)[a]	7.7 (2.2)	7.83 (2.193)	7.50 (2.431)
GDS (total score)[a]	5.04 (3.19)	5.51 (3.090)	2.92 (2.906)
Not depressed[c]	62.7 (42)	56.4 (31)	91.7 (11)
Mild depression[c]	28.4 (19)	34.5 (19)	0.0 (0)
Severe depression[c]	9 (6)	9.1 (5)	8.3 (1)
Physical capacity			
TUG (s)[b]	13.03 (11.05 – 16.07)	13.06 (11.07 – 16.04)	12.55 (10.45 – 19.54)
30CTS (repetition number)[b]	7 (5 – 9)	7 (5 – 8)	8.50 (6.50 – 11.00)
SCT (s)[b]	77 (63.05 – 95.05)	81.02 (67.56 – 100.72)	55.32 (42.03 – 76.54)
40FPWT (s)[b]	37.07 (32.09 – 43.09)	39.05 (33.55 – 44.52)	30.28 (26.54 – 35.01)
6MWT (m)[b]	371.00 (317.00 – 430.00)	365.00 (316.00 – 418.00)	445.00 (410.00 – 524.50)
WOMAC			
Pain (0-20)[b]	10.00 (7.00 – 13.00)	10.00 (8.00 – 13.50)	8.50 (5.00 – 10.50)
Stiffness (0-8)[b]	2.00 (0.00 – 4.00)	3.00 (0.00 – 4.00)	1.50 (0.00 – 2.00)
Physical function (0-68)[b]	31.00 (17.00 – 41.00)	33.00 (26.50 – 41.50)	15.00 (9.50 – 22.00)

Notes: [a]Mean (Standard deviation). [b]Median (P25% – P75%). [c]Percentage (Absolute frequency). MMSE: Mini-Mental State Evaluation. NRS: Numerical Rating Scale. GDS: Geriatric Depression Scale. TUG: Timed Up and Go. SCT: Stair Climb Test. 30CST: 30 Seconds Chair Stand Test. 40FPWT: 40m Fast-Paced Walk Test. 6MWT: Six-Minute Walk Test. WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index

Correlation coefficients between WOMAC and physical capacity are shown in Table 2. In the comparison analyses, significant differences were observed between men and women in all domains; pain (Mean difference=-2.93, [95% CI -5.54 to -0.33], p=0.028), stiffness (Z=-2.11, p=0.034), and physical activity (Mean difference=-16.71, [95% CI -24.96 to -8.47]), p<0.001). Differences in scores were also observed in the physical activity domain (Mean difference=9.49, F=0.009, p=0.015) between groups according to knee joint impairment (uni or bilateral). There was no significant difference between physically active or inactive individuals.

In the univariate linear regression analyses, an association of physical capacity was observed in the 30CST, SCT, 40FPWT, and 6MWT tests with the pain and physical activity domains, and an association of physical capacity in the SCT and 6MWT tests with the stiffness domain of the WOMAC (Table 3).

Table 2. Association between physical capacity scores and WOMAC domains:

Independent variables	WOMAC					
	Pain		Stiffness		Physical function	
	r	*p*	r	*p*	r	*p*
30CST	0.254[a]	0.038	-	-	0.259[a]	0.034
SCT	0.42[a]	<0.001	0.252[b]	0.04	0.552[a]	<0.001
40FPWT	0.329[a]	0.007	-	-	0.397[a]	0.001
6MWT	0.389[a]	0.001	0.279[a]	0.022	0.445[a]	<0.001

Key: [a]Pearson correlation; [b]Spearman correlation

Table 3. Univariate regression, including physical capacity as an independent variable and HRQOL as a dependent variable.

Dependent variable	Independent variable	Univariate regression		
		R^2 (R^2_{adj})	*Beta* (CI 95%)	*p-value*
WOMAC – Pain	TUG	0.014 (-0.015)	-0.010 (-0.197 to 0.176)	0.913
	30CST	0.064 (0.050)	-0.367 (-0.714 to -0.020	0.038
	SCT	0.180 (0.168)	0.064 (0.030 to 0.098)	<0.001
	40FPWT	0.108 (0.094)	0.111 (0.032 to 0.189)	0.007
	6MWT	0.151 (0.138)	-0.019 (-0.031 to -0.008)	0.001
WOMAC- Stiffness	TUG	0.020 (0.005)	0.064 (-0.047 to 0.174)	0.252
	30CST	0.017 (0.002)	-0.113 (-0.326 to 0.100)	0.293
	SCT	0.064 (0.049)	0.023 (0.001 to 0.044)	0.040
	40FPWT	0.035 (0.021)	0.038 (-0.011 to 0.087)	0.127
	6MWT	0.078 (0.064)	-0.008 (-0.015 to -0.001)	0.022
WOMAC- Physical function	TUG	0.001 (-0.014)	0.079 (-0.557 to 0.715)	0.806
	30CST	0.067 (0.053)	-1.279 (-2.461 to -0.097)	0.034
	SCT	0.304 (0.293)	0.284 (0.178 to 0.391)	<0.001
	40FPWT	0.158 (0.145)	0.455 (0.195 to 0.716)	0.001
	6MWT	0.198 (0.186)	-0.076 (-0.114 to -0.038)	<0.001

However, in the adjusted multivariate analysis, it was observed that physical capacity in the 6MWT (β =-0.022; t = -3.88; p<0.001) influenced by BMI (β =0.121; t = 2.08; p=0.041) explained 24.7% of the pain domain [F(2.62) = 10.19; p<0.001; R^2=0.247]. A total of 14.1% [F(2.62)=5.09; p=0.009; R^2=0.141] of the stiffness domain was explained by the 6MWT (β=-0.009; t=-2.37; p=0.021) influenced by BMI (β=0.076;t=2.00; p=0.049). The measure of physical capacity in the SCT (β=0.229; t=4.25; p<0.001) influenced by sex (β=10.724; t=2.77; p=0.007) was also observed and explained 39.5% of the physical activity domain [F(2.62)=20.26; p<0.001; R^2=0.395] (Table 4).

Table 4. Multivariate linear regression (Stepwise forward method) including physical capacity as independent variable and HRQOL as dependent variable:

Dependent variable	Independent variables	Multivariate Regression			
		R^2 (R^2_{adj})	'Cohen's f^2 (Effect Size) (power)	*Beta* (CI 95%)	Individual Significance (p-value)
WOMAC– Pain	30CST	0.247 (0.223)	0.32 (99%)	-	-
	SCT			-	-
	40FPWT			-	-
	6MWT			-0.022 (-0.033 to -0.010)	<0.001
	Female Sex			-	-
	BMI			0.121 (0.005 to 0.237)	0.041
	GDS			-	-
WOMAC-Stiffness	SCT	0.141 (0.113)	0.16 (83%)	-	-
	6MWT			-0.009 (-0.016 to -0.001)	0.021
	Female Sex			-	-
	BMI			0.076 (0.000 to 0.151)	0.049
WOMAC-Physical function	30CST	0.395 (0.376)	0.65 (99%)	-	-
	SCT			0.229 (0.121 to 0.336)	<0.001
	40FPWT			-	-
	6MWT			-	-
	Female Sex			10.724 (2.985 to 18.463)	0.007
	BMI			-	-
	Bilateral KOA			-	-
	GDS			-	-

After analysis, it was possible to establish three equations for all domains of HRQOL from the WOMAC:

(i) Pain domain= 14.436 + (-0.022* 6MWT) + (0.121* BMI)

(ii) Stiffness domain= 3.729 + (-0.009* 6MWT) + (0.076* BMI)

(iii) Physical function domain= -8.674 + (0.229 * SCT) + (10.724 * *sex*)

6MWT = performance in the six-minute walk test in meters (m); BMI = Body Mass Index in Kg / m^2; SCT = performance on the stair climb test in seconds (s); Sex = 1 for men and 2 for women.

DISCUSSION

The study examined the association between physical capacity and health-related quality of life in older adults with symptomatic KOA. The results showed that the HRQOL declined together with

the worsening ability to walk long distances and to climb stairs, even when BMI and sex influences were considered. These data will help in the establishment of rehabilitation strategies to assist in improving function in KOA patients.

Although some studies[21,22] have investigated the individual relationship between these abilities and perceived HRQOL, the authors are not aware of any studies on the main databases that concomitantly assessed the main daily transfer activities performed by this population, understood as global physical capacity. We found the ability to walk long distances adjusted for BMI explained 22.3% of HRQOL in the pain domain of the older adults with symptomatic KOA. Our findings revealed that participants with a lower BMI walked longer distances and reported a higher HRQOL regarding the pain domain. Juhakoski and colleagues (2008)[23] also identified this association between the pain domain of the HRQOL and a greater walking distance, regardless of BMI in participants with unilateral or bilateral hip OA.

The ability to walk long distances is reduced in older adults (> 65 years) with a diagnosis of KOA[21], and several factors can impact this activity, mainly overweight and knee pain[5]. Concerning overweight, the increase in body weight may overload and decrease joint movements, favoring a decrease in the activity level of these individuals[19], an increase in local pain[24], and a reduction in physical capacity, not only to walk long distances but also to chair stand and stair climb[22]. In patients with knee OA, the walking distance, BMI, duration of knee pain (years), life satisfaction, walking speed, standing and walking performance (TUG), reported instability[25], and range of knee flexion and extension movements[24] showed a linear relationship with the pain domain of the HRQOL[23].

We observed that the ability to walk long distances together with BMI also explained 11.3% of the stiffness HRQOL domain. This finding demonstrated that older adults with a lower BMI who could walk longer distances had a higher HRQOL in the stiffness domain. In KOA patients, joint stiffness is present during the morning, after long periods in the same position, and persists during walking, leading to gait cycle alteration[25,26]. In patients with unilateral knee OA, the joint stiffness can be 13% greater in the symptomatic limb compared to the asymptomatic limb[26]. In these patients, asymptomatic knee load can also increase up to 41%, leading to a higher knee flexion angle at the weight-acceptance phase and contributing to approximately 70% of the variation in stiffness along with knee contact forces[25]. Few studies have investigated these relations; however, worsening in the stiffness component also seems to be related to other factors such as age ≥ 65 years, BMI ≥ 25 kg/m^2, the female sex[27], and reported knee instability[25].

We also found that the ability to stair climb and sex explained approximately 38% of the physical activity domain of the older adults in the study. This finding demonstrated that older men with symptomatic KOA with a greater ability to stair climb also had a higher HRQOL in the physical activity domain. These findings are in accordance with the study conducted by Topp et al. (2000)[28], who also found an association between the ability to stair climb and the HRQOL, explaining approximately 50% of the HRQOL physical activity domain in older adults with a clinical diagnosis of KOA. This ability is often limited regardless of the degree of impairment (mild or moderate)[29] and has been reported to be influenced by sex since women present worse physical capacity compared to men with equivalent impairment[30]. In addition to these two determinants evaluated in our study, the presence of pain, even at a mild intensity, also demonstrated a relationship with the domain of physical activity, even in individuals without a KOA diagnosis. After adjusting for BMI, muscle strength, and anxiety, pain explained between 36 and 60% of physical capacity[31,32].

Impairments in physical capacity can compromise the ability to perform dynamic tasks, favoring a sedentary lifestyle and negatively affecting HRQOL[19]. Our findings demonstrated that the assessment of the ability to walk long distances and stair climb using quick, simple, and affordable measures provides an estimation of the pain, stiffness, and physical activity domains of HRQOL. Most of the determinants of HRQOL identified in the present study characterize modifiable factors[33]. Consequently, rehabilitation programs aimed at improving the HRQOL of these patients should consider promoting interventions to increase the ability to walk long distances and stair

climb, associated with weight reduction. Among several interventions available, a standardized exercise program is considered adequate for reducing pain and stiffness, thus contributing to increased functionality and HRQOL[34]. Another important factor to consider is the number of medications in use, polypharmacy, since the number of medications seems to negatively affect the level of physical activity[35] of individuals with KOA. Finally, the assessment of other factors related to physical capacities, such as lower extremity muscle function, can elucidate mechanisms associated with reduced physical performance and HRQOL in individuals with KOA.

Our study has some limitations. First, the inclusion of only symptomatic older adults with severe pain (NRS>7) prevents the generalization of our findings to the asymptomatic and symptomatic older population with mild pain OA. Second, other factors that can also alter pain perception and HRQOL are poor sleep quality, psychological status, and pain catastrophizing, which were not taken into consideration in our study. A further study of KOA patients to assess these components (sleep quality, psychological status, and pain catastrophizing), is warranted. Third, although the average pain perception of our participants was severe, they were not categorized into groups according to their pain intensity (mild, moderate, or severe). Considering that pain alone can explain up to 30% of the physical function domain of HRQOL this could have influenced our results. Further studies should consider cut points for pain. Fourth, even though we verified two main determinants of HRQOL in older adults with symptomatic KOA, a longitudinal assessment would better define causality. Fifth, muscle mass calf circumference was not used. Finally, the low number of subjects.

CONCLUSION

We observed a positive association between the ability to walk long distances and climb stairs and health-related quality of life. Some aspects, such as body mass index and sex may also perform a negative influence on this association. This study should be understood as an initial step towards describing the relationship between HRQOL and functional capacity, also helping health care professionals broaden their understanding regarding modifiable and non-modifiable conditions affecting patients with knee osteoarthritis. Interventions towards improving walking capacity and stair climbing such as gait training, outdoor aerobic activities, and step and stair training may enhance not only balance, strength, and body perception but also the quality of life of older adults suffering from symptomatic knee osteoarthritis, as obese and female individuals may struggle a little.

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Construction of a multidimensional oral health indicator for the older population in the city of Manaus-Amazonas

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Abstract

Objective: Produce a multidimensional indicator of oral health, based on dental and non-dental variables, for the older adult in the urban area of the city of Manaus-AM. *Method*: The data used are from a cross-sectional population-based study conducted in 2008 with randomly selected individuals aged 65 to 74 years, residing in the city of Manaus. To produce the proposed indicator, the dental variables (DMFT- Decayed, Missing and Filled Teeth; CPI- Community Periodontal Index; PIP- Periodontal Insertion Loss Index) and non-dental (socioeconomic and index GOHAI- General Oral Health Assessment Index) were considered. An exploratory factor analysis synthesized these variables, facilitating the construction of the multidimensional indicator. *Results*: The analysis generated three factors that, together, explained 72.9% of the model's variance (KMO = 0.749 and p<0.001 for Bartlett's test of sphericity). These three factors were reduced to the "sum" variable, calculated from the sum of the factor scores per individual. The median of this new variable was the reference value for categorizing the individual's oral health condition into "favorable" or "unfavorable". *Conclusion*: The indicator was able to aggregate several dimensions of oral health into a single measure, in addition to enabling its reproducibility for the construction of other health status indicators.

Keywords: Older Adults. Health Status Indicator. Oral Health. Tooth Loss.

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INTRODUCTION

Healthy aging is defined as "the process of developing and maintaining the functional capacity that enables well-being at an advanced age"[1]. It is important to consider the remarkable growth of longer-lived individuals, over 80 years of age in Latin American countries[2], in addition to the specificity and heterogeneity of aging processes in order to organize the functioning of health systems in the face of these demands[3]. In this context, oral health must be understood as an intrinsic aspect of general health[4]. However, the integration of oral health into national health programs is still incipient in most countries, requiring broad public health actions[5].

In the last national oral health survey (SB Brasil 2010), the results showed a high prevalence of edentulism (53.7%) in the older population and a high DMFT index (Decayed, Missing and Filled Teeth) as a result of the lost component[6,7]. Better oral health conditions can already be observed in children and adolescents in Brazil, this population may have benefited from preventive measures and improvements in the health system, adopted from the 80's onwards, such as the introduction of collective procedures and an increase in the offer of fluoride toothpastes. However, in older adults it is estimated that a reduction in tooth loss will only be significant from the year 2050 onwards[8]. It is known that the decrease in tooth loss in the older population is already observed in countries with high income, but with no impact on the oral health condition, since these teeth remain in the mouth, but with a high prevalence of decay and periodontal disease[9].

In view of the above, the oral health of older adults, when evaluated only by traditional dental indices, can be biased due to tooth loss, which impairs the accuracy of these indices[10]. Elani et al.[11], for example, demonstrated, using algorithms to assess the risk of tooth loss among adults, that the performance of models that incorporate the socioeconomic characteristic was better when compared to those based only on clinical dental indicators. Research shows that older individuals living in cities with low income and low education have a higher prevalence of tooth loss[12,13]. On the other hand, richer and more educated older people seek more preventive care[14,15].

These findings reinforce the definition of oral health as a physical, psychological and social state of well-being related to oral conditions, which significantly contribute to the quality of life of adults and older adults, affecting general health[16]. For this reason, the impact of oral health on the quality of life of older adults has been increasingly evaluated. The association between sociodemographic factors, health-related characteristics, functional status and OHRQoL (Oral Heath-Related Quality of Life) using the GOHAI (General Oral Health Assessment Index) scale shows consistent results on associations between self-rated health (subjective conditions) and oral health-related quality of life[17].

The importance of maintaining good oral health at older ages and the incorporation of oral health indicators in routine geriatric assessments has been discussed in the literature[18]. Thus, a comprehensive assessment of the oral health of these individuals is urgent, focusing on the comprehensive care of this population, which has peculiar characteristics regarding the presentation, installation and outcome of diseases and health problems, translated by greater vulnerability to adverse events[19]. Thus, the objective of the present study is to produce a multidimensional indicator of oral health, based on dental and non-dental variables, for older adults in the urban area of the city of Manaus-AM.

METHOD

Data from the only cross-sectional population-based study carried out in 2008 with older people living in the city of Manaus-AM, aged between 65 and 74 years, were analyzed, according to the methodology adopted by the SB Brasil 2003. Data were observed about the socioeconomic and demographic conditions, clinical measures and self-perception of oral health-related quality of life. A stratified random sampling process was designed to obtain a representative sample of 27,853 older people living in Manaus, according to a demographic census carried out by the Brazilian Institute of Geography and Statistics (IBGE) in 2000, distributed among the

administrative areas of the city (North, South, East, West, Mid-South and Midwest). As a population-based survey, the sample was determined by drawing census sectors (1582 classified as urban areas), which were stratified according to the proportion of older residents in each one, totaling 254 sectors to participate in the draw. After the selection of sectors, the recruitment of individuals was carried out according to the methodology of the demographic census, that is, the blocks were covered, house by house, clockwise to identify the residences where there was the population of interest and interrupted when the size of the pre-set sample had been reached. The sample size calculation considered the proportion of edentulism estimated for the North region (53%), according to SB-Brasil 2003, with 95% of significance, margin of error of 2 and non-response rate of 20%, totaling 807 individuals[20].

Data were collected, in their own homes, by a single properly trained and calibrated researcher, whose intra-examiner Kappa statistic presented satisfactory values above 0.76 for the evaluated outcomes.

The baseline study sample after exclusion criteria and non-response rate was 667 subjects. Individuals who did not reach the minimum score in the cognition test (Verbal Fluency Test)[21] (1.5%), those who did not have health conditions to perform the exam (10.7%) were excluded, and the rate of non-response was 5.4%. The current study to formulate the multidimensional indicator used data from 621 individuals, as 5.7% of the sample presented incomplete data for the candidate variables for the construction of the proposed indicator.

After submission to the Research Ethics Committee of the Federal University of Amazonas/UFAM, the study obtained a favorable opinion for its execution 4,542,423. A Data Use Commitment Term (DUCT) was signed by the authors due to the impossibility of obtaining informed consent from the participants.

The variables studied for the construction of the multidimensional indicator are briefly described in Figure 1.

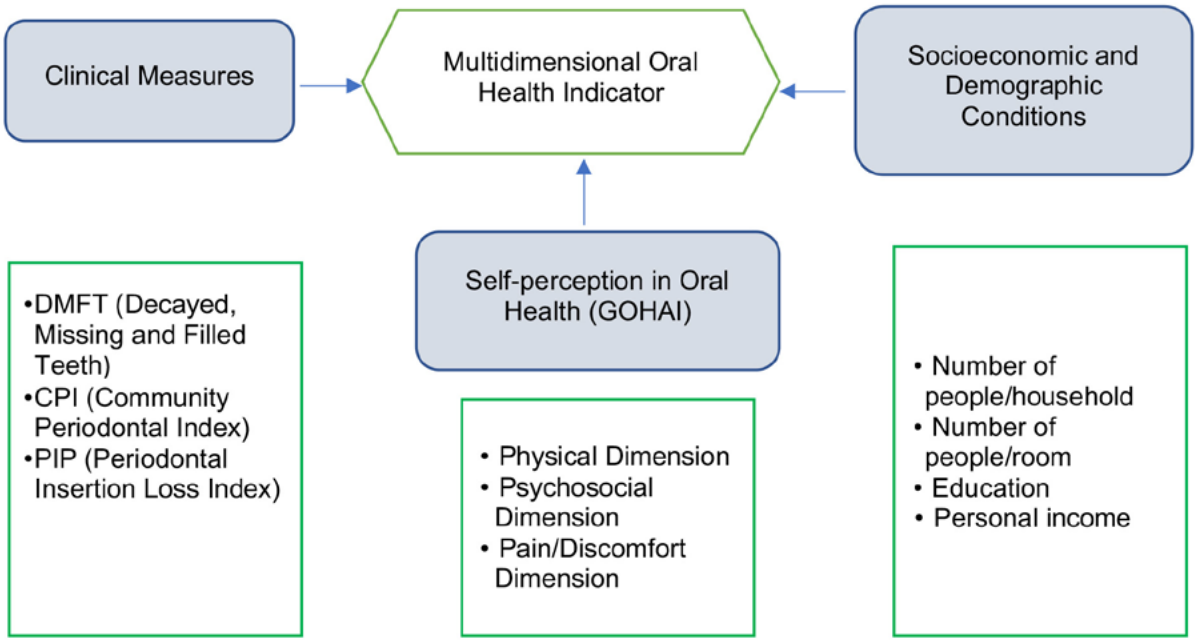

Figure 1. Conceptual model for the production of the multidimensional indicator of oral health of older adults.

Clinical measurements followed the criteria adopted by SB Brasil 2003[20]. Socioeconomic and demographic conditions were measured in interviews carried out using a questionnaire with objective questions and closed answers.

To assess the self-perception of quality of life related to oral health, the GOHAI index was used. Each individual answered twelve questions, whose answers fit into one of the following conditions: always, sometimes or never, corresponding respectively to scores 1, 2 and 3. The scores were added, the highest values indicate better self-assessment and the lowest values correspond to the worst self-rated oral health[22].

Through exploratory factor analysis (type R), the variables were reduced to common factors, which represent different dimensions of the oral health conditions of the older adults examined. To assess the applicability of the statistical model, a correlation matrix was used, based on Pearson's coefficient, followed by KMO statistics (Kaiser-Meyer-Olkin) and Bartlett's sphericity test. The factors were extracted using the Kaiser criterion and interpreted by the factor loading matrix. The production of a single indicator was conducted by adding the factor scores, followed by the dichotomization of this sum from the median for each individual in the sample. Finally, the validation of the indicator produced was carried out, through the criterion analysis. Thus, possible associations between the indicator produced and the variables that were not included in the model were tested, seeking relevant relationships with what was found in the literature.

RESULTS

Among the 621 participating individuals, it was observed that 432 (69.6%) individuals in the sample were female, with a mean age of 69.26 ± 3.00 and a mean monthly personal income of R$ 705.35 ± 908.03. As for skin color, 450 (72.5%) individuals declared themselves to be brown, followed by 96 (15.5%) who declared themselves to be white. Regarding education, 124 (20%) individuals had never attended school.

As for the impact of losses in the sample, related to incomplete data for factor analysis (5.7%), which were not considered in the baseline study, it was observed that they had little influence on the two main outcomes of the study. In the case of DMFT, it went from 29.08 to 29.27. For edentulism, this difference was 2.2, suggesting a low impact for the adopted model.

For the construction of the proposed indicator, initially, there were eighteen variables that could be incorporated into the proposed statistical model (Table 1). However, the best model, that is, the one with the best correlations and statistical applicability, had nine variables: "number of teeth present", "number of healthy teeth", "number of missing teeth", "number of sextants with calculus", "years of study", "personal income in reais", GOHAI score in the "physical", "psychosocial" and "pain/discomfort" dimensions.

The applicability of this model was initially confirmed from the analysis of Pearson's Correlation Matrix, in which a significant number of values greater than 0.30 and less than 0.90 were observed. In addition, other pre-tests were performed, the KMO statistic (Kaiser-Meyer-Olkin), also considered a measure of sample adequacy, whose value was 0.749, that is, a result greater than 0.5, indicated the adequacy of the model. Bartlet's sphericity test showed a p-value <0.001, confirming, once again, the use of factor analysis.

After confirming the adequacy of the model, some criteria must be adopted for the selection of factors (statistical variables). As for the selection of factors, the decision on the number of factors must be guided by the desired objective. For this study, the Kaiser criterion was used, from which three factors were extracted (Figure 2).

Table 1. Descriptive analysis of candidate variables for the production model of the multidimensional indicator of oral health for the older population. Manaus, AM, 2020.

Variables	Average ± SD	Median	$Q_{25} – Q_{75}$	CI (95%)
Age	69.26 ± 3.00	69.00	67.00 – 72.00	69.02 – 69.50
Years of study	4.54 ± 3.97	4.00	1.00 – 7.00	4.22 – 4.85
Personal income in reais	705.35 ± 908.03	415.00	415.00 – 800.00	633.26 – 777.43
Number of people/room	0.98 ± 0.75	0.80	0.58 – 1.25	0.92 – 1.04
Number of missing teeth	28.09 ± 5.37	32.00	25.00 – 32.00	27.67 – 28.52
Number of teeth present	3.82 ± 5.22	0.00	0.00 – 6.50	3.41 – 4.24
Number of healthy teeth	2.64 ± 3.70	0.00	0.00 – 5.00	2.34 – 2.93
number of decayed teeth	0.52 ± 1.46	0.00	0.00 – 0.00	0.41 – 0.64
Number of teeth restored	0.66 ± 1.95	0.00	0.00 – 0.00	0.50 – 0.82
DMFT	29.27 ± 3.86	32.00	27.00 – 32.00	28.97 – 29.58
Number of sextants with calculus	0.34 ± 0.64	0.00	0.00 – 1.00	0.29 – 0.39
Number of sextants with bleeding	0.01 ± 0.1	0.00	0.00 – 0.00	0.00 – 0.01
Number of sextants with shallow periodontal pocket (4-5 mm)	0.03 ± 0.21	0.00	0.00 – 0.00	0.01 – 0.05
Number of sextants with deep periodontal pocket (≥ 6 mm)	0.00 ± 0.00	0.00	0.00 – 0.00	0.00 – 0.01
Total GOHAI score	33.87 ± 2.74	35.00	33.00 – 36.00	33.65 – 34.09
GOHAI score physical dimension	11.29 ± 1.20	12.00	11.00 – 12.00	11.19 – 11.38
GOHAI score psychosocial dimension	14.26 ± 1.26	15.00	14.00 – 15.00	14.16 – 14.36
GOHAI score pain/discomfort dimension	8.32 ± 1.01	9.00	8.00 – 9.00	8.21 – 8.40

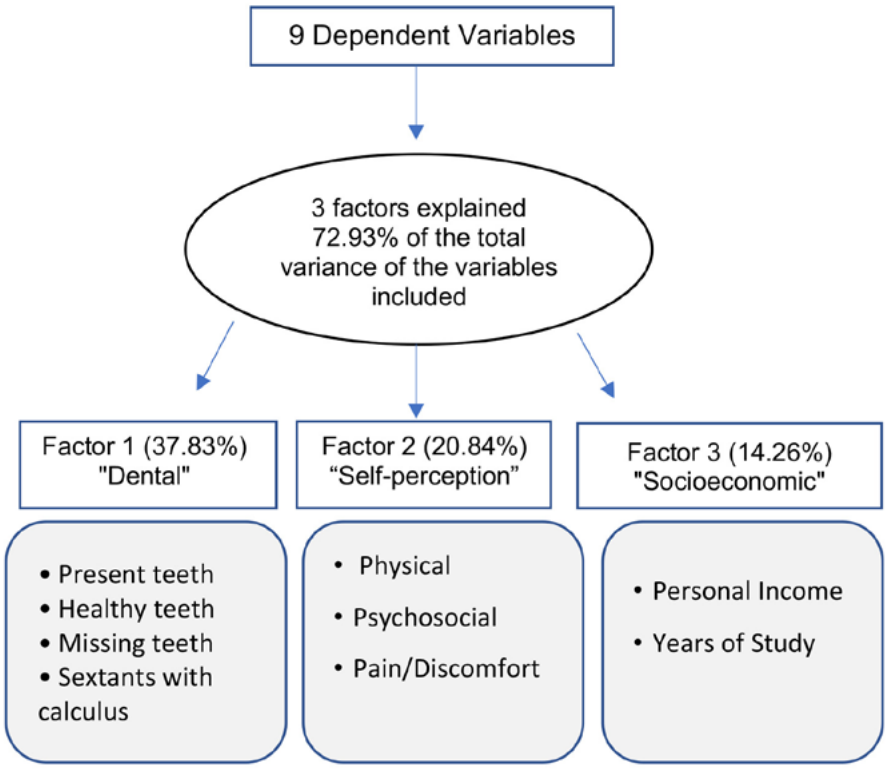

Figure 2. Data reduction, schematically represented, to obtain the factors of factor analysis.

It was also observed that the Sample Adequacy Measures (SAM) reinforced the applicability of the model since no variable presented SAM lower than 0.50 (Table 2). For the interpretation and composition of the extracted factors, the matrix of rotated factor loadings (VARIMAX-type Orthogonal rotation) was considered. The distribution of factor loadings is fundamental for the nomenclature of factors, because in addition to ensuring that the data meet the statistical requirements for an appropriate estimation of the factor structure, it is necessary that the set of variables present a conceptual foundation to support the results[23].

After extracting the three factors, each of the 621 individuals in the sample presented three scores referring to the factors obtained. Then, for each individual, the sum of the three scores was performed, where a new variable called "factorial sum" was added to the database. In this way, the oral health condition of older adults started to be categorized based on the median of the variable "factorial sum". Therefore, individuals who presented factorial sum values above the factorial median had their oral health condition classified as "favourable". On the other hand, individuals with factor sum values below this median had their oral health condition classified as "unfavorable".

For the criterion validation of the indicator produced, possible associations between the multidimensional indicator and independent variables that were not included in the model were investigated, in order to observe plausible associations according to the literature (Table 3).

Table 2. Factor loadings, Sample Adequacy Measures (SAM) and Commonalities of the final model for producing the multidimensional oral health indicator for the older population. Manaus, AM, 2020.

Variables	FACTORS			SAM	Commonalities
	F1	F2	F3		
Nº of missing teeth	**-0.961**	-0.007	-0.111	0.708	0.936
Nº. of teeth present	**0.965**	0.001	0.118	0.690	0.946
Nº. of healthy teeth	**0.940**	0.021	0.053	0.942	0.887
Years of study	0.155	0.019	**0.813**	0.612	0.686
Personal Income	-0.016	0.038	**0.810**	0.523	0.658
physical GOHAI	0.091	**0.823**	0.090	0.618	0.694
psychosocial GOHAI	-0.089	**0.773**	-0.109	0.631	0.617
pain GOHAI	-0.016	**0.760**	0.087	0.682	0.585
Nº. of sextants with calculus	**0.744**	-0.046	-0.026	0.958	0.556

Table 3. Criterion validation of the multidimensional oral health indicator for the older population. Manaus, AM, 2020.

Variable	Oral health status	Median ± DP	Difference between the medians	CI (95%)	*p**
Age	Unfavorable Favorable	69.52 ± 3.07 69.00 ± 2.92	0.52	0.05 – 0.10	0.03
Number of people/ room	Unfavorable Favorable	1.07 ± 0.84 0.90 ± 0.63	0.17	0.04 – 0.28	0.007
Family Income	Unfavorable Favorable	1153.62 ± 892.98 2058.06 ± 1974.61	-904.44	-1147.68 – -661.20	<0.001
Variable		Oral health status			*p***
		Unfavorable n (%)	Favorable n (%)		
Sex					
Male		72 (38.1)	117 (61.9)		<0.001
Female		238 (55.2)	193 (44.8)		
Housing Zone					
East		54 (69.2)	24 (30.8)		<0.001
Midsouth		20 (32.8)	41 (67.2)		
West		39 (39.0)	61 (61.0)		
South		114 (52.1)	105 (47.9)		
North		39 (52.0)	36 (48.0)		
Midwest		41 (55.4)	33 (44.6)		

* T test for independent samples; ** Pearson's Chi-Square Test.

DISCUSSION

This study found the importance of a multidimensional assessment of the oral health of older adults using a single indicator, since some variables that composed the model presented values that alone do not reflect the real situation of the oral health of this individual. Based on the factors extracted, it was observed that some variables with low factor loading, such as "pain GOHAI", proved to be adequate for the proposed model, that is, with acceptable values of SAM and commonalities. Thus, the oral health condition was measured by quantitative variables, capable of measuring dental and non-dental dimensions related to this outcome.

Unlike other indicators already proposed that sought to overcome the limitations of the DMFT index for the older population, such as the T-Health (*Tissue Health*) that assesses changes in soft tissue and the FS-T index (*Filled and Sound Teeth*), which considers dental functionality[24], the proposed indicator encompasses, in addition to dental variables, socioeconomic and quality of life aspects related to oral health, with all these dimensions represented by three factors that together explained 79.23% of the total variance.

The factors extracted from the linear relationships between the variables showed a greater representativeness (variance) of the first factor extracted (37.83%), that is, the dental characteristic. Within the "dental" factor 1, a low factor loading of the variable "number of sextants with dental calculus" can be observed, despite the great relevance of the periodontal condition for the Brazilian older population[6]. Even with the WHO goal to increase the number of older individuals with a functional dentition in the year 2000, the clinical indicators evaluated showed a difficulty in the analysis of periodontal indexes due to the high prevalence of excluded sextants, that is, a reduced number of teeth present[20].

The second factor extracted, "self-perception", is based on the residual amount of variance, and can be characterized as one of the factors that most differentiates the individuals in the sample[25]. A previous study corroborates this specificity of the older population, since only in this population the self-assessment of oral health presents better results in edentulous individuals[26]. Normally, the older person is more resilient and admits the loss of teeth as a natural process of aging, not realizing their negative condition. The absence of painful processes or aesthetic impairments leads them to underestimate oral problems, evidencing the importance of social and cultural determinants for the perception of the concept of oral health for the older population[27].

The validity of the model was verified from associations between oral health and contextual variables already described in the literature. It was observed that male individuals had a higher percentage of favorable indicator ($p<0.001$), which may be associated with a higher prevalence of edentulism among women and greater use of dentures[28]. Male sex and better socioeconomic conditions have already been identified as protective factors for edentulism among older individuals[29]. Furthermore, the worse health condition of older women may be associated with their greater longevity and implies a greater need for attention in all life cycles[30]. Regarding the family income variable, it is observed that individuals with a family income above R$ 1,974.61 showed a higher percentage of favorable indicator than those with income below this value, demonstrating an association already evidenced in the literature[31,32]. For the older population, lifetime socioeconomic inequities are associated with an increased risk of tooth loss[33].

The impact of the high prevalence of tooth loss and the low use of dentures in the Brazilian older population is reflected in the self-perception of quality of life related to oral health, more markedly in the country as a result of social inequalities[34]. The identification of the influence of contextual and individual health determinants is evidenced in the percentage of individuals with an unfavorable indicator in the East Zone of Manaus (69.2%), considering that it is one of the most populous regions of the city, with disorderly occupation, serious social and environmental problems, in addition to the lowest human development indicator (HDI) in the capital[35].

The results of the present study must be seen in light of its strengths and limitations. A limitation related to the base study was the non-inclusion of important variables in the health context of older adults, such as, for example, multimorbidity and polypharmacy. As strong points, the following stand out: the study scenario, as it is a region that has been little studied, mainly in relation to the outcome and specific population, and the construction of a model that allowed the production of a multidimensional indicator of oral health, approaching the current concept of oral health advocated by the WHO.

CONCLUSION

The indicator produced, by aggregating different dimensions of the oral health condition, was able to overcome the limitations of traditional dental indexes, due to the high tooth loss in the older population. Validation through comparisons with variables already described in the literature proved the role of social determinants of health, throughout life, in the oral health status of these individuals. It is noteworthy the possibility of reproducibility of the model in different databases, in the most diverse research scenarios, regardless of the moment when the data were collected, since the model is fixed for the construction of composite indicators. Therefore, this model allows decision-making for the formulation and improvement of policies, both for prevention and control, as well as for defining priorities and forecasting future demands related to the oral health of the older population.

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Temporal analysis of the incidence of HIV/AIDS in older people from 2007 to 2020

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Abstract

Objective: To analyze the temporal trend of the incidence rate of new HIV/AIDS cases in the old-aged, from 2007 to 2020, in the state of Bahia, in the Northeast Region and in Brazil. *Methods:* Ecological time series study, using secondary data from 2007 to 2020 in an elderly population. Calculations of the HIV/AIDS incidence rate and frequency distribution of sociodemographic characteristics and exposure categories were performed. Simple linear regression models were estimated for trend analysis and calculated by the annual percentage change (APC). *Results:* In Brazil, during the study period, there was stability in the trend of the HIV/AIDS incidence rate for the general population and for both sexes. In the Northeast there was an increase for the general (APC=6.4%), for males (APC=6.9%) and females (APC=6.5%). In Bahia, there was an increase for the general (APC=7.4%) and male sex (APC=7.4%), and stability for females. Higher proportions of new cases in the elderly were observed in males, whites (Brazil), blacks (Northeast and Bahia), low education and heterosexual exposure category. *Conclusion:* Attention should be paid to the increase in cases in individuals in the third age seeking to demystify taboos about the sexuality of the elderly in order to promote the adoption of health promotion measures, aiming at reducing the transmission of the virus.

Keywords: Health Profile; HIV; Health of the Elderly; Epidemiologic Studies.

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INTRODUCTION

In 1980, the first cases of AIDS, caused by the human acquired immunodeficiency virus (HIV), which destroys the human body's natural defense mechanisms, were officially documented by the US Centers for Disease Control and Prevention (CDC)[1]. In that period, homosexuals, injecting drug users, sex workers and hemophiliacs were included in the risk group for contamination by the virus[1-2]. Since then, AIDS has been considered a pandemic, with around 37.9 million infected worldwide[3].

The African and Asian continents have the highest numbers of virus infection, with about 30.6 million people infected. Latin America is just behind with 1.9 million people living with the virus, ranking third in the world[3]. In Brazil, between 1980 and June 2021, 1,045,355 AIDS cases were identified, in 2021, 32,701 new HIV cases and 29,917 AIDS cases were diagnosed, with a detection rate of 14.1 per 100,000 inhabitants[4].

With the advance of the HIV/AIDS epidemic, the profile of those infected has changed. Currently, heterosexual individuals are the most affected by the disease, the idea of a risk group has been replaced by risk or vulnerable behavior[5]. Thus, it allows the expansion of the focus of attention to society as a whole and not just to isolated groups, avoiding the stigmatization of social groups[5].

Regarding vulnerability to HIV/AIDS, individual and collective aspects are important in exposure to the virus[6,7]. In this way, low access to health services, unfavorable economic conditions and lack of sexual and reproductive rights contribute to greater exposure to the virus[6,7]. There is a change in the regional distribution of the disease, previously restricted to the Southeast region, now spread in other regions of the country, such as the North and Northeast regions[8,9]. Probably related to the context of social vulnerability that these regions present and also the reduction of underreporting of the disease[5].

Another change observed in the progression of the epidemic is the increasing infection in people aged 60 years and over[2,7,10]. At the beginning of the infection, in the 1980s, the older population was not affected and only four cases appeared in the first five years of the epidemic[2]. In 1995, 395 cases were reported in the country, rising to 1,119 cases reported in 2005 in this population[11].

With the increase in life expectancy and the achievement of retirement, aging has been re-signified. Older people have increasingly sought an active social life, with physical activity practices, greater social circle, body changes and also in sexual behavior[12]. Thus, there is the introduction of drugs that help sexual life, such as drugs for erectile dysfunction and hormone therapy, which provides a more active sex life[2,7,10,12]. Despite this, there are still many taboos regarding the sexuality of older people, on the part of family members and health professionals[9,13,14].

The taboo on the sexuality of older people is a problem that can lead to a decrease in the early detection of HIV infection, since this group is often not considered among those who have an active sexual life[14,15]. Another factor that contributes to a possible infection is the non-use of condoms by these individuals, because they do not feel vulnerable to the disease, due to taboos and, mainly, due to the lack of orientation of this population when they were young.

With the possible increase in the number of HIV/AIDS infections in people aged 60 and over, it becomes important to estimate whether this increase has been real over the years and how it is distributed in this population group. Given the above, this article aims to analyze the temporal trend of the incidence rate of new cases of HIV/AIDS in older people, from 2007 to 2020, in the state of Bahia, in the Northeast Region and in Brazil.

METHODS

This is an ecological time series study of new reported cases of HIV/AIDS in people aged 60 years and over, between 2007 and 2020, living in the state of Bahia, Northeast Region and Brazil.

Secondary data obtained from the following databases were used: National System of Notification of Diseases (SINAN) made available by the Department of Informatics of the Unified Health System (DATASUS)[11] and data from the 2010

demographic census[16] and intercensus estimates for the other years, made available by IBGE, through TABNET – DATASUS[17].

The absolute and relative frequencies of reported AIDS cases in older people were calculated according to sociodemographic and exposure characteristics for the state of Bahia, the Northeast Region and Brazil. The variables studied were: age group (60-69; 70-79 and 80 years or older); sex; year of diagnosis (from 2007 to 2020); years of education (none, 1 to 3 years, 4 to 7 years, 8 to 11 years and 12 years or more); race/color (white, black, brown, yellow and indigenous) and exposure category (heterosexual, homosexual, bisexual, IDU injecting drug use, hemophiliac and vertical transmission).

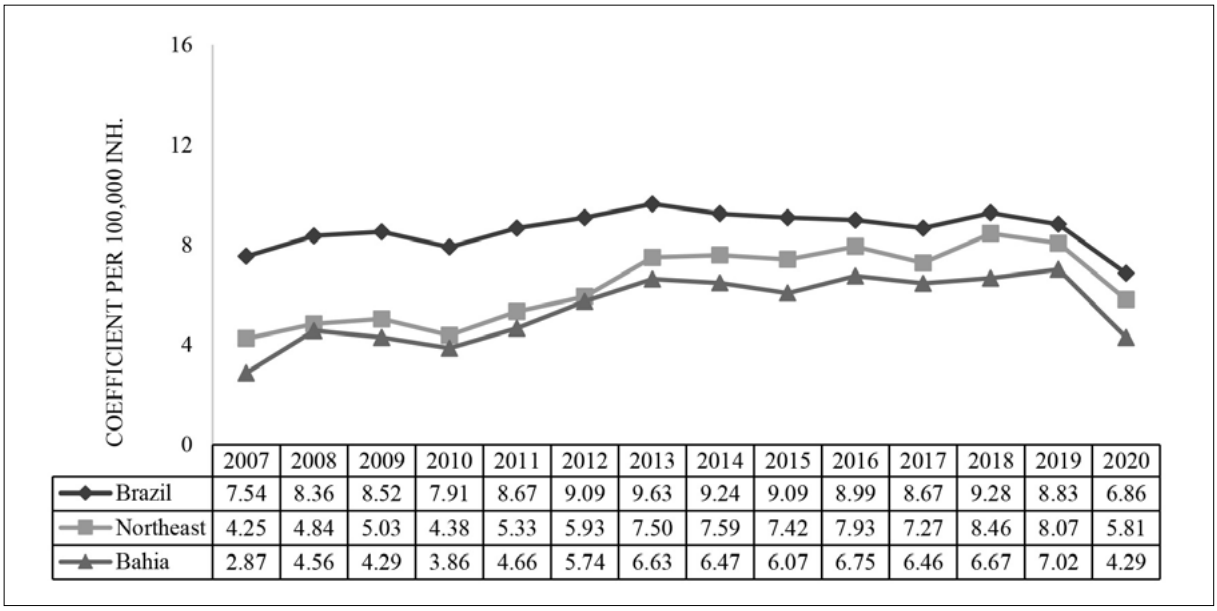
The HIV/AIDS incidence rate was calculated stratified by year, sex and geographic area, and considered the new reported cases of HIV/AIDS in older people in the numerator and the older population multiplied by 100,000 in the denominator. To assess the time trend of the rates, the annual percentage change (APC) of the incidence rates was calculated through the ratio of the regression coefficient in relation to the rate at the beginning of the period.

To estimate the regression coefficients and their 95% confidence intervals, simple linear regression was used, considering the incidence rate as the dependent variable and the years of the historical series as the independent variable. The trend whose regression coefficient was not different from zero, p-value>0.05, was considered stationary. The assumptions of normality, linearity and homoscedasticity of the residuals were verified, respectively, by the Shapiro-Wilk test, scatter plot and Breusch-Pagan test. A 5% significance level was adopted.

RESULTS

From 2007 to 2020, 27,856 new cases of HIV/AIDS in older people were reported in Brazil, 5,207 in the Northeast region and 1,225 in the state of Bahia.

In Brazil, the incidence of HIV/AIDS in older people increased from 7.54/100,000 inhabitants in 2007 to 6.86 in 2020. In the Northeast region, the incidence rate was 4.25 in 2007, rising to 8.73 in 2020, and in the state of Bahia, the incidence increased from 2.87/100,000 in 2007 to 4.29 in 2020. In these three regions, a drop in rates was observed in 2020 (Figure 1).



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Brazil	7.54	8.36	8.52	7.91	8.67	9.09	9.63	9.24	9.09	8.99	8.67	9.28	8.83	6.86
Northeast	4.25	4.84	5.03	4.38	5.33	5.93	7.50	7.59	7.42	7.93	7.27	8.46	8.07	5.81
Bahia	2.87	4.56	4.29	3.86	4.66	5.74	6.63	6.47	6.07	6.75	6.46	6.67	7.02	4.29

Figure 1. Incidence coefficient (100,000 inhabitants) of HIV/AIDS in older people in the state of Bahia, Northeast Region and in Brazil, 2007-2020.

In older males in Brazil, in 2007, the incidence of HIV/AIDS was 10.3 per 100,000 inhabitants, and in 2020, it decreased to 9.6. In the Northeast region, the incidence rate in 2007 was 6.7 and 8.7 in 2020. In Bahia, in 2007, the incidence rate was 4.3 and increased to 6.6 in 2020 (Figure 2).

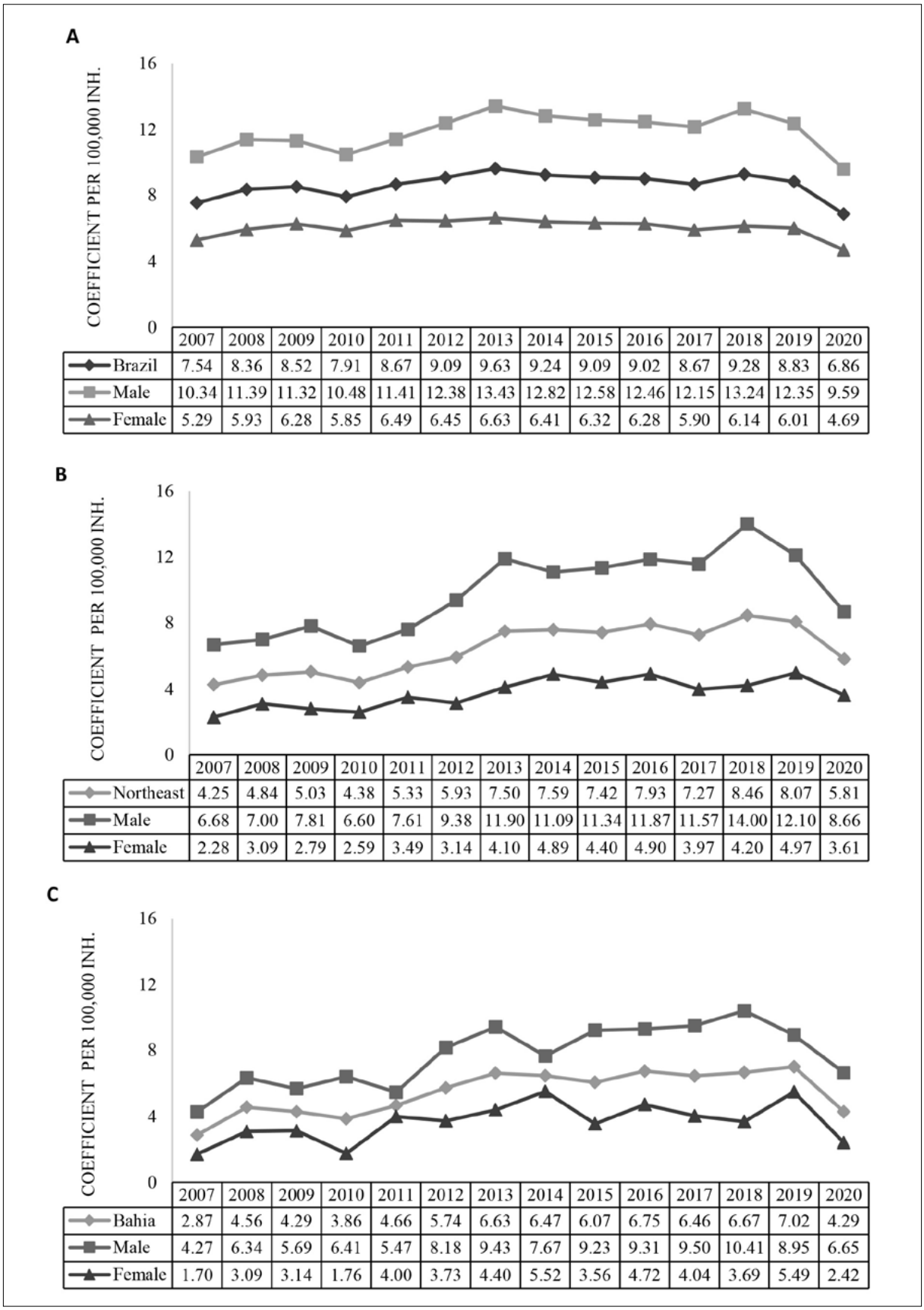
In older females, in 2007, in Brazil, the incidence per 100,000 inhabitants was 5.3 and 4.7 in 2020. In 2007, the rate was 2.3 in the Northeast region and 1.7 in Bahia, in 2020 it was 3.6 in the Northeast and 2.4 in Bahia (Figure 2).

The average HIV/AIDS incidence rate was 9.5/100,000 in Brazil, 6.7/100,000 in the Northeast region and 6.0/100,000 in the state of Bahia, with an average rate about 2 times higher in men than in women. In Brazil, the incidence rate trend was stable for the total population and for sex. There was an increasing trend in the incidence rate for the Northeast region (APC=6.4%) and the state of Bahia (APC=7.4%), and a similar behavior was observed for males. In females, an increase in incidence was observed only in the Northeast region (APC=6.9%), being stable in Bahia (Table 1).

In the three regions analyzed, a reduction in the incidence rate of HIV/AIDS was observed with increasing age (Figure 3).

Among the new reported cases of HIV/AIDS in Brazil, the highest percentage of white individuals (30.5%) was observed, followed by browns and blacks. In the Northeast region and in the state of Bahia, a higher percentage of the black population (blacks and browns) was observed. As for the education of the new cases, a higher frequency was observed in the category of 4 to 7 years of study in all regions, in this variable, more than half of the population in each region was classified as ignored, exceeding 60% in the state of Bahia (Table 2).

Regarding the category of exposure in older people with HIV/AIDS, the predominance of contamination in heterosexual relationships was observed in the three regions analyzed, accounting for 42.8% of cases in Brazil, followed by homosexual (3.5%) and bisexual (2.2%) other categories such as Injectable Drug Use (IDU) and vertical transmission showed to be frequent. The number of ignored people in this category was 59.9% in the state of Bahia (Table 2).



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Brazil	7.54	8.36	8.52	7.91	8.67	9.09	9.63	9.24	9.09	9.02	8.67	9.28	8.83	6.86
Male	10.34	11.39	11.32	10.48	11.41	12.38	13.43	12.82	12.58	12.46	12.15	13.24	12.35	9.59
Female	5.29	5.93	6.28	5.85	6.49	6.45	6.63	6.41	6.32	6.28	5.90	6.14	6.01	4.69

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Northeast	4.25	4.84	5.03	4.38	5.33	5.93	7.50	7.59	7.42	7.93	7.27	8.46	8.07	5.81
Male	6.68	7.00	7.81	6.60	7.61	9.38	11.90	11.09	11.34	11.87	11.57	14.00	12.10	8.66
Female	2.28	3.09	2.79	2.59	3.49	3.14	4.10	4.89	4.40	4.90	3.97	4.20	4.97	3.61

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Bahia	2.87	4.56	4.29	3.86	4.66	5.74	6.63	6.47	6.07	6.75	6.46	6.67	7.02	4.29
Male	4.27	6.34	5.69	6.41	5.47	8.18	9.43	7.67	9.23	9.31	9.50	10.41	8.95	6.65
Female	1.70	3.09	3.14	1.76	4.00	3.73	4.40	5.52	3.56	4.72	4.04	3.69	5.49	2.42

Figure 2. Incidence coefficient (100,000 inhabitants) of HIV/AIDS in older people from 2007-2020: a) sex for Brazil; b) sex for the Northeast Region; c) sex for the state of Bahia.

Table 1. Average coefficient per 100,000 inhabitants and trend of HIV/AIDS incidence rates in older people according to sex for Brazil, Northeast Region and Bahia in the period 2007-2020.

Geographical unit / sex	average coefficient	APC (%) [a]	95%CI [b]	p-value	Interpretation
Brazil	9.52	0.28	-1.20; 1.77	0.684	Stable
Male	13.09	0.74	-0.84; 2.33	0.328	Stable
Female	6.67	-0.39	-1.85; 1.06	0.567	Stable
Northeast	6.72	6.43	3.11; 9.76	0.001	Increasing
Male	10.10	6.54	2.93; 10.15	0.002	Increasing
Female	3.98	6.93	3.04; 10.82	0.002	Increasing
Bahia	5.98	7.38	2.22; 12.55	0.009	Increasing
Male	8.32	7.42	2.76; 12.08	0.005	Increasing
Female	4.04	7.83	-1.42; 17.08	0.090	Stable

a Annual percentage change.

b Confidence interval.

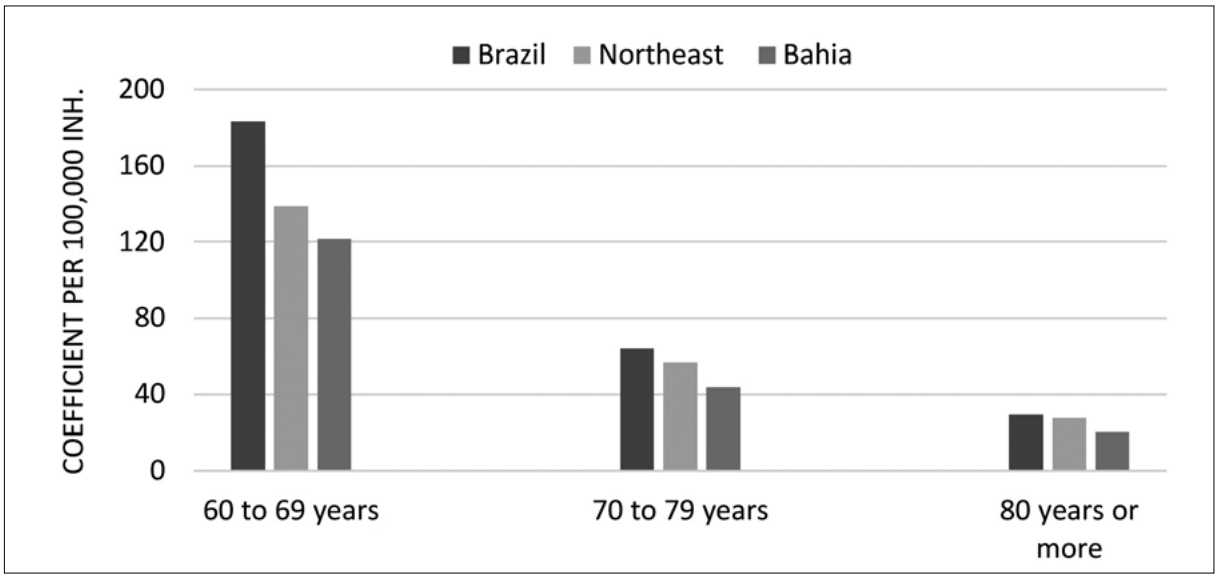


Figure 3. Incidence coefficient (100,000 inhabitants) of HIV/AIDS in older people by age group in Brazil, the Northeast region and Bahia, in the period 2007-2020.

Table 2. Distribution of new HIV/AIDS cases in individuals aged 60 years and over, according to sociodemographic characteristics, years of education and exposure category in Brazil, the Northeast Region and Bahia in the 2007-2020 period.

Variables	Brazil		Northeast		Bahia	
	n	%	n	%	n	%
Sex						
Female	11,015	38.9	1,733	32.7	466	37.0
Male	17,315	61.1	3,559	67.3	794	63.0
Ignored	1	0.0	0	0.0	0	0.0
Age						
60 to 69 years	22,455	79.3	4,129	78.0	1,012	80.3
70 to 79 years	4,977	17.6	952	18.0	203	16.1
80 years +	899	3.2	211	4.0	45	3.6
Total	28,331		5,292		1,260	
Skin colour						
White	8,632	30.5	512	9.7	122	9.7
Black	1,427	6.1	333	6.3	119	9.4
Yellow	112	0.4	15	0.3	1	0.1
Brown	8,898	20.8	2,096	39.6	298	23.7
Indigenous	61	0.2	7	0.1	4	0.3
Ignored	11,901	42.0	2,329	44.0	716	56.8
Education						
None	1,305	4.6	466	8.8	56	4.4
1 to 3 years	2,645	9.3	511	9.7	92	7.3
4 to 7 years	4,064	14.3	574	10.8	117	9.3
8 to 11 years	3,532	12.5	519	9.8	97	7.7
12 or more	1,076	3.8	155	2.9	30	2.4
Ignored	15,709	55.4	3,077	58.1	868	68.9
Exposure Category						
Homosexual	991	3.5	203	3.8	39	3.1
Bisexual	628	2.2	117	2.2	24	1.9
Heterosexual	12,124	42.8	2,074	39.2	424	33.7
IDU	142	0.5	20	0.4	9	0.7
hemophiliac	3	0.0	3	0.0	3	0.2
Transfusion	12	0.0	0	0.0	0	0.0
Acc. Biological material	1	0.0	0	0.0	0	0.0
Vertical Transmission	65	0.2	16	0.3	6	0.5
Ignored	14,365	50.7	2,859	54.0	755	59.9

IDU*= Injectable drug use, **Acc. Biological Mat = Accident with biological material.

DISCUSSION

In the present study, it was possible to observe the temporal trend of the HIV/AIDS incidence rate in the older population over a period of 14 years (2007 to 2020) according to gender and geographic area. In Brazil, this trend was stable for the total population of older people and for both sexes, in Bahia for the female sex, while in the Northeast and Bahia there was a growing trend for the total population and for the male sex. The reported cases of HIV/AIDS in the three regions analyzed were higher in males, in the 60-69 age group, in the 4-7 year-old category and among heterosexuals. As for the distribution of cases by race/color, white was more frequent in Brazil and blacks in the Northeast region and in the state of Bahia.

The HIV/AIDS epidemic in Brazil is currently expanding to groups that were not considered "at risk", starting to be found throughout society, regardless of gender, sexual orientation and age. A study that evaluated the temporal trend of the incidence of HIV/AIDS in people aged 50 years or older found stability in Brazil and in the Southeast, South and Midwest regions, and an increase in the North and Northeast regions[8]. The increase in the number of diagnosed cases of HIV/AIDS in older people has been described in the literature, Castro et al 2020 in the period from 2007 to 2016, found in Minas Gerais an increase in the incidence rate of HIV/AIDS in all age groups[18]. In the states of Piauí[19] and Ceará[5], an increase in the number of cases among older people was also observed.

The increase in cases of HIV/AIDS in older people has been observed since 1990[9]. This increase is attributed to socioeconomic aspects such as: unfavorable economic conditions, low perception of the risk of acquiring the infection, unprotected sexual practice and the lack of information about the disease[6,8,12,20,21]. The lack of health campaigns that address older people sexuality and the taboo on sexuality in this population may contribute to health professionals not providing guidance on protective practices[21].

It is therefore important to reflect on the transmissibility of the virus and the increase in the number of cases in this specific population. Taking into account the latency period of the virus, since many individuals spend years asymptomatic and when they present the symptoms of the disease, such symptoms are confused and/or related to other age-related comorbidities[2,15]. The HIV diagnostic test can be requested/performed at different levels of health care, but it is only performed after excluding other diseases[2,14,15].

In 2020, lower rates of new HIV/AIDS cases were observed in relation to the previous years investigated, in the three regions analyzed. This fact may have occurred due to the COVID-19 pandemic that started in 2020, which possibly led to underreporting of new cases of HIV/AIDS and other diseases. A lower demand for health services aimed at sexually transmitted diseases due to social distancing measures[22] and the mobilization of health professionals from different areas to face the pandemic[4], shortening the opening hours and sometimes running out of professionals to serve the public are some of the situations that can explain such falls[22]. In addition, there was a significant reduction in HIV/AIDS prevention actions due to the overload of health services in the face of COVID-19 cases[23]. This reduction in new cases may be related to the lack of screening and, consequently, the scarcity of diagnoses of individuals[22].

In the present study, the highest number of HIV/AIDS cases was in males. The result was similar to that observed in other studies carried out in different regions of Brazil[2,20,21, 24,25]. HIV infection has been more frequent among men, with the main route of transmission being sexual, and mostly in heterosexual relationships[2,20,21]. Consistent data in the literature show less concern about health by the male population and, consequently, less search for health services[24]. The lack of adherence to health services can be related to the stereotype of the male figure, where masculinity is linked to strength and the idea of less possibility of illness[24,26,27].

Sexual practices are often unprotected, due to lack of information, and taboos that permeate the use of condoms, which can be associated with marital infidelity to discomfort in the sexual act[21,27,28,29]. Despite health campaigns aimed at the

distribution of condoms and safer sex, couples in monogamous relationships do not use them, due to the stabilization of the relationship and the trust placed in the partner[6,21].

An increasing number of reported cases in women was also observed in this research in the Northeast region. Some authors refer to the feminization of the epidemic[8,21]. The insertion of women in the epidemic may be linked to the heterosexual transmission route, the main means of infection. Pereira et al 2008 points out that there are other factors linked to female vulnerability, especially in the domestic sphere, such as in cases of violence and financial dependence[30]. In addition, the lack of access to education and health, associated with some cultural and religious patterns, can discourage condom use.[7,8,29,30].

The age group with the highest number of diagnosed cases was 60 to 69 years old, considered young seniors. Part of this population may have been infected in the younger age group, from 50 to 59 years old[12]. For Affeldt et al 2015, young seniors can benefit from pharmacological treatments, which may modify the severity and lethality of the disease, increasing survival even when infected with HIV. Despite the growing increase in cases, educational and HIV/AIDS prevention campaigns for this public have not been promoted in the country[13,25].

Regarding the characteristic of the infected older population, for the race/color variable, differences were observed in the analyzed regions. In Brazil, the largest number of infected were white, followed by browns and blacks, while in the Northeast region and in the state of Bahia, the majority were blacks and browns. This difference can be explained due to population differences. In a study carried out in Tubarão SC[31], the vast majority of older people with HIV/AIDS were white, the authors related to the high number of descendants of Europeans. On the other hand, in the Northeast region[9], in the state of Rio Grande do Norte[32] and in Ceará[5], most of the diagnosed cases were of brown and black individuals.

Regional characteristics can influence the difference observed in the proportions in relation to race/color, taking into account the historical and social context of the regions studied. The black population, predominant for example in the state of Bahia, is mostly residents of peripheral areas, living with various social inequalities, with lack of access to health, education and security[33]. These historical characteristics of social vulnerability experienced by this population contribute to the higher incidences not only of HIV/AIDS but also of several other diseases. Low access to health services results in vulnerability to HIV/AIDS, making it difficult to acquire condoms and prevention guidance materials, as well as adequate treatment and diagnosis of this and other sexually transmitted infections[27,28,30].

The distribution of cases in terms of education followed the pattern found in other studies[2,5], with the highest number of cases occurring in the strata with less education. In this study, it was noticed that the highest percentage of infected individuals comprised the subcategory of no education up to 7 years of education. Lower levels of education are related to the difficulty in accessing and understanding information about the mode of transmission and prevention of the disease[21]. The trend seen by the epidemic to reach social classes with low education has been referred to as impoverishment[12,25].

For the category of exposure, the main route of infection of the virus was the sexual route, by heterosexual transmission, this shows an important characteristic of the dynamics of the epidemic, being observed in all regions. This mode of transmission as the main one confers the heterosexualization of the epidemic, given that it is in accordance with the Brazilian panorama[31]. The transmission route through injecting drug use presented lower percentages in the Northeast region and in Brazil, a result observed in other studies[2,12]. Older people have maintained an active sex life associated with unprotected sex, which indicates the need for HIV prevention actions for this group[2].

This research was used as a secondary data source due to its ease of acquiring them and for being within the reach of the population and managers. However, they are subject to underreporting, which may be related to the lack of organization of epidemiological surveillance systems, non-reporting, delay in case investigation and diagnosis performed after death, in addition to the low quality of the information collected that feeds the system[34]. As described in

other studies[2,14,17], a high percentage of ignored information was observed in several variables, such as education, skin color and exposure category. The magnitude and trend of HIV/AIDS among older people stands out as a limiting factor for adequately tracing the population profile. Thus, it is necessary to carry out permanent education on the notification of diseases in relation to filling out the notifications, typing and recording the information.

CONCLUSION

The profile of HIV/AIDS infection in the three regions studied is still mostly characterized by men, predominantly brown and/or white, with sexual intercourse being the main form of transmission and contamination and predominant in heterosexual relationships. There is also an increase in cases, year by year, in women from the Northeast region, thus characterizing a trend of the epidemic.

The importance of this type of study is highlighted for a better characterization of the older population and HIV/AIDS infection, assuming the magnitude of the epidemic and, thus, acting early in the prevention of infection. Although the older population is growing in the country, the sexuality of older people still remains a taboo, as well as the diagnosis of HIV/AIDS, reflecting the scarcity of published works on this topic for this target audience.

Therefore, attention should be paid to the increase in cases in older people, seeking to demystify taboos about sexuality, in order to promote sex education in this population and the adoption of health promotion measures aimed at reducing the transmission of the virus. Educational campaigns aimed at this public, as a way of encouraging the adoption of condoms in sexual practices and raising awareness about the importance of performing diagnostic tests on a regular basis, can contribute to a reduction in cases. The use of comprehensive and easily accessible means of communication such as television, internet and visual campaigns contribute to the effectiveness of the strategies.

Public campaigns to promote the continuing education of health professionals regarding the request for rapid testing and health promotion, including sexual health, for the older population, are of great importance. One should also think about new studies that analyze the use of antiretroviral drugs in relation to existing comorbidities in this population.

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Oral health of homebound older adults followed by primary care: a cross sectional study

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Abstract

Objective: to characterize the life, health, and oral health conditions of homebound older people registered in the primary care teams and oral homecare provided. *Method:* cross-sectional, household based study with a convenience sample, in Florianópolis, southern Brazil. Data collection through a questionnaire and clinical oral examination which included sociodemographic variables, condition of teeth and mucosa, oral hygiene, access to dental care and dentist providing homecare. Absolute and relative frequency analysis and bivariate analysis (chi-square, CI=95%) were performed. *Results:* 123 older people participated with mean age of 81.3 years, 62.6% were women. Living with a caregiver were 87%, 60% were domiciled for up to 5 years, and 89.4% were frail. Regarding the presence of teeth, 56.1% were edentulous and 40.5% had from 1 to 8 teeth. Root remains were observed in 12.8%, untreated caries lesions in 25.2%, visible biofilm in 69.9%, tooth mobility in 57.7% and mucosal lesions in 8.9% of the elders; 45.5% needed help with oral hygiene and 24.4% did not perform daily mouth cleaning. The difficulty in accessing dental care due to homeboundness was reported by 32.5% and home visits provided by the dentist occurred in only 16.3%. *Conclusion:* the oral health of the older adults studied is poor due to the presence of oral problems that require intervention. There is dependence on third parties for oral care, which is not consistently guaranteed at home. The study points to the need for dental homecare provided by public health services.

Keywords: Aged. Oral Health. Primary Health Care. Frailty. Homebound Persons.

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INTRODUCTION

The aging process is complex and, with senility, it can lead to deterioration in the functionality of older adults, thus increasing the chances of compromising their health - general and oral - and the living conditions of this population - disabilities, frailty, and dependence[1,2]. Chronic degenerative comorbidities associated with advanced age can compromise the quality of life of older adults, since they lead to loss of independence and autonomy, resulting in an increase in the number of older adults living restrictedly in their homes (homebound) due to the accumulation of frailty[1,2].

The literature reports a prevalence of homebound older adults of 5.6% in the US[3], 17.7% to 19.5% in Israel[4], and 24.1%[5] in Spain. In Brazil, it is estimated that 4.9% of older adults are bedridden[6]. These numbers are relevant, because home isolation is strongly associated with negative outcomes for older adults[6,7], such as pressure ulcers[8], depressive symptoms[6,7], poor nutritional health[9], oral diseases[10], and sarcopenia[11]. When coupled with social isolation, home isolation increases the risk of mortality[12]. Although the literature reports an improvement in the living and health conditions of the population in general, due to political, economic, social, and environmental progress, as well as advances in public health and medicine, the occurrence of oral diseases in older adults is still prevalent[13]. Limited access to oral health services throughout life increases the risk and severity of oral diseases, with compromised overall health[13]. The oral situation of older adults becomes even more serious for those who are homebound, because, in addition to the oral health demands, there are barriers related to physical limitations, cognitive impairment, and dependence on others, resulting in reduced access to dental services[10,14], worse oral health status, and greater need for care[10,15,16].

The literature points out that the home environment influences the difficulty of access to health services by older adults, and that living alone influences the need for oral health care in the home context[4]. In addition, financial constraints prevent older adults from accessing dental services[13,17]. The home care provided to older adults in primary health care (PHC) aims to ensure completeness with actions that meet the needs of this specific population. With the home visits, and the diagnosis of the reality, it is possible to plan interventions that are necessary for each family. Through the home-based and multidisciplinary PHC action, the oral health team comes into contact with the reality of homebound older adults and their caregivers[14,18]. However, with the overload of clinical care services, preventive and preservation actions are hindered, which leads to low frequency and low prioritization of home care actions involving oral health professionals[18,19].

Studies that contribute to depict the current oral health condition of the homebound older adult population, their quality of life, and their demands and those of their caregivers, can provide important data to help in the planning of home and multidisciplinary care actions in the context of PHC organization. Thus, this study aimed to characterize the conditions of living, health, and oral health of homebound older adults registered by the PHC teams in Florianópolis, capital of the state of Santa Catarina, southern Brazil, as well as the oral health care provided at home.

METHODOLOGY

Type of Study and Context

This is a cross-sectional study, carried out in the context of primary health care services in Florianópolis, capital of the state of Santa Catarina (SC), southern Brazil. This city has a high human development index (HDI=0.847). According to the 2010 Census, people aged 60 years and over represent 48136 people in this city, 11.4% of the population.

The research was submitted to the Human Research Ethics Committee and approved under decision 3.230.210. Participants were provided with a hard copy of the Informed Consent Form (ICF). All of them agreed to participate in the research by signing the ICF. When the older adult lacked the capacity to express consent, it was given by the responsible caregiver.

Participants and Eligibility Criteria

The study population consisted of individuals aged 60 years and older who are homebound (restricted to their home for some reason). A homebound older adult is considered to be one who has disability(ies) (physical, mental, and/or other) that result(s) in a limited ability to move out of the home[7]. People that were eligible for the study were older adults registered and cared for in PHC. In cases where the older adults were physically, mentally or emotionally unable to answer the survey, caregivers (who needed to be over 18 years old) represented them. Those who were hospitalized at the time of data collection were excluded.

Sampling Plan

The sample size calculation was based on the 2010 Census data, which counted 48423 people over 60 years old in the municipality. Of these, an estimated proportion of 4.9% were bedridden[6]. Considering a homogeneous sample, a sampling error of 5% and a confidence level of 95%, we reached the number of 223 people.

To reach this number, we used convenience sampling, stratified in two stages. In the first stage, 20 coverage areas of health teams were chosen (out of 120 in the municipality), five in each of the municipality's four Sanitary Districts. It was estimated that there would be 10 to 12 homebound older adults followed up per health team. In the second stage, in each coverage area, the corresponding team was asked, in person or by telephone, for an updated list of the homebound older adults followed up in PHC, with name, address, telephone number, and date of birth. All the people on the list were sorted by date of birth in a spreadsheet.

In possession of the lists, the 20 health teams were contacted again by the researchers and invited to contribute to the continuation of the study, allowing them to participate in the home visits to the older adults. In cases where it was not possible to go with the members of the health teams, contact was directly via telephone, by one of the researchers. In the case of acceptance after the telephone contact, the researcher's visit to the home was previously scheduled. Older adults and/or caregivers who refused to participate in the survey after the first contact by the researchers, either in person at the time of the home visit or by telephone, who were not at home after three attempts at in-person contact by the research team, or had moved, were considered as sample loss.

The initial sample of the study was defined after the health teams made available the lists of older adults. Considering the 20 lists provided, and after applying the inclusion and exclusion criteria, a total of 236 homebound older adults were counted. During the data collection process, there were 31 losses.

Variables

We collected data on the sociodemographic, living and health, and oral health conditions of the homebound older adults, and on the oral health care performed at home.

To outline the profile of the participant older adults, the sociodemographic variables were: gender, age (at the time of collection), family income (total household income, in minimum wages), education (years of formal education), presence of a caregiver, length of time homebound (in years, at the time of collection; when less than 11 months, it was rounded up to one).

The Kihon Checklist[2,20,21], a multidimensional assessment instrument, was used to assess health and living conditions. It includes the following domains: physical strength, nutrition, eating, socialization, memory, mood, and lifestyle, consisting of 25 yes/no answer items. Because most of the older adults are bedridden, the item regarding the measurement of weight and height, to measure the Body Mass Index of the older adults, was replaced by the Measurement of Calf Circumference[22]. The overall score and score of each domain[21] were evaluated, namely:

- Lifestyle (items 1 to 20): the frail older adults scored 10 points or more;
- Physical strength (items 6 to 10): three points or more indicate low physical strength;

- Nutrition (items 11 and 12): two points indicate low nutritional status;
- Eating (items 13 to 15): two points or more in this domain suggests impaired eating;
- Socialization (items 16 and 17): a negative answer to question 16 or 17 indicates homeboundedness;
- Memory (items 18 to 20): one point or more in the memory domain suggests low cognitive function;
- Mood (items 21 to 25): two points or more in the mood domain indicates risk of depression.

The oral health condition, assessed by means of a clinical oral examination, considered the following variables: presence of visible dental biofilm on teeth and/or prostheses (yes/no); number of natural teeth; number of caries lesions; number of residual roots; presence of fistula or exudate (yes/no); and presence of tooth mobility (yes/no); oral mucosa lesions/alterations (yes/no).

Regarding oral care performed at home, the variables were: daily oral cleaning (yes/no); need for assistance in oral hygiene (yes/no); difficulty in accessing dental care when needed due to being homebound (yes/no), and dental surgeon home visits (yes/no).

Data Collection Procedures

Four teams, each composed of a dental surgeon and an undergraduate dental student, as an assistant, participated in a 4-hour training session to standardize the workflows, instruments, and criteria. Data collection took place between September 2, 2019 and March 17, 2020, the latter date defined by the impossibility of continuing collection due to the Covid-19 pandemic. Prior to this, a pilot study was conducted in a coverage area not randomly selected in the sampling process. This served to test and improved the instruments, as well as to help organize the fieldwork.

Data collection was carried out in the homes, by means of a questionnaire answered by the older adults or caregivers. Afterwards, the dentist performed a clinical examination using a wooden tongue depressor and under artificial light (flashlight). The bedridden older adult was interviewed and examined in bed, otherwise sitting on a chair or sofa. The information collected was recorded by the student, in a Google Forms® form specifically created for the research. In the absence of an internet connection, paper forms were used.

Data Analysis

The data were processed first by descriptive statistical analysis of the variables. Bivariate analysis was also performed using chi-squared test and Fisher's exact test (CI=95%), with gender, age (</≥ 80 years), education (≤/> 4 years), and income (≤/> 3 minimum wages) as independent variables. The dependent variables were the dimensions of the Kihon checklist and those related to oral health condition and care at home. A statistical significance level of 95% was adopted.

RESULTS

A total of 123 homebound older adults participated in the study, 52.1% of the initial total number of homebound older adults followed up by the PHC teams. In addition to the 31 losses, it was not possible to contact 82 more older adults to reach the calculated sample size, due to the early interruption of the collection. The 123 older adults were distributed in the four Sanitary Districts of the municipality: 44 in the Center, 43 in the South, 21 in the North, and 15 in the Mainland.

Table 1 presents the sociodemographic characterization of the participants, with a predominance of women (62.6%), corresponding to the age range between 70 and 79 years (35%), average of 81.3 years (min. 61 and max. 107 years) with up to four years of education (61%), with an income of up to three minimum wages (70.7%), homebound for up to four years (52%), and with a caregiver on a daily basis (87%).

Table 1. Sociodemographic characterization (N=123). Florianópolis, 2019/2020.

Variables		n	(%)	CI 95%
Gender	Male	46	37.4	29.3-46.2
	Female	77	62.6	53.7-70.6
Age range	60 to 69 years old	13	10.6	6.2-17.2
	70 to 79 years old	43	34.9	27.1-43.7
	80 to 89 years old	39	31.7	24.1-40.3
	90 years or older	28	22.8	16.2-30.9
Education	1-4 years	75	61.0	52.1-69.1
	5 or more years	48	39.0	30.8-47.8
Length of time homebound	1-4 years	64	52.0	43.2-60.6
	5 or more years	59	48.0	39.3-56.7
Total household income	1-3 MW*/month	87	70.7	62.1-78
	>3 MW/month	29	23.6	16.9-31.8
	No income	7	5.7	2.7-11.2
Presence of caregiver	No	16	13.0	8.1-20
	Yes	107	87.0	79.9-91.8

*Minimum wage (MW) reference in the year 2019 = R$1158.00.

CI=Confidence interval.

Source: survey data.

Regarding life and health condition, frailty (89.4%), low physical strength (95.1%), risk of depression (73.2%), social limitation (69.9%), and low cognitive function (65.9%) stood out (Table 2).

The oral health of the homebound older adults was marked by edentulism (56.1%), visible biofilm (69.9%), and caries lesions (57.4%). The need for help to perform oral hygiene on a daily basis was identified (45.5%), as well as the lack of this self-care (24.4%). Difficulty in accessing dental care due to being homebound was reported by 32.5% of the participants, and home visits by a dental surgeon were reported by only 16.3% of the participants (Table 3).

Table 4 presents the data distribution regarding living and health condition, oral health, need for help with oral hygiene, difficulty to access dental services, and dentist home visit, according to gender and age. Regarding gender, there was a statistically significant association (p<0.05) for physical strength, number of natural teeth, and residual roots. Women have more compromised physical strength, have a higher frequency of edentulism or the presence of 9 or more teeth, and fewer residual roots when compared to men. There was no statistical association when considering the difference in distribution between the age groups under 80 and 80 and over.

Table 5 presents the distribution of the same data, according to the education and income of the older adults. Regarding education, there was a statistically significant association (p<0.05) for lifestyle, physical strength, mood, and the number of natural teeth. Older adults with less formal education are more frail, have compromised physical strength, have a higher risk of depression, and are more edentulous, when compared to those with more formal education There was no statistical association when considering the differences between income groups.

Table 2. Life and health condition according to the Kihon Checklist (N=123). Florianópolis, 2019/2020.

Domains		n	%	CI 95%
Lifestyle	Not Frail	13	10.6	6.2-17.2
	Frail	110	89.4	82.7-93.7
Physical Strength	Normal	6	4.9	2.2-10.2
	Compromised	117	95.1	89.7-97.7
Nutrition	Normal	104	84.6	77.1-89.8
	Poor Nutritional Status	19	15.4	10.1-22.8
Eating	Normal	66	53.7	44.8-62.2
	Compromised	57	46.3	37.7-55.1
Memory	Normal	42	34.1	26.3-42.8
	Low Cognitive Function	81	65.9	57.1-73.6
Mood	No Risk of Depression	33	26.8	19.7-35.2
	Risk of Depression	90	73.2	64.7-80.2
Socialization	No Limitation to Go Out	37	30.1	22.6-38.6
	Limitation to Go Out	86	69.9	61.3-77.3

CI=Confidence interval.

Source: survey data.

Table 3. Oral health condition and oral care at home (N=123). Florianópolis, 2019/2020.

Variables		n	%	CI 95%
Visible biofilm	No	37	30.1	22.6-38.7
	Yes	86	69.9	61.3-77.3
Number of natural teeth	0	69	56.1	47.2-64.5
	1-8	28	22.8	16.2-30.9
	9 or more	26	21.1	14.8-29.1
Caries lesions*	No	23	42.6	30.3-55.8
	Yes	31	57.4	44.1-69.6
Number of residual roots*	0	26	48.1	35.3-61.1
	1	19	35.2	35.3-61.1
	2 or more	9	16.7	9-28.7
Fistula/Exudate*	No	53	98.1	90.2-99.6
	Yes	1	1.2	1.4-8.6
Tooth mobility*	No	43	79.6	67.1-88.2
	Yes	11	20.4	11.7-32.9
Mucosal changes	No	112	91.1	84.6-94.9
	Yes	11	8.9	5-15.3
Performs/receives daily oral hygiene	No	30	24.4	17.6-32.6
	Yes	93	75.6	67.3-82.3
Needs help with oral hygiene	No	67	54.5	45.6-63
	Yes	56	45.5	37-54.3
Difficulty of access to dental services	No	83	67.5	58.7-75.1
	Yes	40	32.5	24.8-41.2
Dentist home visit	No	103	83.7	76.2-89.2
	Yes	20	16.3	10.4-24.2

*In dentates (n=54).

Source: survey data.

Table 4. Bivariate analysis of the distribution of data on living and health condition, oral health, and oral care at home, according to gender and age. Florianópolis, 2019/2020.

Variables	Gender			Age		
	Female n(%)	Male n(%)	*p* value	<80 n(%)	≥80 n(%)	*p* value
Lifestyle						
Not Frail	6(46.2%)	7(53.8%)	0.195	7(53.8%)	6(46.2%)	0.654
Frail	71(64.5%)	39(35.5%)		52(47.3%)	58(52.7%)	
Physical Strength						
Normal	01(16.7%)	05(83.3%)	**0.027****	2(33.3%)	4(66.7)	0.681
Compromised	76(65.0%)	41(35.0%)		57(48.7%)	60(51.3)	
Nutrition			0.645			
Normal	66(63.5%)	38(36.5%)		53(51.0%)	51(49.0%)	0.120
Poor Nutritional Status	11(57.9%)	08(42.1%)		06(31.6%)	13(68.4%)	
Eating						
Normal	38(57.6%)	28(42.4%)	0.215	34(51.5%)	32(48.5%)	0.397
Compromised	39(68.4%)	18(31.6%)		25(43.9%)	32(56.1%)	
Memory						
Normal	27(64.3%)	15(35.7%)	0.781	19(45.2%)	23(54.8%)	0.663
Compromised	50(61.7%)	31(38.3%)		40(49.4%)	41(50.6%)	
Mood						
No Risk of Depression	21(63.6%)	12(36.4%)	0.886	15(45.5%)	18(54.5%)	0.736
Risk of Depression	56(62.2%)	34(37.8%)		44(48.9%)	46(51.1%)	
Socialization						
No Limitation to Go Out	22(59.5%)	15(40.5%)	0.637	14(37.8%)	23(62.2%)	0.129
Limitation to Go Out	55(64.0%)	31(36.0%)		45(52.3%)	41(47.7%)	
Number of natural teeth						
9 or more teeth	16(61.5%)	10(38.5%)	0.034*	15(57.7%)	11(42.3%)	0.179
1 to 8 teeth	12(42.9%)	16(57.1%)		16(57.1%)	12(42.9%)	
Edentulous	49(71.0%)	20(29.0%)		28(40.6%)	41(59.4%)	
Caries lesions						
No	13(56.5%)	10(43.5%)	0.077	12(52.2%)	11(47.8%)	0.144
Yes	15(48.4%)	16(51.6%)		19(61.3%)	12(38.7%)	
Residual roots						
No roots	20(64.5%)	11(35.5%)	0.014*	19(61.3%)	12(38.7%)	0.153
1 root	09(47.4%)	10(52.6%)		07(36.8%)	12(63.2%)	
2 or more roots	02(22.2%)	07(77.8%)		06(66.7%)	3(33.3%)	
Tooth mobility						
No	72(64.3%)	40(35.7%)	0.218	52(46.4%)	60(53.6%)	0.350
Yes	05(45.5%)	06(54.5%)		07(63.6%)	04(36.4%)	
Needs help with oral hygiene						
No	46(68.7%)	21(31.3%)	0.129	32(47.8%)	35(52.2%)	0.960
Yes	31(55.4%)	25(44.6%)		27(48.2%)	29(51.8%)	

to be continued

Continuation of Table 4

Variables	Gender			Age		
	Female n(%)	Male n(%)	*p* value	<80 n(%)	≥80 n(%)	*p* value
Difficulty of access to dental services						
Yes	24(60.0%)	16(40.0%)	0.695	23(57.5%)	17(42.5%)	0.142
No	53(63.9%)	30(36.1%)		36(43.4%)	47(56.6%)	
Dentist home visit						
No	63(62.4%)	38(37.6%)	0.912	49(48.5%)	52(51.5%)	0.795
Yes	14(63.6%)	08(36.4%)		10(45.5%)	12(54.5%)	

*Chi-squared test; $p<0.05$

** Fisher's exact test; $p<0.05$

Source: survey data.

Table 5. Bivariate analysis of the distribution of data on living and health condition, oral health, and oral care at home, according to education and income. Florianópolis, 2019/2020.

Variables	Education			Income		
	1 to 4 years n(%)	> 4 years n(%)	*p* value	1 to 3 MW n(%)	> 3 MW n(%)	*p* value
Lifestyle						
Not Frail	4(30.8%)	9(69.2%)	**0.018****	9(69.2%)	3(23.1%)	0.947
Frail	71(64.5%)	39(35.5%)		78(70.9%)	26(23.6%)	
Physical Strength						
Normal	00(0.0%)	06(100.0%)	**0.003****	03(50.0%)	2(33.3%)	0.373
Compromised	75(64.1%)	42(35.9%)		84(71.8%)	27(23.1%)	
Nutrition			0.832			
Normal	63(60.6%)	41(39.4%)		73(70.2%)	24(23.1%)	0.502
Poor Nutritional Status	12(63.2%)	07(36.8%)		14(73.7%)	05(26.3%)	
Eating						
Normal	39(59.1%)	27(40.9%)	0.645	47(71.2%)	16(24.2%)	0.835
Compromised	36(63.2%)	21(36.8%)		40(70.2%)	13(22.8%)	
Memory						
Normal	21(50.0%)	21(50.0%)	0.072	27(64.3%)	11(26.2%)	0.332
Compromised	54(66.7%)	27(33.3%)		60(74.1%)	18(22.2%)	
Mood						
No Risk of Depression	15(45.5%)	18(54.5%)	0.033*	22(66.7%)	10(30.3%)	0.465
Risk of Depression	60(66.7%)	30(33.3%)		65(72.2%)	19(21.1%)	
Socialization						
No Limitation to Go Out	25(67.6%)	12(32.4%)	0.149	25(67.6%)	10(27.0%)	0.213
Limitation to Go Out	50(58.1%)	36(41.9%)		62(72.1%)	19(22.1%)	
Number of natural teeth						
9 or more teeth	11(42.3%)	15(57.7%)	0.047*	16(61.5%)	09(34.6%)	0.592
1 to 8 teeth	16(57.1%)	12(42.9%)		21(75.0%)	06(21.4%)	
Edentulous	48(69.6%)	21(30.4%)		50(72.5%)	14(20.3%)	

to be continued

Continuation of Table 5

Variables	Education			Income		
	1 to 4 years n(%)	> 4 years n(%)	*p* value	1 to 3 MW n(%)	> 3 MW n(%)	*p* value
Caries lesions						
No	10(43.5%)	13(56.5%)	0.061	12(52.2%)	09(39.1%)	0.141
Yes	17(54.8%)	14(45.2%)		25(80.6%)	06(19.4%)	
Residual roots						
No roots	16(51.6%)	15(48.4%)	0.166	20(64.5%)	10(32.3%)	
1 root	09(47.4%)	10(52.6%)		13(68.4%)	05(26.3%)	0.690
2 or more roots	05(55.6%)	04(44.4%)		08(88.9%)	01(11.1%)	
Tooth mobility						
No	69(61.6%)	43(38.4%)	0.647	78(69.6%)	27(24.1%)	0.593
Yes	06(54.5%)	05(45.5%)		09(81.8%)	02(18.2%)	
Needs help with oral hygiene						
No	40(59.7%)	27(40.3%)	0.751	47(70.1%)	16(23.9%)	0.984
Yes	35(62.5%)	21(37.5%)		40(71.4%)	13(23.2%)	
Difficulty of access to dental services						
No	49(59.0%)	34(41.0%)	0.525	60(72.3%)	17(20.5%)	0.335
Yes	26(65.0%)	14(35.0%)		27(67.5%)	12(30.0%)	
Dentist home visit						
No	64(63.4%)	37(36.6%)	0.244	72(71.3%)	22(21.8%)	0.313
Yes	11(50.0%)	11(50.0%)		15(68.2%)	7(31.8%)	

*Chi-squared test; p<0.05

** Fisher's exact test; p<0.05

MW=Minimum wage.

Source: survey data.

DISCUSSION

The results of this study reinforce the literature on the precarious oral health condition of the older adult population in general[13], and especially of those homebound[10,15], who have a worse self-perception of oral health and more difficulties in eating and chewing when compared to those that are not homebound[15]. This scenario is the result of an oral health care model that excludes the older adult population group, with little preventive care, focused on curative procedures, and mutilating dental elements, combined with individual habits and behaviors that are harmful throughout life[13]. Likewise, this study identified both past (tooth loss) and present (untreated caries lesions or residual roots) problems, which demand some type of dental care.

Taking these findings into account, it is important to discuss the need for oral health care for homebound older adults, in order to have a positive impact on health and quality of life indicators. It is important to consider the observed influence of gender and the educational level of the homebound older adults[3] on health and oral health conditions, which reflect the repercussions of the life course and the pattern of utilization of health and oral health services. Therefore, as there is a proportional increase in the number of older adults in the population[1], we face a new problem to be addressed through public

policies, especially health policies. New care strategies are necessary, since the service offers in this field do not exactly match the needs of older adults[17,23].

Most of the study participants had a frail condition. In these circumstances, it is important to know the limitations imposed by this situation, which include physical, psychological, emotional, and social aspects[2,28]. This condition can result in compromised functions and the need for long-term care, including oral health care[24,25].

By observing that this older adult population has functional limitations, a longitudinal evaluation of the frail condition enables the anticipation of actions that provide less chance of future disabilities and need for care[2,20,21]. It is initially up to the PHC, through health teams, to identify the relationships between oral and general health conditions of these older adults, visualizing the complexity of demands and problems considered in their health context, thus leading to better planning and provision of care, as well as better orientation for the formulation of public policies[26].

Similar to other studies[27,28], the results indicate that homebound older adults have poor oral health due to having visible biofilm, untreated cavities, and residual roots, situations that require an intervention. The participants were mostly edentulous, even with the current tendency of older adults to retain teeth[13]. A lower percentage of edentulism (24%) was observed in homebound North American older adults. However, among those with teeth, 45.6% needed exodontia, and 78.9% had at least one tooth with caries lesions[10]. These numbers are even worse considering the observation that 96% had never received a visit from a dentist after becoming homebound; 58.6% had seen a dentist more than 3 years ago[10]. In Brazil, the poor oral health condition of older adults is also recognized, a situation that is worse among those who are institutionalized and homebound, due to the presence of edentulism and high prevalence of tooth loss, caused mainly by cavities[26]. Data from Brazil also indicate little use of dental services after the older adult becomes homebound, since the vast majority report not having seen a dentist in 5 years[26]. This pattern seems to be different from what occurs with medical consultations. A study conducted in Brazil indicated that bedridden older adults had 4 or more medical appointments in the year prior to the survey[6].

Given that the oral health condition influences the general health condition of the older adults[10,16,29], the results are an alert to the situation of vulnerability in the health status of this population. Thus, we emphasize the need for caregivers/family members to be properly instructed on routine oral health care, handling and cleaning of teeth, prosthetics, and oral mucosa. Furthermore, it is important to pay due attention to the responsibility of the PHC team to identify and overcome these needs, by means of targeted actions that lead to the practice of correct oral hygiene and control of the presence of visible biofilm in homebound older adults.

Although there was the presence of visible plaque, caries lesions, residual roots, situations that create risk of infection, and exposure to pain, only a minority reported the presence of a dental surgeon throughout the homebound time. Therefore, it could be estimated that being homebound implied greater difficulty in accessing oral health services. Gluzman et al.[10] showed that almost all of the older adults investigated have not seen a dentist since they became homebound. Bonfá et al.[28] revealed that there are home visits by PHC professionals, especially by the community health agent and the physician; however, there is an absence of knowledge about the dental surgeon's work at home.

Although it was not considered as a study variable for the evaluation of homebound older adults' oral health, it is worth highlighting the results of the Eating domain of the Kihon Checklist, which was found to be compromised for almost half of the older adults. This domain is composed of items related to difficulty in chewing hard food and discomfort due to dry mouth, situations linked to the oral health condition of the older adults. Mikami et al.[29] report an association between chewing difficulty and dry mouth and decreased frequency of leaving the house. Also, a cross-sectional study, with follow-up after 6 years, showed that having chewing difficulty and having less than 20 remaining teeth are predictive conditions for homeboundedness. This effect was also seen in reverse, which indicates that being

homebound at the beginning of the study predicted chewing difficulty at follow-up[30].

The literature also points out relevant obstacles in the access to oral health care in this population, especially dental care. Since they cannot leave their homes because they have comorbidities, physical limitations, and loss of autonomy[30], there is a need for oral health care in their homes[31]. Therefore, it is necessary that the actions, especially those carried out by PHC, are within the reach of this population, through home care services, which must include the oral health team[32,33]. However, this study found that the presence of a dental surgeon (from both public and private services) performing consultations at home or home visits was minimal. Thus, not only is access to curative procedures limited, but it is also believed that preventive procedures such as the rational use of topical fluorides or the follow-up of potentially malignant oral lesions, for example, are neglected[10,27].

The assistance provided by PHC teams at home is planned by means of home care, planned as a PHC attribution, based on strategies that, due to being multidisciplinary, must include the oral health team. This care practice is very important for maintaining the health of older adults with some degree of functional capacity impairment, besides encouraging the effective participation of families in care[14,34]. Thus, providing oral health care to populations with limited access to traditional services at a clinic should be a priority for health systems[34,35].

This study has limitations arising from the convenience sampling strategy, sample losses, and the impossibility of follow-up due to the Covid-19 pandemic. Since they are not representative for the municipality, due to the convenience selection of the participants, the data cannot be generalized. Also, the care practices currently performed by PHC for the participants, other than home visits, were not explored in this research. This would be worth investigating for better understanding the context of care of the older adults. We suggest the continuation of studies on the oral health of homebound older adults in order to build the best evidence on oral health care practices in this context and population, in public health services, that result in better indicators of health and well-being.

CONCLUSION

The homebound older adults presented frailty and precarious oral conditions due to having oral problems that require intervention, such as: residual roots, untreated caries lesions, tooth mobility, and the presence of biofilm. Dependence on other people for oral care, which is not consistently guaranteed, at home, was identified, suggesting a situation of vulnerability.

Therefore, the study pointed out the need for dental care and oral health care at home on a continuous basis. In the scope of public health services, we advocate the full incorporation of oral health care at home, through actions developed in primary care by health and oral health teams. The need for investment in health promotion and oral disease prevention actions throughout life is also considered, to avoid the accumulation of dental needs in the complex situation of being homebound in old age.

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Factors associated with functional disability in older adults with cataract: integrative review

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Abstract

Objective: to identify the scientific evidence available in the literature on factors associated with functional disability in older people with cataract. *Methods*: integrative literature review carried out in PubMed, Web of Science, LILACS and CINAHL databases. Original articles that answered the guiding question were included: what is the scientific evidence on the factors associated with the functional disability of older people with cataract? *Results*: six articles were included, most were published from the year 2000 (n=4) and carried out in America (n=3). Longitudinal (n=3) with level of evidence IV, and cross-sectional (n=3) with level of evidence VI predominated, and that performed path analysis (n=3). Based on the findings, three thematic categories emerged: demographic characteristics; related to eye, physical and mental health, and behavioral. *Conclusion*: the functional disability of older people with cataract may be the result of demographic, related to eye, physical and mental health, and behavioral characteristics.

Keywords: Aged. Activities of Daily Living. Cataract. Visual Acuity.

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INTRODUCTION

Cataract, the clouding of the lens, is the most common cause of decreased visual acuity and reversible blindness in the world, and one of the most prevalent chronic diseases in the older population[1]. The prevalence of cataract is 17.6% in those under 65 years of age; 47.1% between 65 and 74 years and 73.3% in individuals over 75 years of age[1]. It is noteworthy that this condition is related to increased morbidity and mortality among older people, due to the greater risk of falls, depression and functional disability[2–5].

Functional disability is commonly determined by the difficulty and/or need for help to perform daily tasks of different levels of complexity, which are essential for maintaining independence and autonomy[6]. According to the degree of difficulty and vulnerability to functional changes, activities of daily living (ADL) can be stratified into: basic (BADL), instrumental (IADL) and advanced (AADL)[6]. Functional disability occurs in a hierarchical way[7], in which older people have difficulties to perform activities that require greater complexity, independence and social participation, measured by the AADL[8], later for those related to commitments and/or daily tasks, evaluated by the IADL[9] and finally self-care measures measured by BADL[10].

In the study that analyzed secondary data from 11,177 older Brazilians, a prevalence of functional incapacity for IADL was 28.0%, and for BADL, 15.5%[11]; similarly, in a systematic review conducted with older people in China, the prevalence of functional disability was 26.2%, being 20.5% for BADL, and higher among women (28.5%) compared to men (22.7%)[12]. In the survey among 1,750 individuals aged 60 years and over assisted by Family Health Strategy teams, in Montes Claros (MG), it was observed that 71.3% of the older people with cataract were dependent for performing ADLs[5].

Functional disability, together with visual changes caused by cataract, can limit self-care and social participation, negatively impacting the human aging process[2–5]. Thus, research that systematizes knowledge about factors associated with functional disability can support the definition of priorities and health interventions.

In this perspective, the integrative review is considered a useful tool to gather and synthesize scientific knowledge[13], enabling the planning of actions aimed at older people with cataract, based on evidence-based practice. Thus, the results of this study may help to advance knowledge, based on the definition of priority areas on the subject.

Thus, this research aims to identify the scientific evidence available in the literature on factors associated with functional disability in older people with cataract.

METHODS

Bibliographic study, integrative literature review, with a research protocol registered on the *Open Science Farmework* platform (https://osf.io/mc6fv/) and based on six steps for its elaboration[13].

In the first stage, the theme of the review was defined, the factors associated with the functional disability of older people with cataract, and the research question was established, through the *Patient-Intervention-Comparison-Outcomes* (PICO) strategy, as follows: what is the scientific evidence on factors associated with functional disability in older people with cataract? From the acronym in question, the following stood out: "P", referring to the target population, older people with cataracts; as "I" (exposure), the associated factors; the "C" (comparison) was not applied; and item "O" (outcome), represented, in this question, by functional disability.

Based on the guiding question, the inclusion criteria were defined: original articles that described the factors associated with the functional disability of older people with cataract, without delimitation of time frame and language, published in scientific journals and available electronically. Literature reviews, case reports, monographs, dissertations, theses, abstracts published in annals of scientific events, book chapters, books, manuals, editorials, reviews, letters to the editor and study protocols were excluded.

The search for studies was carried out in May 2021 on the Portal of Periodicals of the Coordination for the Improvement of Higher Education Personnel

(CAPES), with access through the Federated Academic Community (CAFe), with the following databases being consulted: MEDLINE/PubMed (via *National Library of Medicine*), *Web of Science*, Latin American and Caribbean Literature in Health Sciences (LILACS) and *Cumulative Index to Nursing and Allied Health Literature* (CINAHL).

The search and selection of studies were performed by two researchers simultaneously and independently. To perform the search, combinations with the following Health Sciences Descriptors (DeCS) were used: *"older people", "daily activities", "cataract", "phacoemulsification", "visual acuity", "vision disorders", "blindness", "visually impaired persons";* and the *Medical Subject Heading (MeSH), "older people", "activities of daily living", "cataract", "phacoemulsification", "visual acuity", "vision disorders", "blindness" and "visually impaired persons",* combined by using the Boolean operators AND and OR.

The articles found were imported into the WebRayyan QCRI - *Qatar Computing Research Institute* (https://rayyan.qcri.org/welcome) application/website, for the identification and exclusion of duplicates and the management of the final sample selection process.

For data extraction, we used a form containing information regarding the title, authors, year and place of publication, method (study design, sample, measurement instruments) and main results. This last item was grouped into thematic categories, considering the most relevant aspects identified in the articles. Article evaluation and data extraction were performed independently by two reviewers (NNO and NGNO), with disagreements resolved by a third reviewer (EMI).

A critical analysis of the methodology of the selected articles was carried out by applying the *Newcastle-Ottawa Scale* (NOS), for longitudinal studies[14], and the adapted NOS[15], for cross-sectional studies, which evaluate publications, through the provision of stars, in three broad perspectives: selection of study groups, comparability of groups and appropriateness of exposure or outcome of interest. It is noteworthy that the higher the number of stars received in each domain, the higher the quality of the study being evaluated14. The *Agency for Healthcare Research and Quality* (AHRQ) classification of scientific evidence levels was also used: I - systematic review or meta-analysis; II - randomized clinical trials; III- clinical trials without randomization; IV - cohort and case-control studies; V - systematic review of descriptive and/or qualitative studies; VI - descriptive or qualitative study; and VII - opinion of authorities and/or report of specialist committees[16].

Data synthesis was performed descriptively considering the construction of categories, which addressed the results of original studies on factors associated with functional disability in older people with cataract.

RESULTS

The *Preferred Reporting Items for Systematic Review and Meta-Analys for Scoping Reviews* (PRISMA)17 diagram was used to present the stages of article selection (Figure 1).

Searches in the databases resulted in 3,614 articles, 763 of which were excluded due to duplicates. After analyzing the title and abstract, 14 studies were selected for full reading. Then, eight articles were excluded because they did not meet the population (n=1) and outcome (n=7) criteria established through the PICO strategy. Therefore, six articles made up the final sample (Figure 1).

Of the six articles analyzed, most were published from the year 2000 (n=4) and carried out in America (n=3). Studies of the longitudinal type (n=3), level of evidence IV and cross-sectional (n=3), level of evidence VI[16], and that performed path analysis (n=3) predominated (Chart 1).

It is noteworthy that the studies diverged in relation to the classification of cataract (self-reported or diagnosed by means of an ophthalmological examination); and functional capacity assessment instruments, using the *Functional Assessment Inventory* (FAI)[18]; Functional Disability Index in Cataract Patients (VF-14)19,20; adapted scores from ADL[21]; and standardized scores, such as the Katz Index and the *Lawton & Brody* and AADL scales[7,22] (Chart 1).

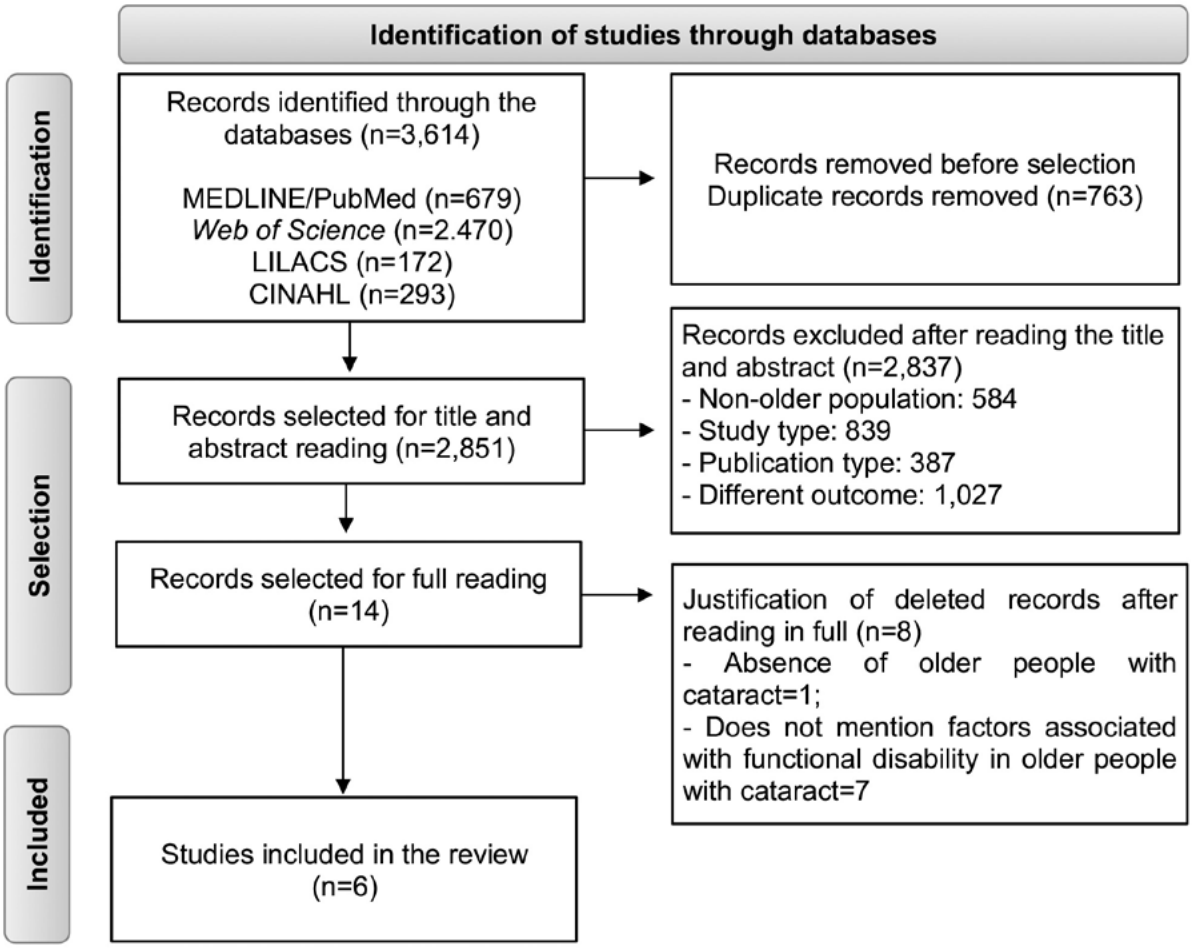

Figure 1. Flowchart of the study selection process.

Chart 1. Compiled description of studies included in the integrative review

Author, year, place	Study design, general characteristics of the sample and statistical analysis	Cataract classification	Functional capacity among older people with cataract (instrument and occurrence)	Methodological quality (*NOS*)	Level of Scientific Evidence (AHRQ)
Borges et al. (2014)[22] Distrito Federal, Brazil	Cross-sectional observational study, with 100 older people, 50% with cataracts, of these 52% women and 60% aged 70 years or over. Simple *Poisson* regression.	Self-reported bilateral cataract.	*Katz* Index (dependent: in one or more ADL), Lawton & Brody Scale (dependent/ semidependent for one or more IADL). Among older people dependent for BADL and IADL, 59.7% and 57.8% had cataract, respectively..	7/10	VI

to be continued

Continuation of Chart 1

Author, year, place	Study design, general characteristics of the sample and statistical analysis	Cataract classification	Functional capacity among older people with cataract (instrument and occurrence)	Methodological quality (*NOS*)	Level of Scientific Evidence (AHRQ)
Elam et al. (1988)[18] Tennessee, USA	Prospective observational cohort study, with 164 older people, 77% women, mean age of 76.5±4.8 years. Path analysis.	Preoperative diagnosis of cataract.	FAI, ranging from 13 (best functional capacity) to 39 (worst functional capacity) points. Average FAI = 14.1±1.8.	6/9	IV
Espallargues et al. (1998)[19] Barcelona, Spain	Prospective observational cohort study with 218 older people, 61% of whom were women, mean age of 70.5±8.7 years. Multiple linear regression.	Preoperative diagnosis of cataract.	VF-14, ranging from 0 (worst perceived visual functional capacity) to 100 (best possible perceived visual functional capacity) points. Preoperative average VF-14 = 64±27	6/9	IV
Tavares et al. (2020)[7] Minas Gerais, Brazil	Cross-sectional observational study, with 957 older people, with 268 with cataract; of these, 67.2% were women, 50.4% were between 70 and 79 years of age. Path analysis.	Self-reported cataract.	*Katz* Index, *Lawton & Brody* Scale, AADL Scale (higher scores for BADL and lower scores for IADL and ADL indicate greater functional disability). BADL score = 0.13±0.39; IADL = 17.67±3.42; AADL = 5.11±2.40.	10/10	VI
Knoll et al. (2004)[21] Germany	Prospective observational cohort study, with 134 individuals, 69% women, mean age of 71.63±9.52 years. Path analysis.	Preoperative diagnosis of cataract.	Difficulty performing ADL, with 0 = very easy and 4 = very difficult. Preoperative average = 1.14±0.69 (0-4 points)	5/9	IV
Walker et al. (2006)[20] Sidney, Australia	Cross-sectional observational study, with 105 participants, 58% women; mean age of 73.69±7.10 years. Multiple logistic regression.	Preoperative diagnosis of posterior subcapsular cataract.	VF-14, ranging from 0 (worst perceived visual functional ability) to 100 (best possible perceived visual functional ability) points. Average score = 78.75 ± 15.91.	6/10	VI

Note: NOS – *Newcastle-Ottawa Scale*; AHQR – *Agency for Healthcare Research and Quality;* BADL – Basic activities of daily living; IADL – Instrumental activities of daily living; AADL – Advanced Activities of Daily Living; FAI – *Functional Assessment Inventory*; VF-14 – Functional Disability Index in Cataract Patients.

Based on the findings of the studies included in this integrative review (n=6), three thematic categories of factors associated with functional disability in older people with cataract were listed, as shown in Chart 2.

The functional disability of older people with cataract occurs in a hierarchical manner, in which dependence for AADL is associated with IADL and the latter with BADL[7] (Chart 2).

In the category of demographic characteristics, it was found, among older people with cataract, that older age was associated with functional incapacity for BADL[22] and IADL[20]. Furthermore, it was observed that the worst cognitive ability mediated the association between older age and functional disability for ADL[18] (Chart 2).

Characteristics related to eye, physical and mental health were identified. It was identified that the worst visual acuity was associated with functional disability for BADL[21], IADL and ADL[20]. High/low visual difficulty[22] and worse physical performance[7] were associated with functional disability for BADL and IADL, as well as higher numbers of impaired components of the frailty phenotype and depressive symptoms for IADL and AADL[7], and the highest level of stress for AADL and ADL[20]. Lower contrast sensitivity was associated with functional disability for ADLs and greater difficulty in driving, considered an AADL[20] (Chart 2).

In addition to the aforementioned variables, functional disability for BADL was associated with the presence of three or more morbidities[21,22]. Functional disability for IADL was also associated with less conscientiousness[21] and greater anxiety[20]. Worse health status was a factor associated with functional disability for ADL[19], as well as lower cognitive capacity and greater binocular visual impairment[18] (Chart 2).

Regarding behavioral characteristics, it was identified that physical inactivity was associated with functional incapacity for BADL among older people with cataract[22] (Chart 2).

Chart 2. Thematic categories of factors associated with functional disability in older people with cataract.

Categories	BADL	IADL	AADL	VF-14	FAI
Demographic characteristics	Age >70 years (p=0.037)[22]	Higher average age (β= -0.21; p=0.04)[20]	-	-	Higher age, mediated by worse cognitive ability (β=-0.09)[18]
Characteristics related to the state of eye, physical and mental health	Having three or more morbidities (p=0.037)[22]; (p<0.001)[21] High/low visual difficulty (p=0.001)[22] Worse physical performance (β=-0.20; p<0.05)[7] Functional disability for IADL (β=-0.20; p<0.05)[7] Worse visual acuity in the eye to be operated on (p<0.05) and in the eye contralateral to the operated one (p<0.05)[21] Less conscientiousness (p<0.01)[21]	High/low visual difficulty (p=0.001)[22] Worse physical performance (β=0.21; p<0.05)[7] Higher number of compromised frailty phenotype components (β=-0.27; p<0.05)[7] Lower participation in AADL (β=0.28; p<0.05)[7] Less conscientiousness (p<0.01)[21] Higher level of depression (β=-0.28; p=0.010)[20] Higher level of anxiety (β=0.31; p=0.03)[20] Worse contrast sensitivity (β=0.24; p=0.03)[20]	Higher number of compromised frailty phenotype components (β=-0.36; p<0.05)[7] Higher number of depressive symptoms (β=-0.28; p<0.05)[7] Higher level of stress (β=-0.45; p<0.001)[20] Worse visual acuity (β=-0.54; p<0.001)[20] Worse contrast sensitivity, greater difficulty driving (β=0.32; p=0.02)[20]	Worse general health status (β=-0.23; p<0.001)[19] Higher level of stress (β=-0.20; p=0.004)[20] Worse visual acuity in the eye with the worst vision (β=-0.38; p<0.001)[20] Worse contrast sensitivity (β=0.24; p=0.03)[20]	Worse cognitive ability (mental state) (β=0.51; p<0.001)[18] Greater binocular visual impairment (β=0.51; p<0.001)[18]
Behavioral characteristics	Physical inactivity (p=0.013)[22]	-	-	-	-

Note: BADL – Basic activities of daily living; IADL – Instrumental activities of daily living; AADL – Advanced activities of daily living; VF-14 - Functional Disability Index in Cataract Patients; FAI - *Functional Assessment Inventory*.

DISCUSSION

The current integrative review identified that there are demographic factors, aspects of eye, physical and mental health, and behavioral factors associated with the functional disability of older people with cataract.

Age was identified as a demographic factor directly associated with the functional disability of older people with cataract[20,22]. In a Brazilian study, older people with cataract, who belonged to the older age group, had a higher prevalence of functional disability (p=0.046)[22]. Similarly, there was a significant association between older age and functional disability for IADL (p=0.040)[20] in older Australians. Still, in the investigation carried out among American older people, older age, mediated by worse cognitive ability, was indirectly associated

with functional disability (β=-0.09)[18]. In the older population, in general, it is possible to observe greater susceptibility to functional and cognitive decline[18,23,24] and the onset of cataracts[1]. Thus, older age, added to this health condition, must be considered in the care provided, as it can cause other adverse events such as reduced autonomy and independence, which negatively impact the quality of life of older people[7].

Furthermore, an association was observed between the functional disability of the older people with cataract and ocular health characteristics, such as visual difficulty[18,20–22], both measured by visual acuity, which interferes with functional capacity in BADL, AAVD, VF-14 and FAI[18,20,21]; and measured by the *Melbourne Edge Test* (MET), which assesses visual sensitivity to contrast, and influences functional capacity for IADL, AADL and VF-14[20]. These findings are consistent with previous studies[5,25,26], which highlighted the positive correlation between the self-report of low visual acuity for far and/or near with the difficulty in performing BADL and IADL[25]; and the 2.68 times greater chance of older people with self-reported visual difficulties, far and/or near, to develop functional disability for BADL (p<0,001)[26]. In the survey with Brazilian older people, the presence of self-reported cataract was associated with functional incapacity for ADL (PR=1.09, p<0.001)[5]. In this scenario, we can see the epidemiological relevance of cataract, the current most common cause of reversible blindness in the world[1], considering that cataract surgery is able to improve, in a statistically significant way (p<0.001), visual acuity, measured by the *Snellen* table[27]; and improve quality of life, autonomy and ADL performance among older people[2].

Regarding the worst contrast sensitivity, assessed by the MET, in the current integrative review, an association with greater difficulty in driving a car, considered an AADL, was found (β=0.32; p=0.020)[20]. This fact is in agreement with the scientific literature, which demonstrates that reduced contrast sensitivity has a positive correlation with driving difficulty, among drivers with cataract (r=0.404, p=0.027)[28], and that there is a worse score of difficulty in driving when compared to those without the aforementioned condition (p<0.001)[28], intensified adversity in situations where the environmental contrast is impaired, such as driving in the rain (p=0.034)[28,29], inducing the affected driver to avoid such adverse situations[29]. It is also known that the increase in cataract intensity significantly reduces the ability of the older person to drive[30].

In addition to aspects related to visual capacity, it was found in the current integrative review that the lowest physical performance score was directly associated with greater functional incapacity for BADL (β=-0.20; p<0.05) and IADL (β=0.21; p<0.05) among the older people with cataract[7]. Corroborating this finding, a Brazilian study observed that the physical performance of older women improved between 30 (p=0.030) and 60 days (p<0.001) after cataract surgery[31]. The reduction in visual acuity, caused by the aforementioned condition, can cause changes in balance and mobility and, consequently, a greater propensity for functional disability[31,32]. The elaboration of strategies for the treatment and/or correction of the visual deficit imposed by the cataract is necessary to minimize and/or avoid functional and psychosocial losses in the future. Furthermore, these data show the demand for investments aimed at health promotion and disease prevention, since the worst physical performance is subject to intervention by health professionals.

As well as the worst physical performance, the frailty syndrome was also identified as a factor associated with the functional disability of Brazilian older people with cataract (β=-0.27; p<0.05)[7]. In a survey carried out among English people aged 65 years and over, who were not frail and had visual problems, a higher risk for the development of pre-frailty and frailty was observed after four years (OR=2.07, 95%CI 1.32-3.24)[33]. This fact reinforces the possibility that age-related eye diseases also influence the frailty syndrome, which makes it essential to identify this association, which is still little explored in the scientific literature[34]. Slow gait speed and reduced level of physical activity, factors evaluated in screening for frailty syndrome[35], can be compromised in the presence of cataracts in older people. Considering that the referred syndrome is one of the factors associated with the functional disability of older people[36], and that there is a possible relationship between the frailty syndrome and cataract[7], screening for vision problems in

primary care is necessary, seeking referral to the ophthalmologist, when necessary, for early diagnosis.

The current integrative review also identified cognitive and psychological factors associated with functional disability in older people with cataracts, such as worse mental arithmetic and remote and recent memories[18], depressive symptoms[7], conscientiousness[21], stress, depression and anxiety[20].

The highest level of stress was related to functional disability for AADL, specifically recreational activities, and with a worse score in the VF-14 instrument, representing greater disability[20]. Furthermore, higher levels of anxiety and depression were associated with functional incapacity for IADL[20]. Regarding depression, a Brazilian study among community-dwelling older people with self-reported cataract, the greater number of depressive symptoms was associated with incapacity for AADL[7].

The performance of basic or complex ADL depends on the integrity of functional systems, including mood[6]. Mood disorders such as anxiety and depression are common in older people and have been associated with a higher risk of developing functional disability[37]. Likewise, these disorders also affect older people with impaired vision[38], which is an important component related to physical functioning, mobility and independence[20]. In this context, it appears that screening for depressive symptoms in older people with cataracts should be included in the approach of professionals, in order to avoid functional decline.

In addition to depressive symptoms, it was found that the negative changes recorded in the ADL evaluated through the FAI, one year after cataract surgery, were indirectly associated with the initial impairment of cognitive functions, and directly with the changes in such functions that occurred in the period[18]. The finding demonstrates the relevance of maintaining cognition for performing ADL, independently and autonomously[6], especially among older people with vision issues, such as cataracts.

In addition, it was identified that more conscientious older people with cataracts tended to report less difficulty in performing ADLs of different levels of complexity, at three different evaluation moments: preoperatively, one week and six weeks after cataract surgery[21]. In addition, conscientiousness was responsible for 7% of the variation that occurred in the change in functional capacity from the preoperative to the postoperative period[21].

Conscientiousness, a personality trait, can be determined by cognitive, social, psychological and health characteristics in older people[39]. A study showed that older people were more likely to have high scores on conscientiousness when compared to adults, indicating that traits adapt to events that occur at each stage of life[40]. Even when exposed to challenging scenarios, conscientious people are more likely to face situations with more competence, a phenomenon called successful self-regulation[21], which may explain the lower report of difficulty in performing ADL, regardless of the limitation caused by cataract.

The repercussions caused by reduced visual acuity or reversible blindness associated with eye diseases such as cataracts are known, however, the psychological impacts have not received due attention, as vision loss is treated as a physical problem[41]. Considering that there is evidence of an association between mental illness and functional disability, it is necessary to expand the understanding of the psychological effects, especially in people with eye problems who suffer from mental disorders[41], through mental health exams[38] to identify those with potential risk of developing functional disabilities, and, consequently, maintaining autonomy and independence[37].

The associations between the presence of polymorbidity[21,22] and worse general health status[19] with the functional disability of older people with cataract were also evidenced in the current review. Similarly, in the scientific literature, the relationship between physical health and functional decline among individuals aged 60 years or older is observed, so that the presence of five or more morbidities was associated with functional disability both for BADL (p=0.023) and for IADL (p=0.017)[36]. In an Indian study, it was found that older people who had any chronic comorbidities were 2.1 more likely (p=0.009) to be functionally incapable than those

without such conditions[42], and that the self-report of chronic comorbidities was positively related to difficulties in BADL and IADL[25]. In this scenario, it is noteworthy that morbidities are also frequent in individuals with senile cataract, according to a survey developed in Turkey, in which 74.6% of the older people with cataract had at least one systemic disease[43], especially arterial hypertension (46.9%), followed by diabetes *mellitus* (32.6%)[43]. Diabetes mellitus has been proven to be a risk factor for lens opacification and acceleration of cataract development in older people[44], especially of the specific posterior subcapsular type[45]; for which high blood pressure, gout and use of calcium channel blockers for more than five years were also risk factors[46].

In the current integrative review, it was observed that behavioral factors, such as physical inactivity[22], are also associated with functional disability in older people with cataract. The decline in sensory functions, especially visual ones, that occur with advancing age[31], can compromise the participation of older people in physical and social activities, favoring sedentary behavior, with consequent repercussions on physical performance, a determining factor for reducing functional decline[7,31,32]. Physical activity is considered one of the most effective interventions to minimize changes related to body composition that occur during the human aging process[47], in addition to helping in the prevention and/or rehabilitation of functional losses[36]. Thus, it appears that the early diagnosis of cataract and the encouragement of physical activity for older people, through health professionals, are necessary for the maintenance of functional capacity.

As possible limitations of the present review, we can mention the diversity of instruments used in research for the assessment of functional disability and cataract, as well as the lack of standardization of these instruments in terms of classification and/or scoring, which can influence the interpretation and comparison of results. In addition, some studies identified considered, in their analyses, the older population together with middle-aged adults, which suggests the need for future investigations comparing the groups. Another issue to be highlighted is the need for future research with designs that allow a cause and effect relationship, to expand the understanding of the associated factors, since half of the identified studies are cross-sectional, and one explored path analysis.

CONCLUSION

It is evident, therefore, that the functional disability of the older people with cataract is associated with advanced age, presence of morbidities, worse physical performance, impairment of the components of the frailty phenotype, physical inactivity, and aspects of eye (impaired visual acuity and contrast sensitivity) and mental health (stress levels, anxiety, depressive symptoms, and less conscientiousness).

However, the findings also show that there is still little research on this topic in the current literature, and new studies that focus on the impacts of cataract treatment on the functional capacity of older people would contribute to the improvement of surgical indications with a view to preventing functional decline and improvement in the quality of life of this population. In addition, intervention studies are suggested that address the modifiable factors associated with the functional disability of older people with cataract, such as physical inactivity, from a multidimensional perspective that addresses the particularities of this public.

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Nutritional interventions for older adults in palliative care: a scoping review

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Abstract

Objective: To analyze the nutritional interventions adopted in older people in palliative care found in the literature. *Method:* A scoping review was conducted involving a search of the following databases: PubMed, LILACS, CINAHL, Scopus, Web of Science, EMBASE and of the gray literature through Google Scholar, OpenGrey and ProQuests & Theses Global, without restrictions on publication date or language. The searches were performed using the descriptors and keywords, combined using Boolean operators AND and OR: "Nutritional Intervention", "*Intervenção Nutricional*", "Palliative Care", "*Cuidados Paliativos*", "Aged" and "*Idosos*". *Results:* Of the 5,942 studies found, 13 studies were selected. The backward citation search strategy identified 13 additional studies, giving a final total of 26 studies. Nutritional interventions adopted in older people in palliative care predominantly comprised nutritional counseling, oral nutritional supplementation and artificial nutrition through enteral and parenteral nutrition. These interventions focused on quality of life, symptom management and nutritional status. *Conclusion:* Although there are gaps in the literature regarding nutritional interventions for older adults in palliative care, the importance of the role of nutritionists in promoting quality of life and relieving suffering of this population is clear.

Keywords: Palliative Care. Nutrition Therapy. Aged. Nutritionists.

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INTRODUCTION

The natural course of human aging is accompanied by a greater susceptibility for developing diseases such as cancer, neurologic disorders and chronic musculoskeletal conditions, among others[1]. These diseases can result in progressive impairment that can lead to functional dependence which, together with declining health status, may require palliative care[2].

Palliative care can be defined as holistic care provided actively to individuals of any age who are suffering from serious diseases, especially those with a terminal illness, aimed at improving quality of life of the patient, family members and caregivers[2].

In this context, a multidisciplinary team is needed for the delivery of palliative care to the older patient, delivering care which takes the individual as a whole into account, assessing all dimensions and devising an effective approach that encompasses all aspects evaluated. Among the different professionals involved in the team, the nutritionist must seek the best strategies for management of patient nutrition, ensuring adequate food intake based on physical, psychological and religious dimensions, all of which influence improvement in the quality of life of patients[4].

The role of the nutritionist entails interventions which can both help maintain or restore nutritional status, as well as promote well-being during the different stages of disease. The goals of nutritional support, as end-of-life approaches, should center more on improving quality of life than achieving adequate nutrition. Thus, nutritional interventions should be reconciled with the aim of palliative care in providing comfort and helping control symptoms[5,6].

Concerns over defining adequate procedures and strategies to cater for the nutritional needs of older patients in palliative care remains a source of discussion among nutritionists, given that many professionals are ill-prepared to deal with situations in practice that stray outside conventional text-book situations[6] , highlighting the importance of further studies on this topic that can help support these professionals in their professional practice. A search of the Cochrane database and Open Science Framework (OSF) and PROSPERO - International Prospective Register of Ongoing Systematic Reviews platforms found no similar reviews involving this population, underscoring the need for further studies in this area. Therefore, the objective of the present scoping review was to analyze the available scientific evidence on nutritional interventions adoption in older adults in palliative care to help guide nutritionists who work clinically with this population.

METHOD

A scoping review was conducted according to the review method of the Joanna Briggs Institute (JBI)[7], using the PRISMA Extension for Scoping Reviews (PRISMA-ScR) reporting guidelines[8]. A protocol was developed and registered on the Open Science Framework (https://osf.io/) platform under DOI: 10.17605/OSF.IO/ECT8K (https://osf.io/ect8k). The databases searched were: Medline/PubMed, Embase, Scopus, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and LILACS. The search of the gray literature was carried out using Google Scholar, OpenGrey and ProQuest Dissertations & Theses Global. The backward citation search strategy was employed by consulting all references of the articles selected for inclusion in the review.

The PCC (Population, Concept and Context) strategy was used, with population defined as older adults, concept as nutritional interventions, and context as palliative care. The following guiding research question was devised: what nutritional interventions are adopted for older adults in palliative care?

Based on application of the PCC strategy, the descriptors present in the MeSH (Medical Subject Headings) and the DeCS *(Descritores em Ciências da Saúde*- Health Science Descriptors) were selected: "nutritional intervention", "*intervenção nutricional*", "palliative care", "*cuidados paliativos*", "aged" and "*idosos"*, together with their synonyms, combined using the Boolean operators (OR e AND) and adapted for each database. The full detailed strategy is available in the supplementary file containing the scoping review design via the link: https://osf.io/e6q4x/?view_only=897c5461698c48f6abe0d03ba310ac24

The process of devising the search and refinement strategy was overseen by a librarian.

The search encompassed all intervention and observational studies, with no constraints on language or search period, that assessed nutritional approaches in older adults in palliative care. Studies were excluded that did not include participants age ≥60 years; studies in which participants did not undergo nutritional intervention; reviews; abstracts; opinion articles; case reports; case series and book chapters.

After the searches, all records retrieved were exported to the EndNote reference manager, where they were grouped for automatic removal of duplicate articles. The studies were exported to the Rayaan[9] software application, where refinement of duplicate articles took place, followed by a two-stage study selection procedure.

In the two stages, 2 independent reviewers (RBBM and JMB) performed screening (reading of titles and abstracts) and reading of full texts. Any differences between the reviewers were resolved by consensus or by decision of a third reviewer (MCRG), while applying the inclusion criteria pre-defined in the protocol.

For data extraction, the reviewers created a form collecting the following information: study characteristics (authors, year of publication, country and study design), population characteristics (sample size, mean age), characteristics of signs and symptoms reported, intervention characteristics, primary and secondary outcomes, and conclusions on intervention effects.

The data were analyzed using quantitative description, expressing results as absolute and relative frequencies, and qualitative analysis was performed using theme-based categories regarding intervention effects for 3 aspects: quality of life, symptoms control and nutritional status.

In the present study, no rating of study quality or level of scientific evidence was conducted as criteria for exclusion of articles, given that, according to guidelines of the Joanna Briggs Institute for scoping reviews[7], there is no need to assess specific quality because this type of study aims to identify the available output on the topic investigated. Ethical approval was also waived, in accordance with Resolution Nº 466/2012 and Nº 510/2016 governing research ethics in Brazil.

RESULTS

An initial total of 5,942 studies were retrieved from the databases and gray literature. After removal of duplicates, 3,666 studies remained. Screening was performed by reading of titles and abstracts, where 37 articles were selected for the second stage. After reading of articles in full, 13 studies that met the eligibility criteria were selected. The backward citation search led to the selection of a further 13 articles, giving a total of 26 articles included in the review. Figure 1 depicts a flow chart showing the study selection process.

The studies included were performed on different continents, with 53.9% conducted in Europe, 23.1% in North America, 11.5% in Asia and 11.5% in Oceania, and were published between 1979 and 2021.

The study design methods were distributed as follows: Randomized Clinical Trial (RCT) 42.3%, Quasi-Experimental (QE) 26.9%, Prospective Longitudinal Cohort (PLC) 23.1%, and Retrospective Cohort (RC) 7.7%.

The characteristics of studies selected are described in Table 1.

In order to organize the results in terms of the study objectives, the main interventions and their effects were summarized and associations with 3 aspects presented: Interventions and effects on Quality of Life (Table 2), Interventions and effects on Symptoms Control (Table 3), and Interventions and effects on Nutritional Status (Table 4).

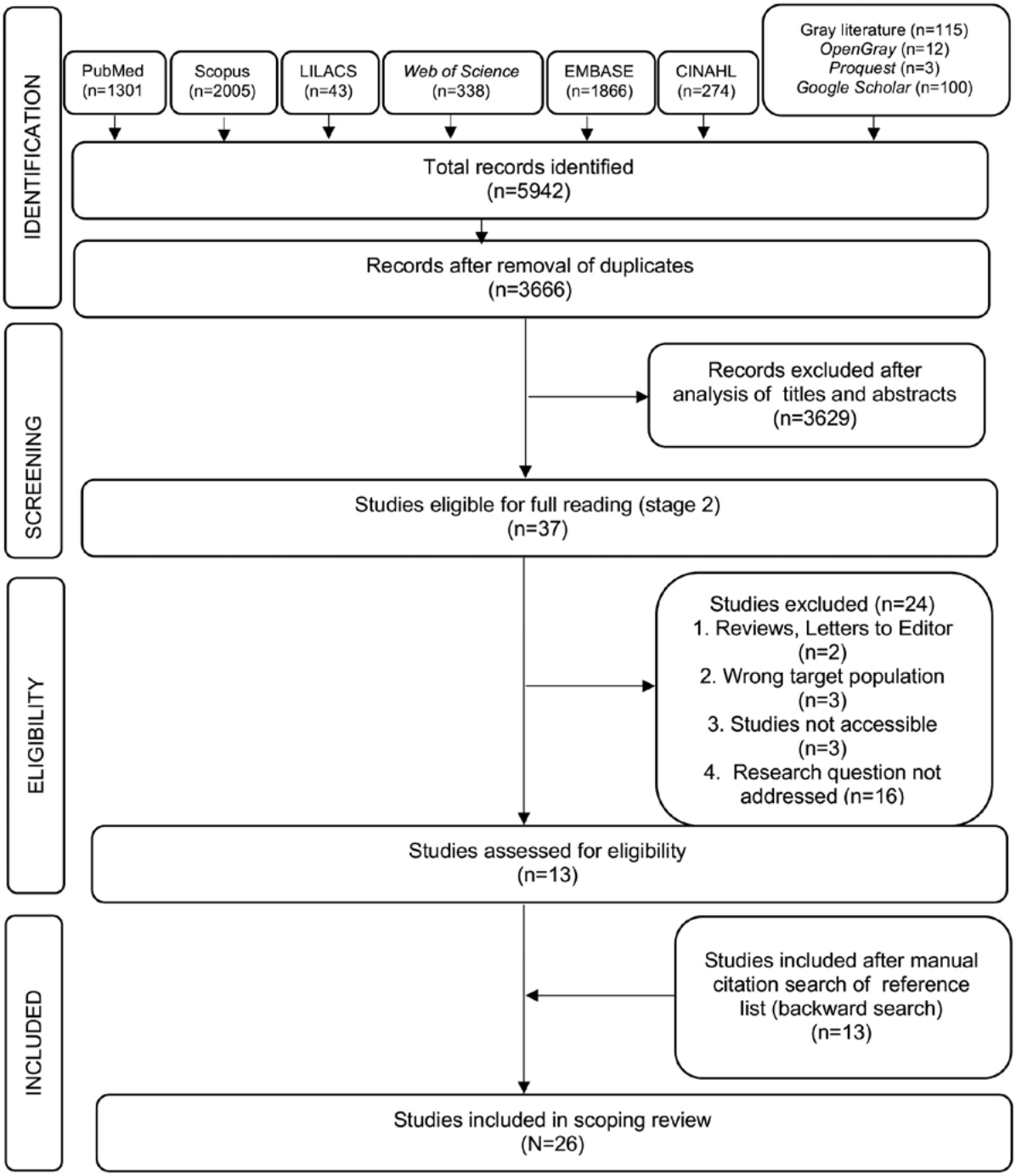

Figura 1. Fluxograma de busca e seleção dos estudos sobre as intervenções nutricionais adotadas em idosos em cuidados paliativos. João Pessoa, PB, 2022.

Fonte: Adaptado de PRISMA-ScR[8].

Table 1. Characteristics of studies (N= 26) on nutritional interventions adopted in older adults in palliative care included in review João Pessoa, Pernambuco, 2022.

Study	Design	Population (n)	Mean age	Intervention	Intervention Objective
Amano[10] (2012), Japan	PLC	63	69 (SD: 14)	Encouragement, snacks and ONS, TPN	Bedsores, edema and antibiotic therapy
Andrew[11] (2009), UK	PLC	40	72 (62-81)	NC	Early satiation, poor appetite, xerostomia
Aramaki[12] (2019), Japan	RCT	39 (15 older adults)	62 (34-76)	PEG	QOL
Arnold[13] (1989), USA	PLC	50	64.1 (34-88)	ONS	NS
Baldwin[14] (2011), UK	RCT	358	66.8 (24-88)	NC, ONS,	Survival, QOL, NS
Barber[15] (1999), UK	QE	20	62 (51-75)	ONS with fish oil (omega 3)	Weight loss
Bouleuc[16] (2020), France	RCT	111	67 (60-72)	TPN	QOL, intake, digestive symptoms, weight
Ching[17] (1979), USA	QE	45	60-86	ONS, EN and TPN	Hypoalbuminemia
Cotogni[18] (2017), Italy	PLC	111	62 (32-79)	Home TPN	QOL
Crogan[19] (2015), USA	PLC	22	≥ 65	Lemon-lime sorbet	Xerostomia
Culine[20] (2014), France	QE	437	63 (SD: 11.4)	Home TPN	QOL, NS
Del Fabbro[21] (2011), USA	RC	151	60 (19-86)	NC and pharmacological measures	Weight loss, poor appetite
Ester[22] (2021), Canada	QE	10	64.4 (51-83)	PA, nutrition and symptom control	QOL, fatigue, low intake, xerostomia
Fearon[23] (2003), UK	RCT	200	67	Omega-3 fatty acid and antioxidants	Weight, QOL, body composition, intake
Ha[24] (2010), Norway	RCT	124	78.5 (SD: 7.4)	SNI	Malnutrition, weight loss, QOL, strength
Isenring[25] (2004), Australia	RCT	60	61.9 (SD: 14)	Early intensive intervention with NC	Weight, NS, QOL, physical function
Isenring[26] (2007), Australia	RCT	60	61.9	Early intensive intervention with NC	Protein and energy intake
Lindh[27] (1986), Sweden	QE	20	65 (51-83)	EN and TPN	Malnutrition
Lundholm[28] (2004), Sweden	RCT	309	68 ± 1	ONS and home TPN	Weight loss
Ma[29] (2020), China	PLC	50	68 (35-88)	Home TPN	NS, QOL
McCann[30] (1994), USA	QE	10	74.7 (44-92)	Small amounts of food/ fluids	Experience of hunger and thirst
Persson[31] (2002), Sweden	RCT	137	69 (48-89)	SNI	Weight, intake, QOL and survival
Ravasco[32] (2005), Portugal	RCT	75	60 (36-79)	NC and ONS	NS, morbidity and QOL
Ruggeri[33] (2020), Italy	RC	969	65.7 (±12.7)	Home artificial nutrition	Malnutrition
Senesse[34] (2015), France	QE	370	64.5 (SD: 11)	TPN	QOL and NS.
Silvers[35] (2014), Australia	RCT	21	72 (SD:12)	NC aimed at symptoms and NOS	NS, Symptoms control

PLC: prospective longitudinal cohort; TPN: total parenteral nutrition; QOL: quality of life; NC: nutritional counseling; RCT: randomized clinical trial; PEG: percutaneous endoscopic gastrostomy; ONS: oral nutritional supplementation; NS: nutritional status; QE: quasi-experimental; EN: enteral nutrition; RC: retrospective cohort; PA: physical activity; INS: individual nutritional support

Interventions and effects on quality of life

In the overall sample, 13 studies addressed nutritional interventions adopted for promoting quality of life[12,14,32,34,35,16,18,20,22–25,29]. The most frequent interventions were nutritional counseling, use of oral nutritional supplementation and home parenteral nutritional support[14,18,20,25,29,32,34,35] reporting benefits with the use of these interventions.

A multimodal intervention, which included physical activity, nutrition and symptoms control in palliative care, was adopted in one study[22], appearing to be beneficial and safe in promoting quality of life in advanced lung cancer patients. However, owing to the study design lacking a control group, further studies exploring this type of intervention are needed.

The use of percutaneous endoscopic gastronomy (PEG) in patients with malignant bowel obstruction promoted improved quality of life compared with the use of nasogastric (NG) tube, with no serious adverse events and fewer complication reported in the PEG group[12].

Only one study addressed the use of protein and energy supplements enriched with omega 3 fatty acid, promoting positive outcomes for quality of life. However, further more in-depth studies examining the potential of these supplements in the treatment of cancer cachexia are required[23].

One of the studies investigated individual nutritional support as a protection strategy in post-stroke patients at nutritional risk, using an individual nutritional treatment plan, via the oral route, or feeding tube in the case of dysphagic patients. This strategy was associated with improved quality of life[24].

Regarding impacts of nutritional counseling and use of oral nutritional supplementation on quality of life, of the 4 studies[14,25,32,35] involving this type of intervention, only 1 reported no effect on quality of life, in advanced cancer patients receiving chemotherapy[14].

Interventions and effects on symptoms control

Of the total sample, 11 studies addressed the effects of the interventions on the control of different symptoms[10,11,35,19,21,22,26,28,30–32], as presented in Table 3.

One study observed that the prevalence of bedsores, edema and the use of antibiotic was attenuated by individual nutritional support, which included nutritional counseling, the use of oral nutritional supplements and total parenteral nutrition, when necessary[10]. Individual nutritional support was also effective for improving protein-energy intake of cancer patients in 2 of the studies reviewed[28,31], while another study found improved protein-energy intake with the use of nutritional counseling and oral nutritional supplementation compared to standard practice[26].

Nutritional counseling was the intervention which promoted positive effects on the highest number of symptoms, namely: digestive symptoms, fatigue, dyspnea, poor appetite, protein-energy intake, anorexia, nausea/vomiting, xerostomia and dysgeusia[11,21,35]. Two articles investigated the positive effect of nutritional counseling with the concomitant use of oral nutritional supplement[26,32].

Xerostomia was significantly relieved with the use of sugar-free lime-lemon sorbet prior to 2 daily meals[19]. A positive outcome was also achieved using small amounts of liquids, foods and/or icechips, which also helped reduce discomfort, hunger and thirst[30].

A multimodal intervention involving palliative physical activity, nutrition and symptoms control appeared to be beneficial for reducing fatigue symptoms in advanced lung cancer patients, but further studies are needed for more robust conclusions[22].

Table 2. Interventions and effects on quality of life in studies included in scoping review. João Pessoa, Pernambuco, 2022.

Type of intervention	Results obtained
Multimodal (PA, nutrition and symptoms control)	The intervention appeared to be beneficial and safe in improving QOL in advanced lung cancer patients, but further studies are needed[22].
PEG	The use of PEG proved superior to NG as an intubation method for terminal patients with malignant bowel obstruction[12]
NC / ONS	Neither NC or ONS had an effect on QOL in patients with cancer and weight loss receiving chemotherapy [14]. Early intensive intervention with NC and ONS offered beneficial results in terms of overall QOL and physical function in patients receiving readiotherapy[25]. In cancer patients, all QOL function scores improved in the NC and ONS groups, whereas all QOL function scores worsened in controls [32]. Early intensive intervention with NC in cancer patients, and ONS prescription when indicated, promoted higher QOL functional scores for physical, emotional and social functioning in the intervention versus control group [35].
TPN/Home TPN	TPN promoted no improvement in QOL of advanced cancer patients with malnutrition, causing more severe side-effects[16]. Supplemental or total home NP was associated with improved QOL in advanced cancer patients, depending on clinical condition and oncologic state, and should be considered when patients start to lose weight or become hypophagic[18]. Home TPM was associated with improved QOL in cancer patients, but an RCT is needed[20]. Home TPN had a positive impact on NS and QOL in malnourished gastric cancer patients receiving chemotherapy shortly after start of treatment[29]. Home TPN in cancer patients promoted an overall improvement in QOL, particularly the physical component[34].
Omega 3 Fatty Acid	The analysis of potential dose-response potential showed that, if taken in sufficient quantity, only the protein and energy omega-3 fatty acid enriched supplement resulted in gain of weight, lean tissue, and improved QOL[23]
INS	INS can protect older stroke patients at nutritional risk against undernutrition and improve QOL[24].

TPN: total parenteral nutrition; QOL: quality of life; NC: nutritional counseling; PEG: percutaneous endoscopic gastronomy; ONS: oral nutritional supplementation; NS: nutritional status; PA: physical activity; NG: nasogastric tube; PN: parenteral nutrition; INS: individual nutritional support.

Table 3. Interventions and effects on Symptoms Control in studies included in scoping review. João Pessoa, Pernambuco, 2022.

Type of intervention	Results obtained
Individual support with NC, ONS and TPN when necessary	Bedsores, edema and use of ATB: Reduced prevalence of bedsores, edema and ATB use[10]
Individual nutritional support	Protein-energy intake: Estimated daily dietary intake and daily energy balance were superior in patients receiving nutritional support[28]. Individual nutritional support can promote increased energy intake in patients with gastric colorectal cancer and weight loss[31].
NC	{Digestive symptoms: Total digestive symptoms scores were significantly reduced after 2 weeks[11]. Fatigue, dyspnea and poor appetite: Early intensive intervention with NC shortly after diagnosis in upper gastrointestinal cancer patients, and ONS prescription when indicated, promoted lower scores in the intervention group on symptoms scale (indicative of improved symptoms control) compared to control group for fatigue, dyspnea and poor appetite[35]. Poor appetite: NC, associated with simple pharmacological measures, resulted in significant appetite improvement in cancer patients[21].

to be continued

Continuation of Table 3

Type of intervention	Results obtained
NC / ONS	The intensive nutritional intervention with NC and ONS resulted in improved average protein-energy intake compared to standard practice[26]. Anorexia, nausea/vomiting, xerostomia and dysgeusia. There was a 90% reduction in these symptoms in the cancer patients who received NC, 67% in the ONS group and 51% in the control group. Energy intake was increased in the NC group and was maintained throughout the 3 months[32].
Sugar-free lime-lemon sorbet prior to 2 daily meals	Xerostomia: significantly improved food intake by stimulating saliva production[19].
Multimodal (PA, nutrition and symptoms control)	Fatigue: appeared to be beneficial and safe in reducing symptoms such as fatigue in advanced lung cancer patients, but further studies are needed[22].
Small amounts of fluids and food	Hunger, thirst and xerostomia: these symptoms can be attenuated, generally with small amounts of food, fluids and/or by applying ice chips and lubrication. Providing only the food and fluids necessary to relieve patient discomfort can be more effective, satisfying the patient desires while providing discomfort relief[30].

TPN: total parenteral nutrition; ATB: antibiotic; NC: nutritional counseling; ONS: oral nutritional supplementation; PA: physical activity

Interventions and effects on nutritional status

A total of 17 studies involved interventions to improve nutritional status[13,14,28,29,31–35,15,17,20,21,23–25,27]. Five of these reported improvement in nutritional status following nutritional counseling[13,21,25,32,35]. This intervention promoted a positive outcome which was superior to the use of oral nutritional supplement alone[32], in addition to significant improvements in weight gain of cancer patientsr[21]. A randomized clinical trial[14] was the only study that failed to show efficacy of this type of intervention on nutritional status of patients with cancer and weight loss receiving chemotherapy. However, the study was suspended early upon recommendation of a data monitoring committee.

With regard to the use of omega-3 fatty acid enriched supplements, those studies which administered this intervention had conflicting results[15,23]. One of the studies showed positive results for weight gain, with a significant improvement in appetite after 3 weeks[15]. Another study compared the effect of antioxidant and omega-3 enriched supplements with a standard supplement on nutritional status over an 8-week period. It was concluded that the study failed to address the hypothesis developed from pilot data, with further studies needed to confirm the potential efficacy of the use of omega-3 enriched supplements in cancer cachexia[23].

Artificial nutrition and its efficacy for improving nutritional status of palliative patients was assessed by 7 of the studies reviewed[17,20,27–29,33,34]. Results showed that when intake of a regular diet complemented with oligomer supplement was possible, serum albumin was better preserved[17].

With regard to the use of enteral nutrition, the findings showed that this can serve as a palliative treatment for undernutrition, albeit with limited effect, with this approach being more indicated for patients with regular functional capacity, no intense pain symptoms or neurological disorders[27]. When use of enteral nutrition is indicated, special silicon tubes provide greater comfort for patients[17].

The use of total parenteral nutrition for improving nutritional status was addressed in 6 of the studies selected[17,20,28,29,33,34]. One of these investigations noted the intervention may be reserved for certain stages, particularly the pre-operative stage, and also more critical stages of care for supporting primary surgery, chemotherapy or radiotherapy for cancer[17]. Another study concluded that home parenteral nutrition can prevent death due to undernutrition in 73% of cases[33]. A 2015

study found improved weight gain in 63% of older adults with cancer[34], while another study, published in 2010, found a positive impact on both nutritional status and quality of life in malnourished patients receiving salvage chemotherapy treatment[29].

An RCT documented a significant increase in body fat over time in older cancer patients, but no difference in muscle mass between the groups was evident[28]. Similarly, a prospective observational study found that home parenteral nutrition was associated with improved nutritional status in cancer patients, recommending that an RCT be conducted to provide more solid conclusions[20].

Also, a study involving older stroke patients at nutritional risk observed that individual nutritional support can protect against malnutrition[24].

Table 4. Interventions and effects on Nutritional Status in studies included in scoping review. João Pessoa, Pernambuco, 2022.

Type of intervention	Results obtained
NC / ONS	NC and ONS maintained albumin levels in cancer patients[13]. Neither NC or ONS had an effect on NS in patients with cancer and weight loss receiving chemotherapy[14]. NC and ONS is beneficial for weight loss and NS decline in radiotherapy patients[25]. NC in cancer patients and ONS prescription, when indicated, showed higher body weight and lower nutritional risk in intervention group[35]. Improvement in NS was seen in the group receiving NC, but not in the ONS or control groups[32]. NC and simple pharmacological measures resulted in improved weight gain in cancer patients[21].
Omega 3 Fatty Acid	Omega-3 fatty acid ONS promoted greater weight gain relative to conventional supplements[15]. The use of omega 3 fatty acids conferred no therapeutic advantage. The analysis of potential dose-response potential showed that, if taken in sufficient quantity, only the protein and energy omega-3 fatty acid enriched supplement resulted in improved NS and QOL[23].
Artificial nutrition	Oligomer ONS: In older adults with cancer, serum albumin was better preserved with an adequate dietary intake or complemented with a special low residue diet. EN using special silicon tubes can be used with minimal discomfort. TPN can be reserved for more critical phases[17] Home TPN was associated with improved NS in cancer patients[20]. ONS and home TPN: Lean mass did not differ between the two groups, but changes in total fat differed. Body fat was lower in the intervention group at inclusion, but increased over time, whereas levels remained unchanged in the control group[28]. Home TPN had a positive impact on NS and QOL in malnourished patients receiving chemotherapy[29]. Home artificial nutrition can be effective for preventing death due to malnutrition and in maintaining and improving performance in 1 month[33]. Home TPN in cancer patients promoted weight improvement in patients, screening reduced nutritional risk and performance improved or stabilized. Most patients gained weight and 17.5% attained ideal weight[34]. ENS can serve as palliative treatment of progressive malnutrition in anorectic cancer patients. However, this should only be considered for patients with regular functional capacity and no intense pain symptoms or neurological disorders[27].
INS	INS can protect older stroke patients at nutritional risk against undernutrition and improve QOL[24]. INS can promote weight gain in cancer patients[31].

NC: nutritional counseling; ONS: oral nutritional supplementation; NS: nutritional status; QOL: quality of life; EN: enteral nutrition; TPN: total parenteral nutrition; ENS: enteral nutritional support; INS: individualized nutritional support.

DISCUSSION

In the sample selected, nutritional counseling, in association with use of nutritional supplementation or otherwise, was the most commonly adopted intervention among the 3 aspects evaluated: quality of life, symptoms control and nutritional status[11,13,14,21,25,26,32,35].This intervention provided patients with guidance on the amount and frequency of meals, fortifying of foods, changes in consistency, according to current clinical condition and symptoms present, as well as family support and a pleasant environment for meals, where good communication was key to achieving more successful outcomes[36]. This finding corroborates the European Society of Parenteral and Enteral Nutrition guidelines (ESPEN) guidelines[37] recommending that, for radiotherapy patients, nutritional intake should be underpinned mainly by individual nutritional counseling and/or with the use of oral nutritional supplements, improving nutritional intake, body weight and quality of life, benefitting patients and preventing interruptions in treatment[37].

Concerning survival and response to treatment, although there is often no positive impact, in some studies[36,38], nutritional counseling is recommended given that many patients report greater benefits for health and general well-being than individuals not receiving counseling. This highlights the importance of the role of the nutritionist, committed to providing, on an individual level, the guidance and recommendations needed to promote well-being and comfort of these patients[36,38].

The literature shows that, with regard to indication of artificial nutrition in older adults in palliative care, contradictions exist over its true risks and benefits[39]. In the present review, 11 studies [10,12,34,16–18,20,27–29,33] addressing this intervention were found, particularly the use of home parenteral nutritional support[18,20,28,29,33].

With regard to quality of life, only the study by Bouleuc et al.[16], of the 11 studies[10,16–18,20,27–29,33,34] on parenteral nutrition reviewed, reported negative quality of life outcomes for use of total parenteral nutrition in malnourished advanced cancer patients, noting more severe side-effects. Thus, the authors did not recommend prescribing parenteral nutrition for advanced cancer patients with a life expectancy of less than 3 months.

The ESPEN guidelines on clinical nutrition and hydration in geriatrics[40] recommend that artificial nutrition be considered as a clinical treatment rather than basic care and, hence, should be used only in cases of a realistic chance of improvement or maintenance of the patient´s quality of life. Ratifying this guidance, the practical guidelines for clinical nutrition in cancer of the Brazilian Society of Parenteral and Enteral Nutrition (BRASPEN)[41], and also of the ESPEN[42], carry a similar recommendation, stating that the benefit of nutritional support for advanced cancer patients in palliative care should be considered carefully, taking into account both the patient prognosis and survival. Patients with a good prognosis and expected overall survival of at least a few months, as well as patients with low tumor activity and no inflammatory reaction, should receive adequate counseling and nutritional support, including oral, enteral or, if necessary, parenteral nutrition or a combination of these approaches. There is little or no benefit of nutritional support in the last weeks of life, given this will result in no functional or comfort benefit for the patient[41,42].

Six of the studies[18,20,28,29,33,34] reviewed showed benefits of home artificial nutrition for quality of life and nutritional status. Similarly, Orrevall et al.[43] concluded that patients with cancer and intake and nutrient absorption deficits can be indicated home artificial nutritional support, even at advances stages of the disease, provided survival is longer than a few weeks. This benefit is evident from the extended survival of months or years seen in cancer patients receiving exclusively parenteral nutrition, patients which without feeding would have otherwise died[44].

For use of home artificial nutrition, careful patient selection is recommended, with eligible candidates presenting chronic insufficient dietary intake and/or uncontrollable poor absorption[37]. Home parenteral nutrition is a complex therapy, requiring proper screening of patients for this type of treatment. Assessment of cognitive and physical abilities of the patent prior to embarking on the training program is fundamental. In addition, the home environment,

clinical suitability, potential for rehabilitation, social and economic factors and sources of financing, should also be assessed by the multidisciplinary team before commencement of training for home parenteral nutrition[45].

Regarding nutritional status, only one[27] of the 4 studies[12,17,27,33] addressing enteral nutrition reviewed showed a limited effect of this nutritional support, which should be considered only in patients with regular functional capacity and absence of debilitating symptoms. In cancer patients, to prevent or treat malnutrition, the ESPEN guidelines recommend the use of enteral nutrition if oral nutrition is inadequate, despite the use of counseling nutritional intervention and oral nutritional supplementation, and recommend parenteral nutrition in cases where enteral nutrition proves insufficient or not possible[37].

In patients with a poor prognosis and life expectancy of just weeks or days, the literature stresses the importance of considering bioethical aspects of feeding, particularly with respect to religious, cultural and ethnic aspects, and also social, emotional and existential dimensions[37]. Complementing this aspect, the study of Cardenas[46], examined, as one of the special situations, nutritional therapy and hydration in older individuals, given that this population is at greater risk of developing malnutrition due to multiple comorbidities and associated polypharmacy. Nevertheless, the indication of artificial nutrition should be reviewed at regular intervals, weighing the risks and benefits, while respecting the principles of beneficence, non-maleficence and autonomy[46].

Another important finding of this review is the highlighting of some important strategies for the management of symptoms commonly shared by older patients in palliative care, such as xerostomia, dysgeusia, fatigue, dyspnea, poor appetite, anorexia, bedsores, edema, nausea and vomiting, with positive outcomes in all studies[10,11,35,19,21,22,26,28,30–32] addressing this management, where nutritional counseling emerged as the most used intervention for symptoms relief.. Consistent with these findings, Pinho-Reis[47] described the management of many of these symptoms, using nutritional counseling strategies, while also addressing the need for changing feeding routes[47].

Nutritional care in the context of managing symptoms encompasses different interventions, including for instance nutritional counseling, enriching meals, provision of snacks, changing consistencies, administration of oral nutritional supplements, as well as enteral and parenteral nutrition, which can mutually complement one another in terms of their effects on the symptoms. However, nutritional care goes beyond interventions, also covering feeding assistance, adaptation of environmental factors and eliminating underlying causes, thus calling for multidisciplinary action involving nutritionists, nurses, helpers for general services, cooks, physicians, therapists, family members, caregivers and the patients themselves[40].

Symptoms assessment in palliative care includes both objective and subjective components and requires the use of validated scales and tools available to guide professionals in assessing pain and other sources of suffering, e.g. the Edmonton Symptom Assessment Scale (ESAS), widely used in research of palliative care for its ease of use as a system or manually as a checklist[48].

Only 2 of the studies selected[15,23] explored the use of omega 3 fatty acid. Of these, the study by Fearon et al.[23] concluded that the study failed to demonstrate that use of supplements enriched with this nutraceutical compound promoted anabolism in patients with cachexia. However, analysis of the dose-response potential showed that, if used at sufficient quantity, this intervention promoted net weight and lean tissue gains and improved quality of life. The study by Leite et al.[49] showed several benefits of omega 3 supplementation in the promotion of quality of life of patients receiving cancer treatment, providing improvements in inflammatory and immunological response, muscle synthesis, xerostomia, healing of surgical wounds and cancer-induced cachexia. Similarly, the guidelines of the BRASPEN[41] recommend omega-3 supplementation for patients on chemotherapy, who are malnourished, or experiencing weight loss, with the aim of establishing or enhancing appetite. This guideline, however, emphasizes that the evidence supporting the use of omega 3 remains inconclusive, requiring further studies to determine the ideal dose and timing for its use.

The present review has important implications for the practice of nutritionists, and also contributes to future studies. This is the case because the majority of nutritionists involved in palliative care, particularly end-of-life, are not specifically trained in palliative care, highlighting the tendency for therapeutic obstinacy, overlooking the distress caused by some interventions and failing to recognize the need to minimize ethical conflicts in decision-making[50]. This knowledge must be disseminated among nutritionists, with the exchange of experiences on care protocols used in each care setting designed for older patients in palliative care, guiding professional conduct in this area. It is also important to revisit spiritual aspects and the role of the nutritionist, toward performing a full holistic assessment.

Regarding design methodology of the studies, there were 11 RCTs[12,14,35,16,23–26,28,31,32] and 6 prospective longitudinal cohort studies[10,11,13,18,19,29] involving nutritional interventions. There were also 7 quasi-experimental studies[15,17,20,22,27,30,34] and only 2 retrospective cohort studies[21,33]. Of the 26 studies reviewed, only 11 were published within the last 10 years[10,12,35,16,18–20,22,29,33,34], pointing to the need to carry out more multi-center studies with greater methodological rigor that can elucidate the most effective nutritional interventions in clinical practice for the older patient population in palliative care.

The present study has some limitations. Although mean age of participants of the studies was >60 years, most studies did not stratify results for the older adult age group, precluding analysis of specific data for this population. Six studies involved cohorts comprising 10-22 participants[15,19,22,27,30,35], thereby limiting generalization of results. Concerning symptoms management in the studies reviewed, there was an absence of interventions involving symptoms common in the older population in palliative care, such as constipation, diarrhea and mucositis.

CONCLUSION

The present review mapped the main nutritional interventions adopted in older adults in palliative care. The findings highlight the need of knowledge by nutritionists on these interventions, and of further studies to build on this evidence.

Nutritional counseling was identified as providing best results across all aspects assessed, where nutritionists must be alert to the specific recommendations for patients to cater for the individual needs of each. Artificial nutrition was consistently reported as a means of promoting improvement in nutritional status and, consequently, in quality of life in the vast majority of the studies, requiring careful assessment of disease stage and life expectancy. Further studies should be carried out to elucidate the true contribution of omega 3 fatty acid to quality of life and nutritional status. Symptoms management should be conducted individually, with the goal of promoting comfort and relief according to patient needs. This requires a thorough evaluation of the intensity and type of symptoms presented, with interdisciplinary collaboration and using specific assessment tools. Although gaps in the literature on interventions adopted for older patients in palliative care exist, the vital role of the nutritionist in relieving suffering, promoting comfort and enhancing quality of life of this population is clear.

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