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ORIGINAL ARTICLE

Geriatrics, Gerontology and Aging

How do our older adults die? The perception of family members about suffering in the last year of life

Como morrem nossos idosos? Percepção de familiares sobre experiências de sofrimento no último ano de vida

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Abstract

Objectives: To characterize the signs and symptoms of suffering, the circumstances of death, and health service use in the 12 months prior to death in a cohort of community-dwelling older adults according to relatives' perception, as well as to verify the relationships between baseline frailty and signs/symptoms of suffering in the last year of life.
Methods: This retrospective cohort study used data from the Frailty in Older Brazilians (*FIBRA*) Study. Home interviews were carried out with the relatives of deceased older adults. Descriptive statistical analyses were performed, including adjusted prevalence ratios through Poisson regression.
Results: A total of 192 family members participated (64.58% women). The mean age of the deceased was 80.59 years (59.90% women; 27.08% with no formal education). In the year before death, 51.34% had fatigue, 43.68% had pain, 42.63% had anorexia, 41.27% had dyspnea, and 41.21% suffered a fall. Most died either at home (52.10%) or in the hospital (41.66%). The most frequent causes of death were circulatory and respiratory system diseases and neoplasms; 29.63% died suddenly, 51.05% were admitted to an intensive care unit, 52.60% were hospitalized, 58.76% used pain medication, and 27.13% received home care. Relative to non-frailty, baseline frailty was associated with dependence (prevalence ratio = 2.52) and pain medication use (prevalence ratio = 1.52) in the last year of life.
Conclusions: Signs and symptoms of suffering in the last year of life were high among community-dwelling older adults, highlighting the need to support them and their families through provide palliative care.
Keywords: older adults; physical suffering; frailty; end of life; end-of-life care; health services.

Resumo

Objetivos: Caracterizar os sinais e sintomas de sofrimento, as circunstâncias da morte e o uso de serviços de saúde nos 12 meses prévios à morte em uma coorte de idosos residentes na comunidade conforme a percepção de seus familiares, bem como verificar as relações entre fragilidade na linha de base e sinais/sintomas de sofrimento percebidos no último ano de vida.
Metodologia: Estudo de coorte retrospectiva com dados do Estudo Fragilidade em Idosos Brasileiros (FIBRA). Realizaram-se entrevistas domiciliares com os familiares dos idosos falecidos. Foram feitas análises estatísticas descritivas e foram calculadas razões de prevalência (RP) ajustadas utilizando-se regressão de Poisson.
Resultados: Participaram 192 familiares (64,58% mulheres). A idade média dos falecidos foi de 80,59 anos, 59,90% eram mulheres e 27,08% não tinham escolaridade formal. No ano anterior ao óbito, 51,34% tiveram fadiga, 43,68% dor, 42,63% anorexia, 41,27% dispneia e 41,21%, quedas. Mais da metade (52,10%) morreu em casa e 41,66% em hospitais. As causas *mortis* mais frequentes foram doenças dos aparelhos circulatório, respiratório e neoplasias; 29,63% tiveram morte súbita, 51,05% foram internados em unidade de terapia intensiva, 52,60% foram hospitalizados, 58,76% receberam medicamentos para dor e 27,13%, atendimento domiciliar. A fragilidade associou-se com dependência (RP = 2,52) e uso de medicamentos para dor (RP = 1,52) no último ano de vida, em relação à não fragilidade na linha de base.
Conclusões: O estudo encontrou elevadas proporções de indicadores de sofrimento no último ano de vida dos idosos residentes na comunidade e destaca a necessidade de oferecer suporte a eles e a seus familiares, bem como ofertar cuidados paliativos.
Palavras-chave: idoso; sofrimento físico; fragilidade; fim da vida; cuidados de fim de vida; serviços de saúde.

INTRODUCTION

Studies have forecasted an 87% increase in deaths preceded by disease-related physical suffering between 2016 and 2060.[1] These deaths will be more numerous in low-income countries, where they are expected to increase by 155% over the next 44 years.[1,2] Increases are expected in dementia among older adults (264%), in the population aged ≥ 70 years (183%), and in cancer cases (109%). In addition to cancer and dementia, cerebrovascular and pulmonary conditions will substantially contribute to mortality and suffering in older adults.[1,3] The negative impact of frailty on premature mortality, hospitalization, and dependence should also be noted.[4]

Data from 350 relatives of older adults who died in the first and third waves of The Irish Longitudinal Study on Ageing indicated a high prevalence of modifiable problems (50% pain, 45% depression, and 41% falls) in the last year of life.[5] Older people with cancer were more likely to die at home or in hospice care than other cancer patients. The place of death and patterns of health service use were determined not only by clinical needs, but by factors such as age, type of living arrangement, and availability of informal care. Living alone or in a rural area hindered informal support and determined the place of death. Lack of informal care was not compensated for by better-quality formal care.[5]

Singer et al.[6] conducted a retrospective analysis of trends in distress symptoms in the last year of life among older Americans who died between 1998 and 2010, based on the reports of family members and friends in the Health and Retirement Study (n = 7204). During this period, reported pain (11.9%), heart failure and chronic lung diseases (27.0%), periodic mental confusion (31.3%), frailty (39.4%), and sudden death (45.7 %) increased, while cancer, moderate or severe pain, severe fatigue, anorexia, and vomiting did not.[6]

Solano et al.[7] conducted a household survey of 81 informal caregivers of deceased older adults in a low-income region of São Paulo, Brazil. They investigated the presence, intensity, and duration of symptoms in the last year of life and the treatment received. Among the 11 selected symptoms, the most commonly reported were pain (78%), fatigue and dyspnea (60%), and depression and anorexia (58%). Moreover, 79% of those with depression, 77% of those with urinary incontinence, and 67% of those with anxiety went untreated. Based on data from the Brazilian Mortality Information System, Leite & Ribeiro[8] investigated variables associated with dying at home among older cancer patients in São Paulo between 2006 and 2012. A total of 82% of cancer deaths occurred in hospitals. Women, those with higher education, the married, and the widowed were less likely to die at home. Scientific evidence and projections by international health organizations about the burden of population aging in coming decades[1,3,9] suggest that end-of-life care should be included in research and health service agendas for older adults worldwide.

The objectives of this study were to characterize, based on the perceptions of relatives, the signs and symptoms of suffering, the circumstances of death, and health service use in the 12 months prior to death in a cohort of community-dwelling older adults, as well as to determine the relationships between baseline frailty and signs/symptoms of suffering in the last year of life.

METHODS

This retrospective cohort study used baseline and follow-up data on older adults from the Frailty in Older Brazilians (*FIBRA*) study, in addition to deaths reported in the Brazilian Mortality Information System. Four sources of information were considered:

1. Baseline database records of the FIBRA Study, which was conducted in Campinas and São Paulo (Ermelino Matarazzo sub-district) in 2008-2009;
2. Records from the FIBRA follow-up database (2016-2017);
3. Interviews with relatives of the deceased between baseline and follow-up;
4. Mortality Information System death records between September 10, 2008 and April 3, 2016 to identify FIBRA study participants who died during this period.

FIBRA was a multicenter, population-based study that characterized the profiles of frail older adults (≥ 65 years) living in selected cities throughout Brazil based on sociodemographic variables, physical and mental health, subjective well-being, sociability, and stressful events.[10]

At baseline, participants were selected using a simple sampling strategy from a pre-established number of census sectors, including quotas of women and men aged 65-69, 70-74, 75-79, and ≥ 80 years, proportional to their presence in the general population of each city in 2007, plus 25% to replace losses. Data were collected at community centers, schools, churches, and basic health units by trained personnel.[10] In 2015, the records of the names and addresses of participants in the baseline study were used for the follow-up study. Up to 3 attempts were made to find each individual. When located, they were invited to participate

in the follow-up phase and gave written informed consent prior to doing so.[11]

When a resident reported that the participant had died, or when the person's name appeared in the Mortality Information System, the researchers requested an interview with family members about the individual's health in the 12 months prior to death and the circumstances of death. Before the interview was conducted, the researchers confirmed that the respondent knew the older adult well and requested access to the death certificate.

For participants who died prior to follow-up, the following sociodemographic variables were extracted from the baseline data: sex, age, education, race, frailty status, chronic diseases, and dependence in instrumental activities of daily living (IADL) [10]. According to Fried et al.,[11] frailty is as a geriatric syndrome characterized by a decreased reserve and resistance to internal and external stressors due to the action of pathophysiological, environmental, and lifestyle factors. Frailty involves 5 phenotypic criteria: involuntary weight loss in the previous year, fatigue in the last 7 days, low handgrip strength, low gait speed, and low physical activity level (ie, gauged by weekly exercise and household activities). Those scoring in 3 of the 5 criteria are considered frail, those scoring 1 or 2 are pre-frail, and those scoring 0 are non-frail.[12]

Chronic non-communicable diseases were assessed using the question "Has any doctor ever told you that you have any of the following diseases: heart disease, hypertension, stroke, stroke/ischemia, diabetes mellitus, cancer, arthritis/rheumatism, lung disease, depression and osteoporosis?"

Dependence in IADL was measured through 7 items from the Inventory of IADL:[13] using the telephone, transportation, preparing meals, shopping, managing money, and medication. Respondents could report that they needed no help, partial help, or total help to perform the activities. Those who said they needed partial or total help in ≥ 1 IADL were considered dependent.

In the FIBRA follow-up study, interviews with the relatives of deceased participants were based on a questionnaire derived from Singer et al.'s instrument.[6] Sociodemographic data collected from family members included sex, age, education level, and degree of kinship with the deceased. Signs/symptoms of suffering were assessed with yes or no questions about: bed confinement, falls, dependence, urinary and fecal incontinence, fatigue, anorexia, dyspnea, vomiting, persistent pain, severe cognitive decline/dementia, and depression. Data on the circumstances of death included: place of residence in the year prior to death, place of death, cause of death on the death certificate (classified according to the 10th Revision of the International Classification of Diseases and Related Health Problems),[14] and sudden death (yes or no) according to Singer et al.'s definition.[6] Data on health service use (yes or no questions) included: admission to intensive care units (ICU), home care, hospitalization, and pain medication use.

Descriptive statistical analyses were performed using absolute and relative frequencies and confidence intervals (95% CI) to determine the deceased's profile in relation to baseline, the profile of interviewed family members, the deceased's profile regarding signs/symptoms of suffering, the circumstances of death, and health service use in the last year of life. To determine the association between frailty and signs/symptoms of suffering, prevalence ratios (adjusted for sex, age, and education) were calculated using Poisson regression with robust variance. The analyses were performed in Stata 15.1.

The participants were informed about the objectives, procedures, and ethical aspects of the study and gave written informed consent prior to participation. The study was approved by the Campinas State University Ethics Committee (opinions 907575 [December 15, 2014] and 1332651 [November 23, 2015]).

RESULTS

Of the 1284 older adults at baseline, 192 (14.95%) died before follow-up, 549 were interviewed according to the follow-up protocol, and 543 were considered lost to follow-up: failure to locate (n = 314; 57.83%), refusal (n = 187; 34.44%), exclusion (n = 30; 5.52%), withdrawal (n = 9; 1.66%), or for safety reasons (n = 3; 0.55%). The present study analyzed data for the 192 participants who died between the baseline and follow-up phases of the FIBRA study.

The mean age at death was 80.59 (SD, 6.77; min. 63, max. 99) years. The majority were women (59.90%), aged ≥ 75 years at baseline (52.60%), and were either White (59.90%) or of mixed race (26.04%). Regarding education level, 27.08% had no formal education and 54.70% had 1-4 years. The most prevalent chronic conditions were arterial hypertension (64.70%), other heart diseases (34.07%), arthritis/rheumatism (30.15%), diabetes (25.73%), osteoporosis (23.53%), depression (22.06%), lung diseases (15.55%), cancer (9.56%) and stroke (8.82%). Regarding frailty status, 61.98% were pre-frail, 17.71% were frail, and 44.78% were dependent in IADLs (Table 1).

Most interviewed family members were women (n = 124; 64.58%); 58.33% were children, 17.19% were spouses and 24.48% were other relatives (grandchildren, great-grandchildren, nephews, and cousins) of the deceased. The mean

TABLE 1. Sociodemographic characteristics, chronic diseases, frailty, and disability among older adults who died between baseline and follow-up in the Frailty in Older Brazilians (FIBRA) study, Campinas, SP and Ermelino Matarazzo, SP, Brazil, 2008-2009 and 2016-2017.

Variable	n (%)	95% CI
Sex		
Male	77 (40.10)	33.37-47.23
Female	115 (59.90)	52.76-66.63
Age		
65 to 69 years	46 (23.96)	18.41-30.54
70 to 74 years	45 (23.44)	17.95-30.00
75 to 79 years	49 (25.52)	19.82-32.20
≥ 80 years	52 (27.08)	21.23-33.84
Race		
White	115 (59.90)	52.76-66.63
Black	22 (11.46)	7.64-16.82
Mixed	50 (26.04)	20.29-32.75
Other (Asian/Indigenous)	5 (2.60)	1.10-6.13
Education		
None	52 (27.08)	21.23-33.84
1 to 4 years	105 (54.70)	47.55-61.63
≥ 5 years	35 (18.22)	13.36-24.37
Chronic non-communicable diseases		
Arterial hypertension	88 (64.70)	56.25-72.33
Heart disease	46 (34.07)	26.52-42.53
Arthritis/osteoarthritis/ rheumatism	41 (30.15)	22.97-38.44
Diabetes mellitus	35 (25.73)	19.03-33.80
Osteoporosis	32 (23.53)	17.10-31.45
Depression	30 (22.06)	15.82-29.87
Pulmonary disease	21 (15.55)	10.33-22.75
Cancer	13 (9.56)	5.60-15.84
Stroke	12 (8.82)	5.05-14.96
Frailty level		
Not frail	39 (20.31)	15.18-26.64
Pre-frail	119 (61.98)	54.87-68.60
Frail	34 (17.71)	12.91-23.80
Independence in instrumental activities of daily living		
Total Independence	74 (55.22)	46.66-63.49
Total dependence	60 (44.78)	36.51-53.34

95% CI: 95% confidence interval.

interviewee age was 57.22 (SD, 14.94) years; 48.94% were aged 40-59 years, 39.89% were ≥ 60 years, and 11.17% were aged 19-39 years. Regarding years of education, 41.15% had ≥ 9, 32.29% had 5-8, 22.40% had 1-4, and 4.16% had none (data not shown).

The most frequent signs/symptoms of suffering perceived by family members during the last year of life were fatigue, chronic pain, anorexia, dyspnea, and falls; the least frequent were vomiting and fecal incontinence (Table 2). In the year before death, 97.40% of the older adults lived at home or with their children and 2.60% lived in nursing homes. More than half died at home, 41.66% in hospitals, and 2.60% in public places. According to the death certificates, the most cited causes of death were cardiovascular diseases, neoplasms, and respiratory diseases. Relatives reported that 29.63% died suddenly, more than half were hospitalized, admitted to the ICU, and received pain medication in the 12 months prior to death. Nearly 30% received home care (Table 3).

Regarding the relationship between frailty and perceived signs/symptoms of suffering in the year before death, compared to the non-frail group at baseline, the frail group had higher rates of dependency (prevalence ratio = 2.52; 95% CI 1.20-5.32) and pain medication use (prevalence ratio = 1.52; 95% CI 1.06-2.17) (Figure 1).

TABLE 2. Relative-reported suffering indicators among older adults in the 12 months before death (n = 192). Frailty in Older Brazilians (FIBRA) study. Campinas, SP and Ermelino Matarazzo, SP. Brazil, 2008-2009 and 2016-2017.

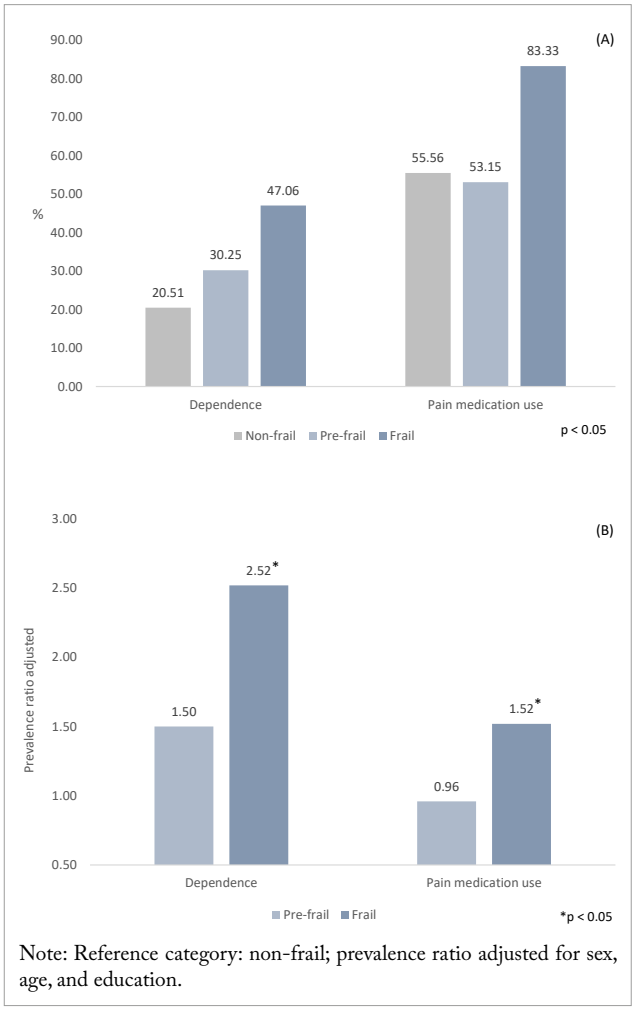
Variable*	n (%)	95% CI
Fatigue	96 (51.34)	43.93-58.70
Persistent pain for > 30 days	83 (43.68)	36.52-51.05
Anorexia	81 (42.63)	35.50-50.00
Shortness of breath (dyspnea)	78 (41.27)	34.17-48.64
Falls (≥ 1)	76 (40.21)	33.16-47.57
Urinary incontinence	67 (36.02)	29.13-43.37
Dependence	60 (31.25)	24.77-38.32
Bed confinement	59 (30.73)	24.29-37.78
Depression	54 (29.03)	22.62-36.12
Severe cognitive decline or dementia	51 (26.56)	20.46-33.40
Fecal incontinence	36 (19.46)	14.01-25.91
Vomiting	28 (14.74)	10.02-20.59

*Signs/symptoms of suffering were investigated using yes or no questions. 95% CI: 95% confidence interval.

TABLE 3. Circumstances of death and indicators of access to health services in the 12 months prior to death. Frailty in Older Brazilians (FIBRA) study. Campinas, SP and Ermelino Matarazzo, SP, Brazil, 2008-2009 and 2016-2017.

Variable	n (%)
Place of residence (n = 192)	
At their or their children's house	187 (97.40)
Nursing home or clinic	5 (2.60)
Place of death (n = 192)	
Residence	100 (52.10)
Hospital	80 (41.66)
Public place	5 (2.60)
Other*	7 (3.64)
Groups of causes of death recorded on death certificates (n = 105)	
IX. Diseases of the circulatory system	40 (38.10)
II. Neoplasms (tumors)	28 (26.67)
X. Diseases of the respiratory system	19 (18.10)
I. Some infectious and parasitic diseases	7 (6.66)
IV. Endocrine, nutritional, and metabolic diseases	3 (2.86)
XI. Diseases of the digestive system	3 (2.86)
VI. Diseases of the nervous system	2 (1.90)
XIV. Diseases of the genitourinary system	1 (0.95)
XIX. Injury, poisoning, and certain other consequences of external causes	1 (0.95)
XX. External causes of morbidity and mortality	1 (0.95)
Sudden death (n = 189)	
Yes	56 (29.63)
No	133 (70.37)
ICU admission immediately before death (n = 190)	
Yes	97 (51.05)
No	93 (48.95)
Home care (n = 188)	
Yes	51 (27.13)
No	137 (72.87)
Hospitalization (n = 192)	
Yes	101 (52.60)
No	91 (47.40)
Pain medication use (n = 177)	
Yes	104 (58.76)
No	73 (41.24)

*For-profit institution, workplace of children/other relatives, nursing home. ICU: intensive care unit. Some items were not answered by all interviewed family members.



Note: Reference category: non-frail; prevalence ratio adjusted for sex, age, and education.

FIGURE 1. Prevalence (A) and prevalence ratio (B) of distress indicators according to frailty status in the 12 months prior to death.

DISCUSSION

The main results of this study were that, in the last year of life, the most frequently reported signs/symptoms of suffering were fatigue, chronic pain, anorexia, dyspnea, and falls. Cardiovascular, neoplastic, and lung diseases stood out among the causes of death, and almost 30% died suddenly. More than 50% were admitted to an ICU, were hospitalized, and used pain medication, while less than 30% received home care. Those classified as frail at baseline had a higher rates of dependency and pain medication use in the last year of life than the non-frail group. The implications of these findings for the health system are relevant in view of the growing demand for care among the older adult population, the cost of care for families and health systems, and the decrease in family caregivers due to demographic, economic, and cultural reasons.

At baseline, a high proportion of the oldest old and the less educated already had heart disease (34.07%), some degree of frailty (approximately 80%), and were dependent in ≥ 1 IADL (45%). This is similar to the findings of other studies.[15,16] A longitudinal study (2014-2017) on all-cause mortality in community-dwelling older adults in Pelotas, RS, Brazil found that almost 10% of the participants died in about 2.5 years. The highest risk was associated with the following variables: male sex, age ≥ 80 years, being widowed, sedentarism, smoking, hospitalization, depression, and dependence in ≥ 2 ADLs.[15] Mortality data were collected from family members and confirmed through the municipality's epidemiological surveillance sector and family documents.[15] Among older adults treated at an outpatient clinic and followed-up over a 6-year period, frailty was associated with decreased survival, regardless of functional status or multimorbidity.[17] A 10-year cohort study found an association between disability in basic ADLs and mortality,[18] which was also found in a longitudinal study in Florianópolis, SC, Brazil.[16]

Regarding the sociodemographic characteristics of family members, in a study on informal caregivers of deceased older adults in the Butantã neighborhood in São Paulo, most interviewees were children (53.8%), spouses (27.5%), and women (87.5%),[7] corroborating the results of this study. In a U.S. study by Singer et al.[6], 44.8% of the respondents were children and 32.9% were spouses of the deceased.

In the present sample, the most commonly reported sign/symptoms of suffering in the 12 months before death were fatigue, persistent pain, anorexia, dyspnea, falls, and urinary incontinence. Those reported in a similar population-based survey in São Paulo were pain (78.4%), fatigue (68.0%), dyspnea (60.0%), depression (58.2%), anorexia (58.0%), and urinary incontinence (57.5%).[7] Pain, fatigue, and depression lasted for ≥ 6 months, and the most reported signs/symptoms of suffering in the last week of life were fatigue, urinary incontinence, anorexia, dyspnea, and pain.[7] An Irish study found that in the year before death, 50% of older adults felt pain regularly, 45.0% were depressed, and 41.0% had fallen in the last 2 years.[5] In a survey of family members or other proxies of deceased older adults in the United States from the Health and Retirement Study cohort (1998-2010), Singer et al.[6] found the following proportions of symptoms: anorexia (64.0%), fatigue (62.4%), pain (57.5%), dyspnea (52.6%), depression (51.4%), periodic confusion (47.9%), urinary incontinence (45.8%), and vomiting (11.8%).

Such data on the most common symptoms among older adults at the end of life are essential for palliative health care planning. In addition to these problems, in countries with high levels of inequality and poverty and low levels of education, repeated and uncontrollable adverse events due to natural or human causes must also be considered.[1]

Regarding the circumstances of death, almost all (97.40%) of the deceased lived at home in the last year of life, which was higher than the 80% found in Butantã, SP, Brazil.[7] More than half died at home, which differed from other surveys. In 2017, among a group of São Paulo state residents aged ≥ 65 years, 75.30% of deaths occurred in hospitals and only 15.90% occurred at home.[19] Solano et al.[7] found that 71% of the older adults in Butantã died in hospitals or emergency care units. In Ireland, 46% of the deaths occurred in hospitals, 27% at home, 11% in hospice care for the terminally ill, and 10% in nursing homes.[5] This same study found that the probability of dying at home was lower for those who lived alone (relative risk = 0.54; 95% CI 0.31-0.94) and higher for those with cancer (relative risk = 2.49; 95% CI 1.29-4.81) or who died after an acute illness (relative risk = 4.06; 95% CI 1.91-8.62).[5] Older people who live alone have less access to informal care,[5] which shows that household organization is an important indicator of social vulnerability.

The main causes of death among older residents of São Paulo state in the FIBRA study followed the same pattern as our study, ie, cardiovascular, neoplastic, and respiratory diseases, in that order,[19] although deaths due to cancer were approximately 10% higher than the overall statewide percentage in 2017 (26.70% vs. 17.60%).[19] This might have been due to the nature of the sample, ie, it was more robust epidemiologically, but sample losses were not corrected by criteria weighting, as in the present study.

The higher frequency of deaths from cardiovascular disease denotes their impact on the population's morbidity and mortality, especially ischemic heart and cerebrovascular diseases in older adults.[20] This also shows the importance of preventing risk factors in all age groups (smoking, obesity, sedentary lifestyle, and inadequate diet), early diagnosis, treatment and follow-up, as well as the timely use of technology. In the state of Santa Catarina, Rodrigues et al.[21] found that cardiovascular disease is one of the most significant primary care sensitive conditions in older adults, accounting for 49.5% of such hospitalizations.

Among older adults in the last year of life, Solano et al.[7] found that 67% received a home visit from the Family Health Program, 82.7% were hospitalized (median = 23 days), and

53% visited basic health units, averaging 6 doctor consultations. In Ireland, older adults had, on average, 2 hospital admissions, 5 outpatient appointments, and were visited 10 times by a general practitioner.[5,22] An Australian study investigated patterns of hospital use among older adults in the last year of life,[23] finding that 82% had been hospitalized, 79% had been to the emergency room at least once, and 9% had been admitted to the ICU. This study found that 55% died in a hospital environment and that the main causes of death were diseases of the circulatory system (39%), cancer (25%), diseases of the respiratory system (9%) and dementia (5%).[23] That is, multimorbidity led to increased health service use by older adults, especially the oldest old, being reflected in more consultations, disabilities, and hospitalizations.[24] Mortality among individuals admitted to an ICU is associated with disease severity and functional status prior to admission.[23]

Among participants in the Irish Longitudinal Study on Ageing, 15% died suddenly.[22] In the U.S., Singer et al.,[6] found a sudden death prevalence of 15.7%, which was significantly associated with periodic confusion and dyspnea. The close relationship between hospitalization and vulnerability, limited autonomy, and post-hospital cognitive decline should be considered.[24] Thus, hospitalization should only occur when the resources of lower health care levels have been exhausted.[21]

In the present study, older adults who were frail at baseline had a higher rate of dependence and pain medication use in the last year of life. The Health, Well-Being and Aging (*SABE*) study demonstrated an association between frailty and age, functional impairment, cognitive decline, hospitalization, and multimorbidity. It was found that 39.8% of frail older adults died within four years.[25] A cross-sectional study of older adults monitored by the Family Health Strategy found significant associations between frailty and polypharmacy, multiple pathologies, mental disorders, cognitive impairment, ADL impairment, falls, hospitalization, and urinary incontinence.[26] These results show the relevance of investing in frailty prevention and recovery among older adults to mitigate adverse effects.

The need for end of life care is not uniform among older adults, since aging is not necessarily synonymous with illness or loss of autonomy. However, for many in this population, who, in addition to illness have suffered from a lack of opportunity over the years, palliative care in can be important for increasing quality of life and mitigating suffering[27] for both patients and their families when faced with a chronic illness or life-threatening condition.

Significant increases have been predicted worldwide for the number of people suffering from chronic diseases, which often require palliative care: from approximately 26 million in 2016 to 48 million in 2060 (an 87% increase).[1] This situation is expected to be even more dramatic in low- and middle-income countries, where there are health care shortages and inequalities.[1] It is estimated that in the coming decades, 83% of deaths preceded by suffering will occur in these countries.[1] Given such a scenario, health professionals and students must be trained in palliative care.[28,29] Palliative care is among the most neglected areas of health systems[30] and health training courses,[28,29] and requires urgent development in the Brazilian Unified Health System's primary care division[31] since it is linked to a person's right to die with dignity.

This study analyzed suffering in the last year of life of older adults as reported by family members (some of whom themselves are at an advanced age), contributing data to a topic that is poorly studied in Brazil. Although the older adults were generally free of cognitive impairment indicative of dementia at baseline (77% of the sample), this should not be considered a methodological limitation but an inherent characteristic of the data. Nevertheless, because the sample was likely to be better off physically and cognitively, selection bias may have been involved, which might be associated with the higher proportion of those who died at home compared to other studies.

Memory bias may have been a methodological limitation, since the events preceding death could have occurred up to 10 years prior to the interview. Furthermore, the reports of relatives may not accurately reflect what the deceased really experienced, given that some people hide the presence, intensity, and impact of pain and suffering to spare their families. The small sample size impedes broad generalizations about the findings and a more detailed investigation of the relationships between variables.

CONCLUSIONS

This study presents data on older adults who died between 2008 and 2017, including sociodemographic characteristics, the circumstances of death, health service use, and suffering in the last year of life. Higher rates of fatigue, chronic pain, anorexia, dyspnea, and falls were the main signs/symptoms of suffering reported by family members. The main causes of death were cardiovascular disease, cancer, and pulmonary disease. ICU admission, hospitalization, and pain medication use were all frequent. There was a lower proportion of home care among health service indicators. Baseline frailty

was associated with dependence and pain medication use in the last year of life.

These findings are indicative of an end-of-life care shortage and highlight the need to alleviate the suffering of older adults. Public policies should provide guidance and support to family caregivers, prepare and support informal caregivers, offer technical training for professionals who care for older adults, and organize and expand health service access to meet the demands of the aging population. The pronounced increase in the oldest old population underscores the need for palliative care and training to deal with death and suffering at the end of life.

Conflicts of interest

The authors declare no conflicts of interest.

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Author contributions

DA: formal analysis, writing – original draft, writing – review & editing, methodology. PMSBF: formal analysis, writing – original draft, writing – review & editing, methodology. GAS: writing – original draft, investigation. RC: writing – original draft, investigation. LPS: writing – original draft, investigation. ALN: project administration, writing – original draft, writing – review & editing, investigation, methodology, funding acquisition, supervision.

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