

Advanced dementia in a sample of Brazilian elderly: Sociodemographic and morbidity analysis

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SUMMARY

Introduction: To investigate the sociodemographic and morbidity profile of advanced dementia patients and sociodemographic data of their primary caregivers.

Method: Data was obtained from 67 elderly recruited for an observational prospective study, through interviews performed with primary caregivers. For statistical analysis, the Statistical Package for the Social Sciences (SPSS®) for Windows®, version 19.0. was employed.

Results: Advanced dementia patients were mostly women, widows, and non-institutionalized, with low-income. An elevated rate of stroke, sarcopenia, and pressure ulcers in this population is noted. Caregivers were mostly women, married, children of the studied patients, and unemployed. Only one third of caregivers were hired for the task.

Conclusion: Patients with advanced dementia present a high morbidity profile, low income, and depend on the care given by family members, mostly unemployed daughters.

Keywords: Alzheimer's disease, comorbidity, socioeconomic factors, aged.

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INTRODUCTION

Demographic transition, characterized by rapid decline in fertility and population growth, leads to a reduction in the proportion of the young population and an increase in the elderly population, aged 60 years or older.^{1,2} The result of this fact is an increased number of cases of chronic degenerative diseases, including dementia.³ The prevalence of dementia in Brazil is estimated at 7.1% among the elderly.⁴ According to the population census, in 2010 there were 20,590,599 inhabitants aged 60 years or older in Brazil (10.79% of the population). Considering the prevalence of dementia, it is estimated that approximately 1,500,000 elderly individuals present this disease.⁵

Advanced stage dementia is characterized by significant cognitive and functional decline. There is a noted dependency for self-care, with the need for assistance in simple tasks such as transfers, bathing, and dressing. This is classified by the Clinical Dementia Rating (CDR) as stage 3, by the Global Deterioration Scale (GDS) as a score ≥ 6 , by the Functional Assessment Staging Tool (FAST) as a score ≥ 6 and by the Mini Mental State Examination (MMSE)

as a score of less than ten points. We can also observe worsening of associated psychological and behavioral symptoms, a higher level of burden on the caregiver, and a greater risk of institutionalization.⁶

It should be noted that among patients with advanced dementia there is a subgroup at a very advanced stage, estimated at 17% of elderly people with dementia aged over 75 years, in which there is a MEEM of less than two points and maximum reliance on self-care.⁶ This is characterized by progressive loss of the ability to walk, causing immobility syndrome, which is defined by the presence of multiple contractures and cognitive decline associated with two of the following conditions: aphasia, dysphagia, pressure ulcers, and the presence of urinary and/or fecal incontinence.⁷ The presence of eating disturbances such as refusal to eat and oropharyngeal dysphagia is common, raising the risk of aspiration pneumonia.

The subpopulation of patients with advanced dementia in Brazil has not been properly characterized and estimated. The clinical and sociodemographic context of these patients is unknown, as well as the sociodemo-

graphic profile of caregivers. Therefore, the objective of this study was to assess the sociodemographic and clinical context of elderly people with advanced stage dementia, as well as the sociodemographic data of the primary caregivers of such patients.

METHOD

The data was obtained from elderly people recruited for an unblinded, non-randomized, prospective observational study that evaluated mortality, the incidence of aspiration pneumonia, and hospitalization of patients in advanced stages of dementia.⁸

The sample consisted of elderly patients with probable or possible Alzheimer's dementia in advanced stage and dysphagia. Half of these patients were using alternative feeding routes (nasogastric catheter or gastrostomy). The other half was fed exclusively by mouth. The elderly individuals included in the study were recruited at the geriatrics clinic of the Universidade Federal de Minas Gerais (UFMG), at the emergency room of the UFMG's Hospital das Clínicas, at the Center-South Emergency Unit (UPA-Center-South), at the wards of Hospital Risoleta Tolentino Neves, and at the patient's home. All of the above-mentioned health units are public and administered by the UFMG. The study was approved by the UFMG Research Ethics Committee under number 0164.0.203.000-11.

We included patients aged over 60 years with probable or possible Alzheimer's dementia (AD) according to the criteria established by McKhann et al. (2011) classified on the Functional Assessment Staging Tool (FAST) scale as 7A to 7F (Sclan and Reisberg, 1992), with complete dependence for Basic Activities of Daily Living (ADLs) as classified using the Katz Index (Lino et al., 2008), with the presence of moderate to severe oropharyngeal dysphagia confirmed by clinical assessment, according to the protocol given by Padovani et al. (2007).⁹⁻¹²

Elderly people with neurological dysphagia after a cerebrovascular accident (CVA), secondary to amyotrophic lateral sclerosis or Parkinson's diseases were excluded. Tracheostomy patients or those with the presence of any type of neoplasm, except for those in complete remission, were also excluded. Dysphagic subjects with a history of CVA, in which the onset of dysphagia presented no temporal association with this neurological event, were not excluded.

The calculation of the sample has been previously published.⁸ The demographic and clinical data was obtained through interviews held with the primary caregivers. Where possible, the information was supplemented by data from medical records, hospital discharge sum-

maries and supplementary examinations. Primary caregiver is defined as the person with main, full or greatest responsibility for the care provided to the patient at home.¹³ All of the caregivers were interviewed exclusively by one of the researchers (MTGC). The burden on the caregiver was analyzed using the Zarit scale.¹⁴

The nutritional status was assessed by measuring the left calf circumference (CC), in which values of less than 31 cm indicate sarcopenia and a worse nutritional status.^{15,16} Pressure ulcers were evaluated and classified, and sorted according to the National Pressure Ulcer Advisory Panel's, revised version 2007.¹⁷ Serum albumin levels were noted when available.

Analysis of the continuous variables was performed by calculating the mean, median, and standard deviation and comparing them using the appropriate tests for the type of distribution. The categorical variables were compared using chi-squared test or Fisher's exact test. Normality assessment of the continuous variables was carried out using Shapiro-Wilk test, and the comparison of averages using Student's t-test (for normal distribution) or Mann-Whitney U test (for non-normal distribution). For the statistical analysis, we used the Statistical Package for the Social Sciences (SPSS®) for Windows®, version 19.0.

RESULTS

Sixty-seven (67) dysphagic elderly people in advanced stages of dementia were recruited, 36 in use of the oral route, 28 using a nasogastric catheter and three submitted to gastrostomy. Most patients were recruited during hospitalization (58.2%). The average age was 84.79 ± 7.02 years, 85.1% were female, with formal education for 2.90 ± 3.73 years and income of 1.23 ± 0.90 minimum wages. Fifty-seven percent (57%) of patients were widows, 25.4% were married, and 14.9% were single. The rate of institutionalized individuals was 9%.

In relation to the etiological diagnosis of dementia, 55.2% had probable AD and the remainder, possible AD. In relation to the assessment of severity, 14.9% presented FAST 7A or 7B, while 85.1% of the elderly people were in FAST phase 7C or worse, with a predominance of FAST 7D (38.8%). On average, the subjects had been diagnosed with dementia for 5.80 ± 3.57 years with onset of dysphagia 12.60 ± 15.04 months before our investigation. The subjects in the group using an alternative feeding route were recruited 51.28 ± 96.94 days (median of 11.5 days) after introducing the feeding device.

The patients resided in households inhabited by 3.79 ± 1.60 people, with 1.64 ± 0.71 elderly individuals and 2.43 ± 1.25 residents contributing to the family income.

Only 6% of the patients did not present any source of income, while the majority of seniors received a retirement pension (50.7%). Figure 1 characterizes the subjects with dementia according to the type of income. The income of these families totaled 4.39 ± 7.50 minimum wages; therefore, the salaries received by the elderly corresponded to 28.2% of the average household income.

On average, 3.78 ± 1.56 comorbidities were reported, with the most frequent being CVA in 41.8%, systemic arterial hypertension (SAH) in 65.7%, and *diabetes mellitus* (DM) in 20.9%. There was no statistical difference between the groups with or without an alternative feeding route in relation to the number of pathologies ($p=0.306$) and the diagnosis of these comorbidities: CVA ($p=0.331$), SAH ($p=0.397$) and DM ($p=0.753$).

The patients received an average of 3.24 ± 1.97 medications, with 25.4% using five or more, which is known as “polypharmacy.”¹⁸ There were no differences between the groups with or without an alternative feeding route in relation to the amount of medication prescribed ($p=0.057$). The classes of medications prescribed the most were antihypertensive drugs (53.2%), antipsychotics (33.9%), antiplatelet agents (29%), benzodiazepines (27.4%), and antidepressants (19.4%). Opioids, dipyrone or acetaminophen were prescribed for analgesia in only four patients, while five subjects (7.5%) were using acetylcholinesterase inhibitors in the very advanced stage of dementia.

We found that 65.7% of the subjects had pressure ulcers, with an average of 1.97 ulcers. The patients with an alternative feeding route had the highest number of pressure ulcers (2.74 ulcers *vs.* 1.31, $p=0.035$). In relation to the severity of the pressure ulcers, stage 2 was the most common (present in 65.9% of patients), followed by grade 1 (45.5%), grade 3 (15.9%), grade 4 (13.6%) and deep tissue injury (13.4%). There was a tendency towards greater severity of ulcers in the group with alternative feeding routes, with 25.8% grade 3 and 4 lesions *versus* 8.3% in the elderly people on the oral route ($p=0.054$).

The average CC value was 26.03 ± 3.72 cm ($p=0.750$) between the oral and alternative feeding groups). Only 13.4% of the elderly people presented calf values greater than or equal to 31 cm. Only 19 patients had serum albumin results, with average values of 2.88 ± 0.86 mg/dL ($p=0.996$ between the oral and alternative feeding groups).

The patients that were institutionalized were excluded from the assessment of the primary caregivers. The caregivers were mostly female (87.1%) and had an average age of 53.23 ± 11.46 years, with 23.9% older than 60 years and average education of 7.80 ± 4.11 years. Most were married (57.6%), followed by single (16.9%), divorced (13.6%), and widowed (10.2%) caregivers. They were, for the most part, the children of the patients (67.2%), followed by grandchildren and spouses (8.2% in each subgroup). Other relatives totaled to 14.8%. Only 1.6% of primary caregivers were hired without family connections.

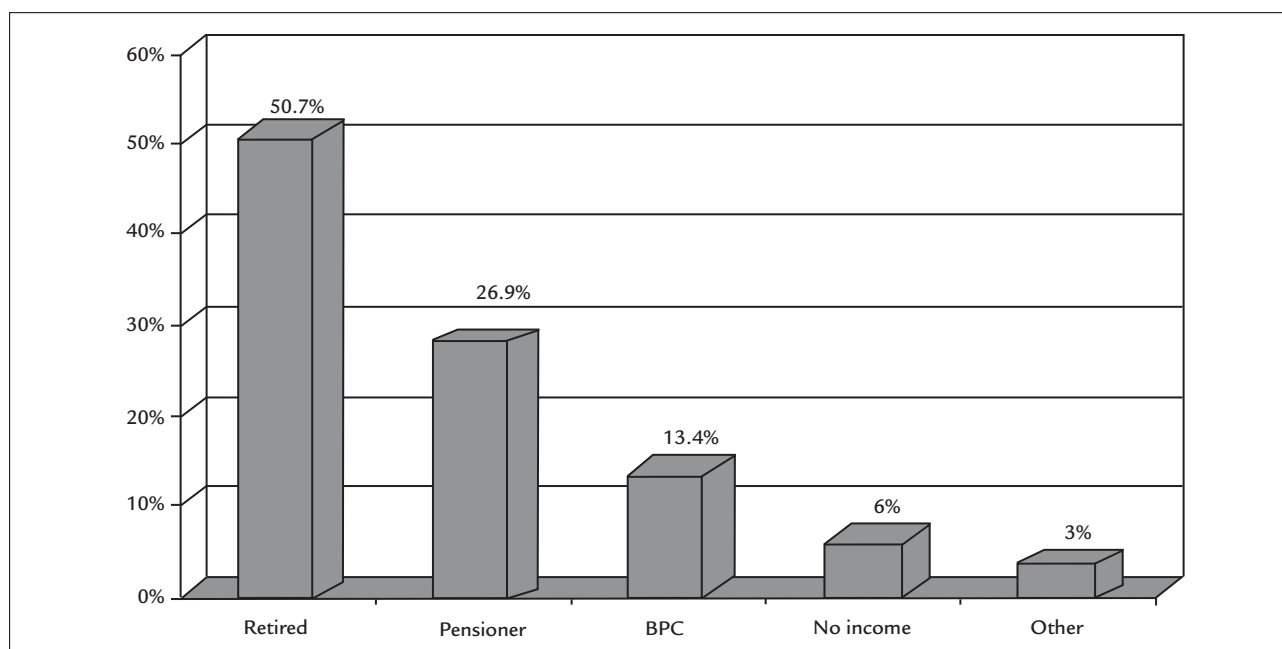


FIGURE 1 Classification of income type.

BPC: Brazilian antipoverty welfare program

The caregivers were mostly unemployed (45.9%), followed by retirees (27.9%), as well as 24.6% who were working at the time of recruitment. One third of the elderly people were assisted by hired caregivers, who received an average of 1.04 ± 0.59 minimum wages. However, the hired professional was the primary caregiver in only one home. There was no difference between the oral and alternative feedings groups in relation to the sociodemographic variables examined (Table 1).

When caregiver burden was assessed, significant burden values were noted in both, those responsible for the care of elderly individuals with exclusive oral feeding (30.0) as well as those responsible for the care of dementia patients with alternative feeding routes (27.04), with no statistical difference between the groups ($p=0.398$). No influence was observed regarding prevalence ($p=0.344$) and number of pressure ulcers ($p=0.355$), calf circumference ($p=0.162$) and the primary caregiver burden ($p=0.870$) when hiring caregivers.

DISCUSSION

The subjects of this study included elderly people with advanced age, who were predominantly female, with low education and widowed, in accordance with that described in the literature.¹⁹ However, we must highlight the low rate of institutionalization when compared to other studies, which present a rate of over 50%.²⁰⁻²⁷ The exception to this is a study by Jaul et al. (2006) which detected that 24% of elderly people with exclusive oral feeding and 45% with alternative feedings routes were

institutionalized.²⁸ All of these studies were performed in other countries, such as the United States, which have economic, social, and cultural differences that could justify the discrepancy.

The low rate of institutionalization may be due to an insufficient number of places at charitable or public long-stay institutions for the elderly (ILPI), in addition to low family income to cover the cost of private ILPIs. This reality has been shown by Chaimowicz and Greco (1999), who demonstrated that 0.9% of women and 0.3% of men over 60 years of age in Belo Horizonte were institutionalized, and that ILPIs presented an occupancy rate of 92%.²⁹ Nevertheless, the results cannot be generalized to the entire Brazilian population because only subjects served by the public health system were included.

Data from the National Survey by Household Sampling (PNAD, in the Portuguese acronym) in 2004 shows that in households with per capita income of one minimum wage have an average of four people in the south-east region, similar to the results in this study.³⁰ It was found that elderly individuals with dementia contributed to 28.2% of the family income, in accordance with studies which have shown that the share of pensions and benefits in total household income is increasing progressively in Brazil.³¹

In the assessment of the sociodemographic data of the primary caregivers of elderly people with advanced dementia, it was found that they are mostly female aged 53.2 years on average. They are mostly the children of patients, married, have 7.8 years of formal education, and

TABLE 1 Analysis of sociodemographic data comparing oral and alternative feeding groups.

	Oral feeding group	Alternative feeding group	p-value
Patient's sex	77.8% female	93.5 female	0.093
Patient's age	84.08 $\pm$ 7.11 years	85.61 $\pm$ 6.93 years	0.378
Patient's educational level	2.59 $\pm$ 3.17 years	3.31 $\pm$ 4.39 years	0.873
Patient's income	1.16 $\pm$ 0.47 MS	1.31 $\pm$ 1.23 MS	0.603
Caregiver's sex	85.3% female	89.3% female	0.719
Caregiver's age	53.79 $\pm$ 13.20 years	52.52 $\pm$ 9.01 years	0.670
Caregiver's educational level	7.56 $\pm$ 3.89 years	8.11 $\pm$ 4.42 years	0.878
Number of individuals per household	3.82 $\pm$ 1.64	3.74 $\pm$ 1.58	0.929
Number of individuals with income per household	2.38 $\pm$ 0.85	2.50 $\pm$ 1.66	0.957
Number of elderly individuals per household	1.71 $\pm$ 0.63	1.56 $\pm$ 0.80	0.198
Family income	3.19 $\pm$ 1.74 MS	5.73 $\pm$ 10.81 MS	0.692
% of elderly individuals with paid caregivers	26.5%	42.3%	0.197
Amount paid to caregiver	0.90 $\pm$ 0.34 MS	1.21 $\pm$ 0.74 MS	0.345
Burden on the caregiver – the Zarit scale	30.0	27.04	0.398

MS: minimum salary.

almost half are unemployed. Requena et al. (2011) conducted a retrospective study with 27 advanced dementia patients in Spain and described that most primary caregivers are women (81.5%), have an average age of 63 years, and are the children of the elderly people with dementia (74.1%).³² Figueiredo and Souza (2008) evaluated 52 patients with dementia in Portugal, 61.5% of whom were completely dependent, and noted that 67.7% of the caregivers were aged between 41 and 60 years, 88.5% were female, 51.9% were the patients' children, 75% were married, 53.8% had up to 4 years of education, and only 25% were employed.³³ Babarro et al. (2004) conducted an intervention study in Spain with caregivers of elderly people with dementia and reported that most caregivers are women (83.9%), aged 54.6 years on average, married (82.5%), with up to 4 years of formal education (70.2%) and are usually the children of the patient (58.5%).³⁴ As such, the social and demographic profile of caregivers to the elderly in this study is similar to that observed in other countries.

We can highlight that only a third of patients had hired caregivers, and that these received low pay. The rate is higher than that found by Toribio-Díaz et al. (2013) in a sample of 129 Spanish individuals with moderately advanced Alzheimer's dementia, among whom only 11.6% had hired caregivers.³⁵

It was observed that 41.8% of the sample presented a CVA episode. A similar rate (46.7%) was found by Arizon et al. (2008) in elderly people institutionalized in Israel.²¹ Lower prevalence rates have been described in the United States by Peck (1990) and Mitchell (1997), as well as in Spain by Alvarez-Fernández (2005) and in Israeli patients by Jaul (2006), who reported rates between 0 and 34%.^{22,26-28}

The proportion of hypertensive patients was 65.7%, and the proportion of patients with DM was 20.9%. Lima-Costa et al. (2011) demonstrated that SAH is self-reported by 53.3% of the elderly population in Brazil, and DM by 16.1%, while Pimenta et al. (2013) detected a SAH rate at 74.3% in subjects over 60 years of age with dementia.^{35,36} Alvarez-Fernández et al. (2005) reported that the proportion of hypertensive elderly individuals among patients with dementia was 22.4%, which is below that found in this study.²² In relation to the prevalence of DM, Arizon et al. (2008) recorded a similar prevalence rate to that found in our study (24.5%), while Mitchell (1997) and Alvarez-Fernández (2005) reported lower values (11.7 and 6%, respectively). Meanwhile, Jaul et al. (2006) found a prevalence of 39% in the group with the alternative feeding route and 60% in the exclusive oral group, which is higher than that found by us.^{21,22,26,28}

According to the aforementioned studies, the rate of hypertensive and diabetic patients is close to that described in the literature.^{37,38}

The presence of four chronic diseases per patient was observed, a high vulnerability clinic profile, which is slightly worse than that verified by Nair et al. (2000), who reported 1.5 disorders per patient.²⁵ On the other hand, this number is similar to that reported by Cassis et al. (2007) with a sample of elderly Brazilians with dementia (3.16±1.8 comorbidities) and near to the results of Martín-García et al. (2013) from a sample of institutionalized elderly Spanish individuals (96.8% had two or more chronic health conditions and 31.5% had four or more).^{39,40} Cassis et al. (2007) also showed that the average amount of medication prescribed per patient was 3.2±2.3, a figure close to that obtained in the present study.³⁹

The significant use of acetylcholinesterase inhibitor in the population under study should be highlighted, noting that such medication should be avoided at this stage of the disease, which may demonstrate some level of lack of preparation among health professionals caring for these patients.⁴¹ As the psychological and behavioral changes associated with dementia become more frequent as the disease progresses, the need for psychotropic drugs to control these symptoms is common, justifying the rates found in use of antidepressants and antipsychotics.⁴¹ On the other hand, a tendency towards underdiagnosed pain and lower use of analgesic medications in elderly individuals in advanced stage of dementia was observed.⁴²

CC measurement is often used to assess the presence of sarcopenia.¹⁵ Bonnefoy et al. (2002) demonstrated that the CC can be used as a marker of nutritional status in frail elderly patients and those with restricted mobility, with a significant correlation with body mass index (BMI) and serum albumin level ($r=0.706$, $p<0.0001$).¹⁶ We noted that only 13.4% of the sample had normal CC values, indicating a high rate of malnutrition.

A high prevalence of undernourishment determined by the CC was verified in German institutionalized patients with advanced dementia, with the rate of malnourished patients in the oral feeding group estimated at 50.2%, and 76.9% in the alternative feeding route group ($p<0.01$).⁴³ Martins et al. (2012) noted a malnutrition rate of 53.4% in Brazilian patients with neurological disease on an enteral diet.⁴⁴

In relation to pressure ulcers, the prevalence we observed was higher than that detected by Peck (1990) and Mitchell (1997), who have shown rates between 13 and 29.6%, but similar to those described by Meier (2001) and Jaul (2006), who reported a prevalence between 49 and 64%.^{24,26-28}

A greater burden on the caregiver was noted in the oral group compared to the alternative feeding group, but there was no statistical difference between the groups. The clinical impression is that the burden on caregivers is high. However, in the light of the available knowledge it is not possible to state what could be considered a high burden based on the Brazilian Portuguese version of the Zarit scale, although it is possible to use the scale for comparison.¹⁴

A similar result to ours was reported by Cassis et al. (2007), who assessed 67 elderly individuals with dementia, whose caregivers were mostly female and with formal education for 9.2 years. The average value on the Zarit scale was 32 points.³⁹ Babarro et al. (2004) demonstrated a high level of burden among the caregivers of elderly individuals with dementia in Spain, with a similar sociodemographic profile to that observed in our study, with a burden on 72.3% of the sample (55.5% at a high level).³⁴

It should be emphasized that a high level of burden on the caregiver increases the risk of depression and raises the self-reported impression of poor quality of life.⁴⁵ Therefore, high caregiver burden may indirectly affect the necessary care for patients with advanced dementia, such as feeding, change of position, and personal hygiene, as well as the financial support for such elderly people. Part of the results found in relation to pressure ulcers and nutritional status may be related to caregiver burden. Hiring a caregiver did not reduce the burden on the caregiver, nor did it have an influence on the prevalence of pressure ulcers and nutritional status.

This study has limitations, mainly related to memory bias of primary caregivers, who may underestimate the results. In addition, the sample size calculation was aimed at the composition of a cohort to evaluate the survival outcome, so it is not possible to say that the study's sample is representative for a socioeconomic analysis.

However, this study represents the first analysis of the socioeconomic profile and morbidities of patients with very advanced dementia in the Brazilian public health system. The results indicate the need for a policy aimed at caring for these patients, who present a high degree of vulnerability, a high cost of care, and, possibly, a reduction in family income, given the high rate of unemployment among primary caregivers.

RESUMO

Demência avançada em uma amostra de idosos brasileiros: análise sociodemográfica e morbididades

Objetivo: investigar o perfil sociodemográfico e de morbidade de pacientes com demência avançada e

dados sociodemográficos de seus respectivos cuidadores primários.

Método: foram obtidos dados de 67 idosos recrutados para um estudo observacional, prospectivo, não randomizado e não cego de pacientes em fase avançada de demência, por meio de entrevistas realizadas com os cuidadores primários. Para as análises estatísticas, foi utilizado o Statistical Package for the Social Sciences (SPSS®) para Windows®, na versão 19.0.

Resultados: a maioria dos pacientes com demência avançada é do sexo feminino, viúva, não institucionalizada e de baixa renda. Destacam-se as elevadas taxas de acidente vascular encefálico, sarcopenia e úlceras por pressão. A maioria dos cuidadores são do sexo feminino, casados, filhos do paciente e desempregados. Somente um terço dos pacientes apresenta cuidador contratado.

Conclusão: os pacientes com demência avançada apresentam elevado grau de morbididades, baixa renda e são dependentes de cuidados de familiares, geralmente filhas desempregadas.

Palavras-chave: doença de Alzheimer, comorbidade, fatores socioeconômicos, idoso.

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