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Adverse events with social or economic impact in patients with dementia attended at a neurology outpatient clinic - Prevalence study in the five years prior to diagnosis

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economic impact in patients with
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the five years prior to diagnosis**

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***“ Vivemos da memória, que é a imaginação do que morreu;
da esperança, que é a confiança no que não existe;
do sonho, que é a visão do que não pode existir”***

Fernando Pessoa

This study is neither the beginning nor the end. It began 13 years ago, in neurology class in my medical school with my dear professor, Dr. Rodrigo Rizek Schultz. His brilliant classes and his dedication to dementia patients inspired me and initiated my interest in dementia, not only in clinical aspects but in social, economic, and legal subjects. Since then, I have studied these issues.

I expect this work may be a bridge for in-depth research concerning the social and the economic aspects of dementia. I hope this study will improve the quality of life of dementia patients, their families, and their caregivers.

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ABSTRACT

Background: In 2018, 50 million people lived with dementia in the world and projections indicate that by 2050, 152 million people will be affected by the disease. Financial costs may reach two trillion in 2030, and they will be greatly supported by the patients and their families. Besides these significant economic numbers, the onset of dementia usually corresponds to a slowly progressive process of losing capacity, making the initial symptoms difficult for patients and family members to recognize. Therefore, it is common for initial diagnosis to occur after a sentinel event or only after a series of adverse events with a social or economic impact those surprises patients and their families and force them to seek specific care. This context raises the importance of researching these possible adverse events that occur before dementia diagnosis.

Objectives: To investigate the prevalence of events with social or economic implications for the patient or caregivers and other third parties potentially related to dementia disease in the 5-year period preceding the diagnosis of dementia.

Methods: 59 participants were recruited from the neurologic outpatient clinic of Pedro Hispano Hospital in Porto. The participants and their caregivers answered a standardized survey about relevant events and signs related with dementia that they had observed in the last 5 years before the dementia diagnosis. Approximately one week after the questionnaire interview, calls were made to the caregivers to find out any other events that had not been reported in the questionnaire. Furthermore, hospital admissions, emergency and urgency episodes or other consultations with specialists were investigated in search for relevant events in the 5 years before the dementia diagnosis that might not have been informed by the patient and family.

Results: The main results found were: the mean age of participants was 78.85 years (SD 7.61) and women were the majority of the sample 43 (72.9%). The main diagnosis found was AD (Alzheimer's Disease) with 33 patients and 55% of the sample. Mixed type dementia (MD) was the second most prevalent diagnosis (10.2%), and the third was vascular dementia (VaD) (8.5%). The MCI (Mild Cognitive Impairment) prevalence found was 8.5%. The most prevalent events found were BPSD (Behavioral Psychological Symptoms of Dementia) with 84.7%. Medication errors on self-Administration presented 69.5% of prevalence. Impaired financial capacity presented 67.5% of prevalence. Falls showed a prevalence of 62.7%. Most participants, 31 (52.5%), reported that the first symptoms appeared 1 to 3 years before the interview.

Conclusion: Firstly, our results suggest that caregivers and family patients can be subject to social burden and stress before dementias were identified due to a high prevalence of behavioral and psychological symptoms. With an early diagnosis and appropriate treatments, some relevant events could be avoided. Secondly, we have noted that a significant prevalence of medication errors is dangerous for patients and a cause of concern for caregivers. Thirdly, the resulting impaired financial capacity can lead to economic impact, sometimes disastrous for patients and their families. Besides, the high prevalence of high impact events found years before the diagnosis emphasizes the importance of establishing public health policies in order to educate family members on the importance of seeking a specialized evaluation of the elderly who presented the first symptoms of the disease.

Acronym

Key-words: dementia; social and economic impact; mild cognitive impairment

RESUMO

Contexto: Em 2018, 50 milhões de pessoas viviam com demência no mundo e as projeções indicam que até 2050, 152 milhões de pessoas serão afetadas pela doença. Os custos financeiros podem chegar a dois trilhões em 2030 e serão amplamente sustentados pelos pacientes e suas famílias. Além desses números económicos significativos, o início da demência geralmente corresponde a um processo lentamente progressivo de perda de capacidade, tornando os sintomas iniciais difíceis de serem reconhecidos pelos pacientes e familiares. Portanto, é comum que o diagnóstico inicial ocorra após um evento sentinela ou apenas após uma série de eventos adversos com impacto social ou económico que surpreendem os pacientes e seus familiares e os obrigam a buscar atendimento específico. Esse contexto levanta a importância da pesquisa desses possíveis eventos adversos que ocorrem antes do diagnóstico da demência.

Objetivos: Investigar a prevalência de eventos com implicações sociais ou económicas para o paciente ou cuidadores e outros terceiros potencialmente relacionados à doença demencial no período de 5 anos anterior ao diagnóstico de demência.

Métodos: 59 participantes foram recrutados no ambulatório de neurologia do Hospital Pedro Hispano, no Porto. Os participantes e seus cuidadores responderam a uma pesquisa padronizada sobre eventos e sinais relevantes relacionados à demência que haviam observado nos últimos 5 anos antes do diagnóstico de demência. Aproximadamente uma semana após a entrevista do questionário, foram feitas ligações para os cuidadores para saber de quaisquer outros eventos não relatados no questionário. Além disso, foram investigadas internações hospitalares, episódios de emergência e urgência ou outras consultas com especialistas em busca de eventos relevantes nos 5 anos anteriores ao diagnóstico de demência que possam não ter sido informados pelo paciente e familiares.

Resultados: a média de idade dos participantes foi de 78,85 anos (DP 7,61) e as mulheres constituíram a maioria da amostra 43 (72,9%). O principal diagnóstico foi DA (Doença de Alzheimer) encontrado em 33 pacientes e 55% da amostra. Demência mista (DM) foi o segundo diagnóstico mais prevalente (10,2%), e o terceiro foi Demência vascular (VaD) (8,5%). A prevalência de CCL (comprometimento cognitivo leve) encontrada foi de 8,5%. Os eventos mais prevalentes encontrado foram SCPD (sintomas comportamentais e psicológicos da demência) com 84,7%. Os erros de medicação na autoadministração apresentaram 69,5% de prevalência. A capacidade financeira prejudicada apresentou 67,5% de prevalência. As quedas apresentaram prevalência de 62,7%. A maioria dos participantes, 31 (52,5%), relatou que os primeiros sintomas apareceram 1 a 3 anos antes da entrevista.

Conclusão: Em primeiro lugar os nossos resultados sugerem que os cuidadores e os familiares de pacientes dementes podem estar sujeitos a carga social e estresse antes que as demências sejam identificadas, devido a uma alta prevalência de alterações comportamentais e psicológicas. Esses sintomas, com um diagnóstico precoce e tratamentos adequados, poderiam ser evitados. Em segundo lugar, observamos que uma prevalência significativa de erros de medicação é perigosa para os pacientes e causa preocupação para os cuidadores. Em terceiro lugar, a capacidade financeira prejudicada resultante pode levar a um impacto económico, às vezes desastroso para os pacientes e suas famílias. Além disso, a alta prevalência de eventos de alto impacto encontrada anos antes do diagnóstico enfatiza a importância do estabelecimento de políticas públicas de saúde, a fim de consciencializar os familiares sobre a importância de buscar uma avaliação especializada dos idosos que apresentaram os primeiros sintomas da doença.

Acrónimo

Palavras-chave: demência; impacto social e económico; comprometimento cognitivo leve

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Abbreviations

AD – Alzheimer’s Disease

AIDS – Acquired immune deficiency syndrome

BPSD – Behavioral psychological symptoms in dementia

CJD – Creutzfeld- Jakob’s disease

COVID-19 – Coronavirus Disease - 2019

DLB – Dementia with Lewy bodies

DSM – Manual of Mental Disorders

FTD – Frontotemporal dementia

GPD – Gross Domestic Product

HPH – Hospital Pedro Hispano

HD - Huntington's disease

IADL - Instrumental activity of daily living

IFC – Impaired financial capacity

MCI – Mild Cognitive Impairment

MD – Mixed type dementia

ME – Medication errors

MMSE – Mini Mental State Examination

LIO – Loss of important objects

OECD – Organization for economic cooperation and development

PDD – Parkinson’s disease dementia

RTA – Road traffic accident

SN – Self-Neglect

SPSS – Statistical Package for the Social Sciences

STROBE - STrengthening the Reporting of OBServational studies in Epidemiology

UHI – Unintentional home injuries

USA – United States of America

VaD – Vascular disease

WHO – World Health Organization

Part I – Introduction

1. Problem Definition

The rising number of people with dementia has become a serious public health issue. According to the World Health Organization (WHO), in 2015, approximately 47 million people worldwide were diagnosed with dementia (1). Projections indicate that the disease would affect 152 million by 2050 (2). Besides, the number of people living with dementia in the OECD (Organization for Economic Cooperation and Development) countries increased by approximately 2.5 million between 2013 and 2018, while the mortality attributed to Alzheimer's disease and other dementias rose by more than 50% in some countries covered by OECD (3).

Furthermore, dementia is a significant cause of hospital admissions, hospitalizations and institutionalization, and studies found that 2/3 of institutionalized elderly have dementia (4)(5). According to WHO dementia is now the 5th leading cause of death. Currently, a new study verified that elderly with dementia have died disproportionately in the severe acute respiratory syndrome coronavirus 2 - COVID-19 pandemic (6).

In 2015, the global cost of dementia was estimated at \$ 818 billion, equivalent to 1.1% of the world's Gross Domestic Product (GDP), ranging from 0.2% in low and middle-income countries to 1.4% in countries with high income (1). In the same year, nearly 85% of these costs were related to family and social rather than due to medical care (7). In 2018 the global cost increased, estimated at \$1 trillion annually (8). However, these numbers will be much higher in the coming years because it is estimated that in 2030 this cost will reach \$ 2 trillion (1)(2).

Portugal is the 3rd country with most cases of dementia in Europe and the 4th among the OECD countries: the first three countries most affected are respectively: Japan, Italy, and Germany(9). A study in the North of Portugal established prevalence rates of 2.7% for dementia in individuals older than 55 years old (10).

Considering the statistics above, it's clear that Portugal has been suffering the social consequences of dementia, and the society and health care system have to deal with the daily difficulties of taking care and supporting this population.

Besides, all through the progression of dementia, the dependence and incapacity rise, and life quality declines (7)(11). Due to difficulties in managing finances, medications, shopping,

and in advanced levels of the disease: hygiene, dressing, eating, bathing, and other basic activities, a caregiver becomes necessary (12).

The other side of the progression of dementia is a social problem in which we found caregivers frequently stressed and depressed as result of the high burden that they bear (13)(14).

In addition, the onset of dementia usually corresponds to a slowly progressive process of this loss of capacity, making the initial symptoms difficult for patients and family members to recognize. Therefore, it is common for initial diagnosis to occur after a sentinel event or only after a series of adverse events with a social or economic impact those surprises patients and their families and force them to seek specific care.

In this context, analyze the prevalence of these events is essential: a) to know better what are these events, when they arise, if the impact of these events touches a specific population, and how to help the patients, their families, and the caregivers avoid these harmful impacts of the disease and; b) to establish public policies in order to reduce the adverse impact of these events.

2. Concept of dementia and epidemiology

Regarding the concept of dementia, we could say that dementia has several facets.

Etymologically, the term dementia derives from the Latin words "*demens*" which means: "de" (out of) and "*mens*" (mind) (7).

Gale SA et al. conceptualizes dementia as "any disorder where significant decline from one's previous level of cognition causes interference in occupational, domestic, or social functioning. Generally, the term dementia should be considered to be an acquired syndrome, with multiple possible causes, rather than a specific disease itself" (15).

Manual of Mental Disorders (DSM) in its latest version - 5th. Edition - abandoned the use of the term dementia, treating dementias as major or mild neurocognitive disorders (16), where dementia is deemed the major disorder.

According to DSM-5, it is considered **major neurocognitive disorder**:

"A. Evidence of significant cognitive decline in relation to a previous level of performance in one or more cognitive domains (complex attention, executive functions, learning and memory, language, motor perceptual capacity or social cognition) based on the following:

1. Concern of the individual, a knowledgeable informant or the clinician that there is a significant decline in cognitive function; and

2. A substantial deficit in cognitive performance, preferably documented by standardized neuropsychological tests or, in its absence, by another quantitative clinical assessment.

B. Cognitive deficits interfere with the independent performance of activities of daily life (that is, at least you need assistance with complex instrumental activities of daily life such as paying bills or managing medication).

C. Cognitive deficits do not occur exclusively in the context of delirium.

D. Cognitive deficits are no longer better explained by another mental disorder (e.g. major depressive disorder, schizophrenia)".

Besides, it's essential to notice another important concept of the cognitive decline: **Mild Cognitive Impairment (MCI). Dementia and MCI** are syndromes, and the key distinction between them is the severity of the cognitive impairment, and the reflex in the functional consequences. Mild Cognitive Impairment is an intermediate stage between cognitive function and dementia (17). In dementia, the cognitive decline is progressive, and it affects daily life activities and social functioning, differently from MCI where individuals continue an independent life (7). If dementia can be considered as a major neurocognitive disorder, MCI can be regarded as mild neurocognitive Disorder in DSM-5.

Concerning DSM-5, **Mild Neurocognitive Disorder** is conceptualized:

"A. Evidence of modest cognitive decline in relation to a previous level of performance in one or more cognitive domains (complex attention, executive functions, learning and memory, language, perceptual motor ability or social cognition) based on the following:

1. Concerning the individual, a knowledgeable informant or the clinic stating that there is a slight decline in cognitive function; and

2. A modest deficit in cognitive performance, preferably documented by standardized neuropsychological tests or, in their absence, by another quantitative clinical assessment.

B. Cognitive deficits do not interfere with the independent performance of activities of daily life (that is, complex instrumental activities of daily life such as paying bills or managing medication are preserved, but may require greater effort, the use of compensation strategies or adjustment).

C. Cognitive deficits do not occur exclusively in the context of delirium.

D. Cognitive deficits are no longer better explained by another mental disorder (e.g. major depressive disorder, schizophrenia)".

There are many different etiology subtypes of dementia, such as Alzheimer's disease, vascular dementia, Lewy bodies dementia, mixed type dementia, frontotemporal degeneration, dementias associated with brain injury, infections, and alcohol abuse (18). The dementia subtypes have characteristics, progression and specific treatments.

Moreover, there is a traditional classification of dementias: **progressive and irreversible degenerative** dementias (neurodegenerative dementias), as well as dementias resulting from a **progressive, but potentially reversible process of secondary origin**, called potentially reversible dementias (non-neurodegenerative dementias) (15)(19).

Maletta GJ, used the denomination **primary dementia** for designated neurodegenerative disease and **secondary dementia** for non-neurodegenerative disease, and he considered the secondary ones generally reversible (20).

Table 01. Neurodegenerative vs Non-Neurodegenerative Dementias (20)

Neurodegenerative Dementia	Non - Neurodegenerative Dementia
1. Alzheimer's disease (AD)	1. Structural Lesions
2. Vascular dementia (VaD)	2. Nutritional deficiencies such as vitamin B12 deficiency, folate deficiency, niacin and thiamin deficiency
3. Dementia with Lewy bodies (DLB)	3. Endocrine disease such as hypothyroidism, hyperthyroidism, adrenal and pituitary gland, diseases, and insulinoma
4. Frontotemporal dementia (FTD)	4. Vascular disease and collagenases such as systemic lupus erythematosus vasculitis, and sarcoidosis
5. Huntington's disease (HD)	5. Infectious diseases such as meningitis, cerebral abscesses, neurosyphilis, Whipple's disease, Lyme disease and AIDS
6. Creutzfeldt-Jakob's disease (CJD)	6. Alcoholic dementia and other disease such as chronic obstructive respiratory disease, sleep apnea syndrome, sleep deprivation, limbic encephalitis, radiation, hypoxia, and dialysis
	7. Exogenous poisoning and metabolic diseases, such as drug poisoning, hydro electrolytic changes and chemical poisoning
	8. Cognitive disorders due to psychiatric diseases, particularly depression and late-onset schizophrenia

In our study we just analyzed the progressive and irreversible degenerative dementia (neurodegenerative dementia) cases.

Regarding the epidemiology of dementia, it differs from the region under study. Globally, Alzheimer's disease is the most common etiology of dementia, and vascular dementia is the second one (2)(21).

Similarly, the leading cause of dementia in Europe is Alzheimer's disease. However, a recent study showed a higher prevalence of vascular dementia in Portugal, with 52.8% of the cases, followed by Alzheimer's disease (36.1%) (22).

3. State of the art

Dementia is a syndrome with many signals and symptoms that could originate undesirable events with many social, economic and legal consequences.

According to *Barbas et al.* "the patient with a degenerative dementia experiences the gradual and progressive impairment of multiple abilities, which may interfere with his or her competence in a number of realms, including medical or legal decision making, driving, and independent living. Patients progress from independent to fully dependent individuals whose abilities and autonomy are inevitably threatened. This is further complicated by the grave concerns of families and caregivers regarding the patient's safety as they observe their loved one's progressive loss of skills, judgment, and memory" (23).

Gagnon et al. explain that patients with cognitive impairment often present judgmental errors and self-neglect behaviors, which may put them at a higher risk of various avoidable injuries (e.g., burning themselves while cooking due to forgetting to turn off electrical appliances, poisoning after eating spoiled food in the refrigerator, falls caused by failure to use walking aids)(24).

Also, in this progressive degenerative cognitive decline, the patients perform activities, give rise to situations that can provoke social and economic consequences for themselves and others.

Below there are some of the main undesirable events with social or economic impacts described by literature could occur in the disease course:

Table 02. Events, signs and symptoms describe by literature

Events described by literature
1. Falls (25),(26),(27),(28)
2. Road traffic accidents (29),(30),(31),(32),(33),(34)
3. Unintentional home incidents (35),(36),(24)
4. Impaired financial capacity (37),(38),(39),(40),(41),(42),(43),(44),(45)
5. Medication errors (self-administration) (46),(47),(35),(48),(49)
6. Behavioral and psychological symptoms in dementia (50)(51)(52),(53)
7. Self-neglect (54),(55)
8. Memory decline (56)(57),(15)

3.1. Falls

The literature describes that falls are the most frequent nonfatal injury and the second most common fatal injury at home. Falls arise as the principal type of incident among older adults, whether associated with an emergency presentation and use of medical services or not (30%– 80%) and as the main cause of the damage (24)(36). The economic burden of falls among older adults is substantial, costing approximately \$34 billion in direct medical costs annually (36). In Portugal, the prevalence of falls in 2017 among elderly over 70 years old was 21.87% (58).

Any cognitive impairment has been identified as a risk factor for falls in aging, and several studies deem falls the principal incident among older adults with cognitive impairment (28)(56)(57)(59). The prevalence of falls in the MCI population in the *GOOD Study* was 31%, and 55% in dementia (26). Another similar study found 41% prevalence falls in mild dementia and 46% in moderate dementia (60). When comparing older adults with and without cognitive impairment, the latter were hospitalized more often due to falls (around 19%) than the general senior population (14% of total hospitalizations) (24).

In 2009 a study found that during the 12-month follow-up period, 65.7% of participants with dementia had at least one fall, compared with 35.9% of controls. The same study found that patients with DLB or PDD were at the highest risk, with DLB patients sustaining 6 times the number of falls in the control group and PDD 20 times more falls (27).

The studies described above demonstrated that the progression of cognitive impairment increases the risk of falls, even when disease severity is mild.

3.2. Road traffic accidents (RTA)

According to a current and global review, the profile of cognitively healthy elderly persons suffering traffic accidents was: between 60 and 69 years old, male, married, with low schooling, and professionally active (30). Pedestrians were the most vulnerable, with a predominance of being knocked down. The accidents occurred most often during the day, and traumatic brain injury was the most frequent damage (30).

In Portugal the prevalence of road injuries in 2017 among elderly over 70 years old was 6.41% (61).

Several studies tried to analyze the relationship between cognitive impairment and crash road accidents (31)(32)(62)(63). Moreover, the association of driving cessation with a decline of cognition was studied (34). Although cognitive impairment had been previously associated with higher crash risk, the strength and significance of the association differ between studies.

Duchek et al. in a longitudinal study to assess on-road driving performance in healthy older adults and those with early-stage dementia of Alzheimer type, found that there was a decline in driving performance especially in the mild Alzheimer disease group. This study submitted all participants to a 45-minute in traffic road test along a predetermined route (62).

Conversely, Laura A. Fraade-Blanar et al. did not depicted the same results, because they did not find a strong association between crash risk and cognitive impairment (31). In the same way Petersen JD et al. in a case-control study found that non-institutionalized older people with dementia in Denmark have a lower risk of road traffic accidents, and they suggested that it might be due to less frequent activities not at home (63).

3.3. Unintentional home injuries (UHI)

According to *Gagnon-Roy et al.* incidents were defined as physical injuries to the driver himself or to others, property loss or property damage. More precisely, avoidable incidents referred to traumatic injuries (e.g., hip, wrist), poisoning (e.g., inadvertent medication overdose, biological substances) and some other consequences of external causes (e.g., frostbite, burn, "heat stroke")(24).

In 2013 in the USA, fire and burn deaths ranked as the sixth leading cause of injury death among 65 year adults and older (36).

In Portugal, the prevalent cases of fire, heat and hot substances in 2017 among elderly over 70 years old was 2.12% (64).

Regarding burns, *Gagnon-Roy et al.* found that they emerged as the third cause of emergency department visits following an incident (2%–3%), and the third cause of home injuries. Burns in cognitively impaired seniors were reported to cause more morbidity and mortality (25%) than in the general senior population (13.8%)(24).

Despite this, *Douglas A. et al.* found that morbidity and mortality in the elderly population are low for injury from fires/burns, wandering, or medication self-administration, and in persons with dementia trends in the data indicated that morbidity and mortality is slightly higher in wandering and medication self-administration, but not burns (35).

3.4. Impaired financial capacity (IFC)

According to *Widera E et al.* “financial capacity is the ability to manage money and financial assets in ways that meet a person’s needs and are consistent with his/her values and self-interest, and essential for an individual to function independently in our society” (37).

Marson DC et al. explained that financial capacity comprises a broad range of conceptual, pragmatic and judgmental abilities necessary to older adults’ independent functioning and is an “advanced” activity in daily life (37). From a clinical standpoint, financial capacity is a highly cognitive mediated capacity vulnerable to neurological, psychiatric, and medical conditions that affect cognition such as dementia, stroke, traumatic brain injury and schizophrenia (40).

In a prospective study cohort with older adults, *Bleijenberg N et al.* depict that the adjusted incidence of difficulty managing finances increased substantially with age, ranging from 23.1% (95% CI 21.6–24.7) in those aged 65–69 to 69% (95% CI 63.7–74.3) in those over age 85 (43). These reports of worsening with aging in the absence of cognitive impairment, may suggest that in dementia, the situation can be worse.

Chiong W et al., in their study, found that financial impairments (of any type) were commonly reported in dementia, and in many cases, they were early indicators of cognitive decline (72% of AD and 84% of bvFTD charts included some report of financial impairment)(65). Other studies found similar results (37)(66)(67).

In addition, financial capacity has been found impaired in MCI. In a six-year longitudinal study on financial capacity in Mild Cognitive Impairment, *Martin R.C. et al.* found that persons with MCI have significant decline in multiple financial skills and in particular

financial judgment (45). *Lindsay MN et al.* found a similar result in a two-year follow-up study with individuals with MCI (68).

3.5. Medication errors in self-administration (ME)

In a broad sense, a medication error is defined as the failure of a planned action to be completed as intended (i.e., error of execution) or the use of a wrong plan to achieve an aim (i.e., error of planning)(69).

A systematic review study of patient medication error on self-administering medication at home found that the frequency of this errors was between 19% and 59%. The most common mistakes were incorrect dosage, forgetting, mixing up medication, failing to recall indications, and taking out of date or inappropriately stored drugs (70).

In a prospective study cohort with older adults, *Bleijenberg N et al.* reported that 15.2% of the participants developed difficulty in dealing with medications, and concluded that among 85-year-olds with no difficulty at baseline, ten years later, nearly half (40%) will present some difficulty in taking medication (43).

Several studies describe difficulties to manage medications in cognitive impairment and dementia (48)(71)(72), given that impaired cognition may reduce memory and cognitive domain (language, visuospatial, executive function), and decrease of cognitive ability can result in confusion and lack of insight which in turn leads to risks of experiencing medication errors (underdose, overdose, wrong drug), or unintentional non-adherence (71).

In a Chinese community-dwelling older adults study, the clinicians deemed a significant proportion of patients with mild AD (42.1%) but not patients with MCI or normal controls mentally incompetent to decide on their own medication management. The study found that mild AD patients' results were also worse (73).

3.6. Abnormal Social Behavior - Behavioral and psychological symptoms in dementia (BPSD)

There is a significant prevalence of mental disorders among the elderly. A cross-sectional database study performed in Europe found a prevalence of 19.1% of mental disorders among the elderly (74).

In Portugal, the prevalence of mental disorders in 2017 among the elderly over 70-years-old was 14.6% (75). Sometimes these mental disorders are the first sign of dementia, and

they can obscure or confuse the correct diagnosis, delaying proper dementia treatment (76).

Neuropsychiatric symptoms are a major problem in cognitive impairment and may occur in 35-85% of MCI patients (77). The studies found that in dementia, the symptoms can occur in 80-90% of patients (51). Indeed, neuropsychiatric symptoms generally increase during the disease (51)(78)(52). In addition to the impairment of patients, neuropsychiatric symptoms are associated with an increase in the burden of caregivers (7)(79)(80).

In a two-year prospective study, *Aalten et al.* found that the most common neuropsychiatric symptoms were apathy (78%) and depression (57%). These results were also found in other studies (52)(81)(82).

3.7. Self-neglect (SN)

Self-neglect in older adults is increasingly prevalent, crossing both the medical and social domains, and it has public health implications (54).

Following *Pavlou M. et al.*, a "self-neglector is a person who exhibits ≥ 1 of the following: 1) Persistent inattention to personal hygiene and/or environment; 2) Repeated refusal of some/all indicated services which can reasonably be expected to improve the person's life quality; 3) Self-endangerment through the manifestation of unsafe behaviors".

The association between dementia and self-neglect is known because there is a high correlation between impaired memory and judgment, which would create an ideal environment for it to occur. Studies indicate that owing to this correlation, patients with dementia invariably develop progressive inability to self-care, emphasizing that cognitive impairment is the most important predisposing factor for self-neglect among the elderly (54)(83).

According to a prospective population-based study realized in Chicago with an elderly population, the decline in the global cognitive function is associated with increased risk of greater self-neglect severity (55).

3.8. Loss of important objects (LIO)

In a longitudinal study on symptoms at initial presentation in patients with Mild Cognitive Impairment (MCI), loss of memory was reported by informants as the first symptom in 80% of the cases, demonstrating that it is a precocious and relevant symptom (53).

Similarly, in a case-control study on prodromal dementia symptoms, the main results were a lack of memory complaints and depression symptoms (84). Regarding other studies about

dementia, loss of memory was reported among the first symptoms by patients diagnosed with Alzheimer's disease (AD) (56)(57).

This damage of memory can result in the loss of essential and valuable objects. However, no statistical data were found in the literature regarding the prevalence or the incidence of these lost in the progress of dementia.

Part II – objectives and methods

1. Objectives of the study

The main objective is conducting an observational prevalence study of events with social or economic implications for the patient, caregivers, and other third parties potentially related to dementia disease. Other objectives are to ascertain the prevalence of these events concerning participants' sociodemographic characteristics and with the different diagnosis of dementia.

The study is limited to the 5-year period preceding the diagnosis of dementia and focused on serious, but preventable events through the implementation of earlier pharmacological and non-pharmacological interventions.

The targeted events found in the literature and object of this study are described below (Table 03):

Table 03. Events

Domains		Definitions	Events Investigated
Road traffic accidents (RTA)		Events involving a moving vehicle and resulting in victims or material damage (62)(31)(63)	Car; motorcycle; bicycle; pedestrian accidents
Falls		Tinetti, 1988, fall is "an event which results in a person coming to fall unintentionally on the ground or other lower level, not as a result of a major intrinsic event (such as stroke) or overwhelming hazard" (25)	Falls
Unintentional home injuries (UI)		Physical injuries to self or others, property loss or property damage at home	Poisonings, fires, burns
Impaired financial capacity (IFC)		Financial capacity, is "the ability to independently manage money and financial assets in a manner consistent with personal self-interest and values" (40)	Inability to recognize or count coins; no-payment of bills or rentals; confusions in bank account management; mistaken purchases; unusual withdrawals or donations; scams
Medication errors (self-administration)		The United State National Coordinating Council for Medication Error Reporting and Prevention defines a medication error as: "any preventable event that may cause or lead to inappropriate medication use or patient harm while the medication is in the control of the health care professional, patient, or consumer" (85)	Drugs errors; dose errors; frequency errors (self-administration)
Behavioral and psychological symptoms in dementia (BPSD)		Behavior with signs of psychological or psychiatric changes with social implication (except mood symptoms)(50)(51)(52)(86)	Delusions; hallucinations; agitation/aggressions, disinhibition; irritability; motor disturbance/wanderings; sleep disturbances; eating disturbances
Self-neglect (SN)		A self-neglector is a person who exhibits ≥ 1 of the following: 1) Persistent inattention to personal hygiene and/or environment; 2) Repeated refusal of some/all indicated services which can reasonably be expected to improve quality of life; 3) Self-endangerment through the manifestation of unsafe behaviors (54)	Consciously neglecting chronic medical problems; unexplained lapses in recommended health maintenance activities; lack of personal hygiene; disheveled appearance (54)
Loss of Important Objects (LIO)		Loss of important or valuable objects that result in injury to the patient or third parties	Loss of important or valuable objects

Mood disorders were not included in the behavioral and psychological domains because there is a debate about whether depression is a prodromal symptom or an independent risk factor for dementia, and it is a widespread diagnosis in the elderly that can occur for many years before the onset dementia (6)(7)(81)(87).

2. Methods

This is an observational study of prevalence, based on standard questionnaires elaborated by the researcher.

This study is reported as per the “Strengthening the Reporting of Observational Studies in Epidemiology” guideline (STROBE Checklist- Appendix 01).

Patients were selected from the neurology service users at the outpatient clinic of Hospital Pedro Hispano, Matosinhos Local Health Unit – Portugal.

The researcher contacted the study participants shortly after their regular consultations at the neurology service. The neurologist who attended the patient identified the individuals who had the eligibility criterion to participate in this study just after the consultation. When the patient agreed to participate in the study, he/she was referred to the investigator to answer the questionnaire after his/her neurological consultation.

At the moment of the interview survey, all participants had the neurological diagnosis and MMSE score.

Approximately one week after the face-to-face questionnaire, the researcher called to participants to find out if any other events that had not been reported in the initial questionnaire were recognized after a family discussion about the study.

The researcher investigated hospital admissions to Hospital Pedro Hispano, emergency services episodes, or other consultations with specialists searching for relevant events in the last five years.

2.1 The questionnaire

The researcher prepared a standardized survey (Appendix 1) considering all events defined in Table 03. It has direct and straightforward questions, chosen due to possible social and economic difficulties associated with dementia. For each question, there were three possible, and standardized answers: yes, no and, I don't remember. The researcher also questioned how many times the events happened (Appendix 2) and if they did not occur before those five years. When the patient or caregiver answered that the symptom had already appeared more than five years before, the response was considered negative to minimize possible information bias.

The interviewer read the questions to the patient and the caretaker, and both could answer.

The survey had two distinct parts. First was the socio-demographic and clinical data. In this part, the patients were identified just by their names' initial letters. In the second part, there were questions about the events, and this part was unidentifiable.

The survey was evaluated and approved by the ethics committee of Hospital Pedro Hispano.

2.2. Criteria for participation in the study:

The study selected patients according to the eligibility and exclusion criteria presented below.

a. The inclusion criteria:

- a) Initial diagnosis of dementia or mild cognitive impairment.
- b) Presence of a caretaker/caregiver responsible for the patient on the date of the interview.
- c) Providing complete data of the patient and his/ her caretaker/caregiver.

b. The exclusion criteria:

- a) Reversible dementias.
- b) Diagnosis of any psychiatric pathology before dementia, except depression.
- c) Serious visual or hearing impairment.
- d) Patients or caregivers who do not express a written desire to participate in the study.

2.3. Ethics and Protection of Personal Data:

The study's' protocol was approved the Ethics Committee of the Local Health Unit of Matosinhos - Hospital Pedro Hispano. The acceptance occurred on 12/07/2019. The researcher received authorization by the Board of Directors of Hospital Pedro Hispano to perform data collection at the institution.

All participants signed a Free and Informed Consent Form in person or through their caregivers/caretakers. The research preserved the anonymity of the participants, with no identification of any kind.

2.4. Population Studied

Participants were selected from the Neurology Service users at the outpatient clinic of Hospital Pedro Hispano, Matosinhos Local Health Unit. The area of direct influence of this

hospital includes the municipalities of Matosinhos, Vila do Conde, and Póvoa do Varzim, with a total population of 318.419 (3.0% of national population) in 2017.

The population over 60 years old represented 2.7% of the total population, and 52.3% of residents were women. In 2017, the illiteracy percentage was 3.54%, and the individuals with higher education were 15.2% (considering the entire population and not just the elderly). The estimated prevalence of dementia in the area was 1.2%. The main population data is summarized below:

Table 04. Population Area

	Illiteracy (%)	Gender (%)	> 60 years (%)	Diagnosis (N,%)
Matosinhos	3.16			
Vila do Conde	3.79			
Póvoa do Varzim	3.76			
Total	3.54			
Women		52.3		
Men		47.7		
60-64			6.2	
65-69			4.8	
70-74			3.9	
75-79			3.1	
80-84			2.1	
above 85 years			1.6	
Total			21.7	
Dementia (estimated)				4088 (1.2)

2.5 Sample size calculation:

There are three types of population (88): 1) **The target population**: this population refers to all individuals with the disease or the condition of interest-based on whom the study findings will be generalized and applied. 2) **The accessible population**: this population refers to all individuals with the disease or the condition of interest, available for the study investigators. 3) **The sample population**: this relates to the individuals with the state of interest, which will be included in a study, namely, the sample is a portion, piece, or segment that is representative of a whole.

In our study, the sample size calculation was performed using the prevalence of each event researched. We took the prevalence existing in the previous reviews for each event and we calculated the ideal sample size in **epi info statcalc online**.

According to the literature, the prevalence for each event is:

- Falls in dementia: 41% - 80% of prevalence (25),(26),(27),(28)
- Road traffic accidents in dementia: 24.3% (34).
- Unintentional home incidents in dementia: the prevalence of events of burns and poisoning were not found for dementia sufferers, just burns morbidity and mortality : 25% (24).
- Impaired financial capacity in dementia: 29.9% - 84% (37),(38),(39),(40),(41),(42),(43),(44),(45).
- Medications errors in dementia: 15.2% - 42.1% of prevalence (43),(73).
- Behavioral and psychological symptoms in dementia: the prevalence of 35-85% (77).
- Self-neglect in dementia: the prevalence of damage due to self-neglect in dementia in literature was not evident (54),(55).
- Loss of important objects in dementia: the specific prevalence of loss of important objects in dementia was not found in reviews. The studies describe just memory loss prevalence.

The variances described above occur because there are different prevalence depending on the population, the level of dementia, the various subtypes of dementia, and the study participants' age.

In the literature, the domains of events that have the highest prevalence are falls (26) and BPSD (50)(52)(82). The researchers chose them to calculate the ideal sample size. Once the ideal sample for the most prevalent events has been calculated, the lowest ones are represented.

In order to perform the calculation, we need to know the sample population. For that purpose, we used the information report regarding the number of dementia patients attended at the emergency department HPH in 2016 (304 patients)(89).

2.6. Variables

The following sociodemographic characteristics were evaluated: age, sex, schooling, professional activity, marital status, the relationship between patient and caregiver. The clinical variables analyzed were neurological diagnosis and MMES score. We assessed the frequency of the date of diagnosis and the date of onset of symptoms. The eight categorical variables regarding events with social and economic impact analyzed were: road traffic accidents, falls, unintentional home injuries, impaired financial capacity, medication errors

(self-administration), behavioral and psychological symptoms in dementia, self-neglect and loss of important objects.

2.7. Statistical analysis:

SPSS version 26.0 software was used to perform the statistical analysis. For the descriptive analysis of continuous variables, mean, standard deviation, median, minimum and maximum were calculated. For categorical variables, frequency and percentage were performed. To compare the domains of the events by age, gender, marital status, schooling, diagnosis, and the MMSE score, the Chi-Square Test was performed. When Chi-Square Test was not possible to carry out the analysis, the Fisher Test and Likelihood Ratio Test were performed. A 5% significance level was used (p -value <0.05).

Part III - Results, Discussion and Conclusion

1. Results

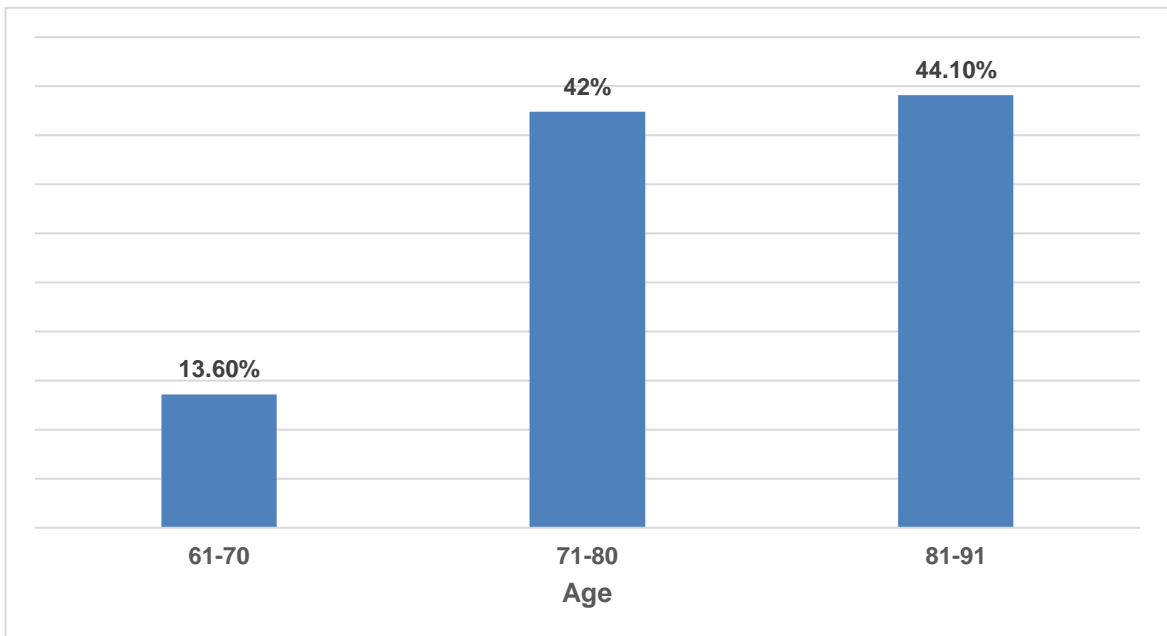
Of the 62 patients with eligibility criteria, 59 agreed to participate in the study. The participants' mean age was 78.85 years (SD 7.61), a median of 79, and a range of 61-91. The majority were women, 43 (72.9%). The main marital status found was married, 31 (52%), followed by widows 24 (40.7%). The vast majority of sample, 49 (83.1%) had up to 4 years of education, with only one participant having more than 12 years of schooling. Only 3 (5.1%) participants were professionally active at the time of the interview. The table below shows the demographic characteristics of the participants.

Table 05. Demographic characteristics of participants

Socio-demographic Informations	Total N=59
1. Age, years	
Mean (SD)	78.85 (7.61)
Median	79
Range	61-91
2. Gender (n)(%)	
Women	43 (72.9%)
Men	16 (27.1%)
3. Marital status (n)(%)	
Married	31 (52.5%)
Widow	24 (40.7%)
Single	3 (5.1%)
Other	1 (1.7%)
4. Schooling (n)(%)	
0-4 yrs	49 (83.1%)
5-9 yrs	9 (15.3%)
> 9 yrs	1 (1.7%)
5. Patient's currently professionally activity (n)(%)	
No	56 (94.9%)
Yes	3 (5.1%)

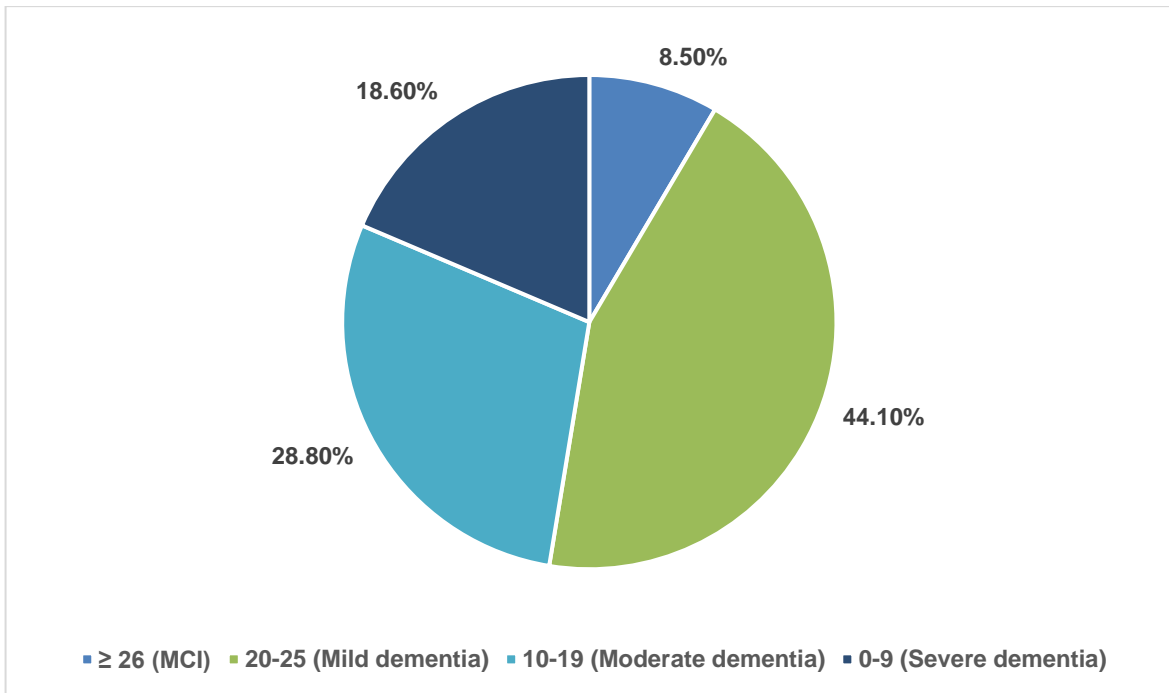
The graphic below shows the frequency of distribution by age, and we can observe that the study population had an advanced age, because more than 44% of the participants had more than 80 years old.

Graphic 01. Frequency distribution by age



The cognitive assessment (MMSE) was carried out up to 6 months before the questionnaire date, and revealed that 5 (8.5%) of the participants had a score above 26 points (MCI), 26 (44.1%) had a score between 20-25 points (Mild Dementia), 17 (28.8%) had a score between 10-19 (Dementia Moderate) and 11 participants had a score below 09 points (Dementia Severe). The graphic below shows these outcomes:

Graphic 2. MMSE outcomes



The principal diagnosis found was AD in 33 patients, 55% of the sample. Mixed type dementia was the second most prevalent diagnosis (10.2%), and the third was vascular dementia (8.5%). There were 5 (8.5%) participants with MCI diagnosis. Most participants (52.5%) reported that the first symptoms appeared between 1 and 3 years before the date of the interview.

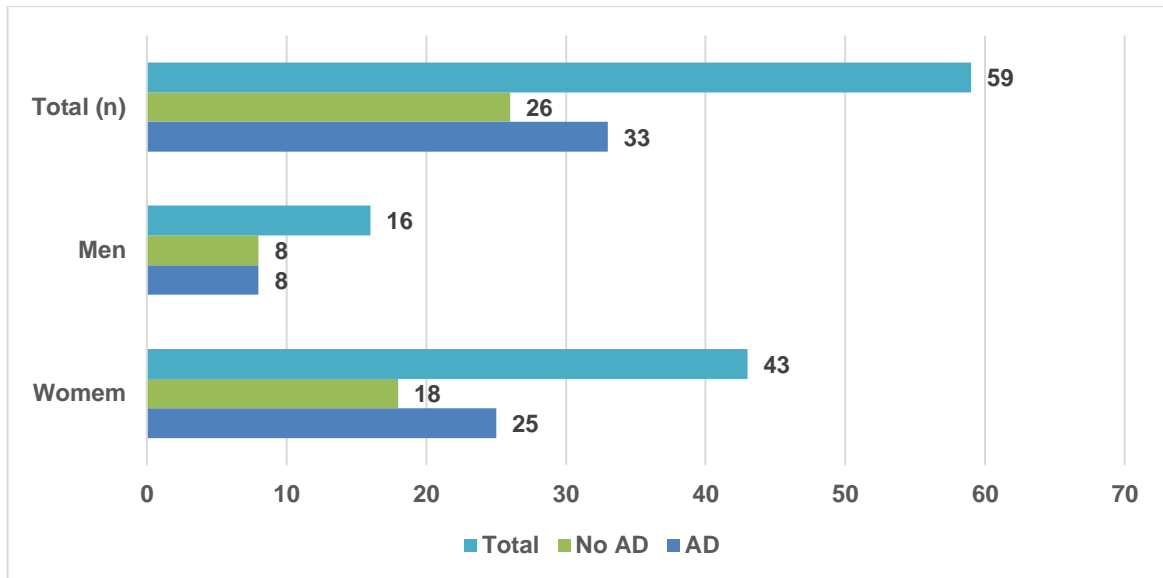
The table below shows the patient's clinic information.

Table 06. Patient's clinic information

Clinic informations	%
Diagnosis	
Alzheimer's disease (AD)	33 (55%)
Mixed type dementia (MD)	6 (10.2%)
Vascular dementia (VaD)	5 (8.5%)
Parkinson's disease dementia (PDD)	4 (6.8%)
Dementia with Lewy Body (DLB)	3 (5.1%)
Frontotemporal dementia (FTD)	3 (5.1%)
Mild cognitive impairment (MCI)	5 (8.5%)
Date of diagnosis	
0-6 months	28 (47.5%)
06-12 months	31 (52.5%)
Symptom onset (approximate date)	
0-1 yrs	10 (16.9%)
1-3 yrs	31 (52.5%)
3-5 yrs	10 (16.9%)
> 5 yrs	8 (13.6%)
Current MMSE (Mini Mental State Examination)	
≥ 26 (MCI)	5 (8.5%)
20-25 (Mild dementia)	26 (44.1%)
10-19 (Moderate dementia)	17 (28.8%)
0-9 (Severe dementia)	11 (18.6%)

AD was the most prevalent diagnosis found (55%). Moreover, in our study, women were also very prevalent (72.9%). The graphic below shows the high prevalence of AD among women 25 (58%):

Graphic 03. Neurological diagnosis by gender

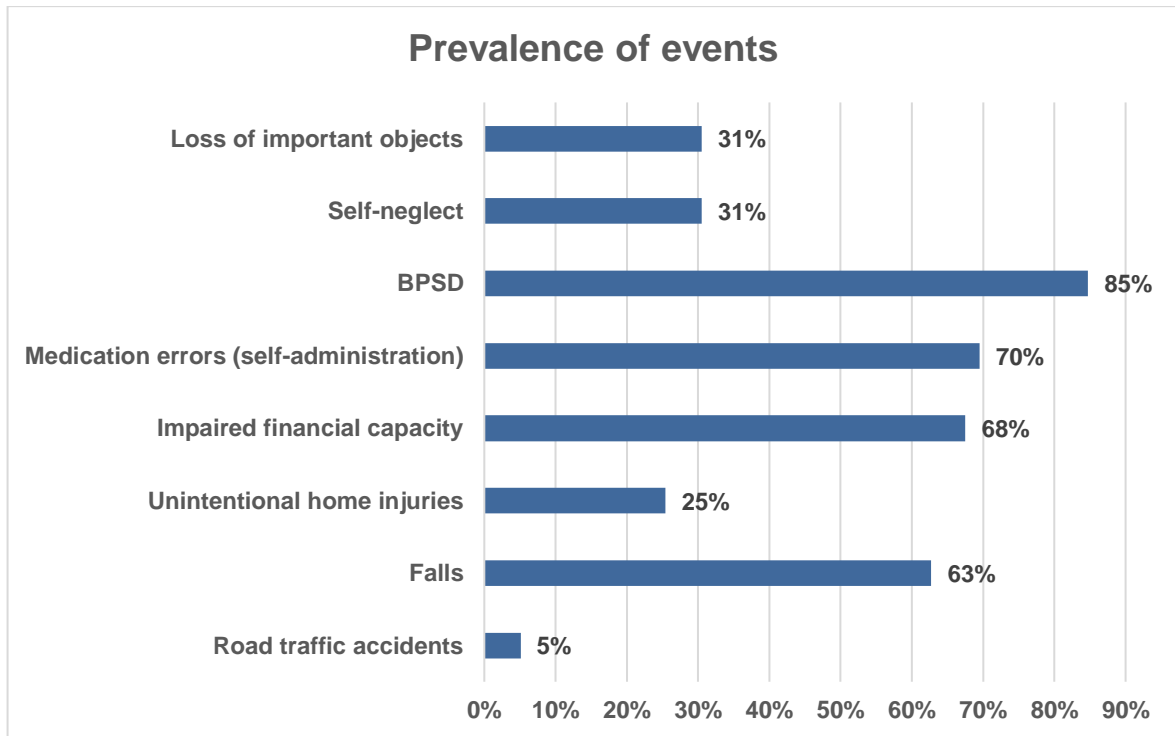


Considering the “**Yes**” responses to the events (having occurred at least once) and “**No**” (never happened), the most prevalent event was BPSD with 84.7% of positive responses. Secondly, medication errors on self-administration were found in 69.5%. Impaired financial capacity in 67.5%. Falls presented a frequency of 62.7%. Self-neglect showed the same prevalence as loss of important objects, with 30.5%. Unintentional home injuries were reported by 25.4% of participants. Only 3 (5,1%) of the participants reported involvement in Road traffic injuries.

All the frequencies of the answers to the questions from the eight domains with their specifications were attached to the study (Appendix 2).

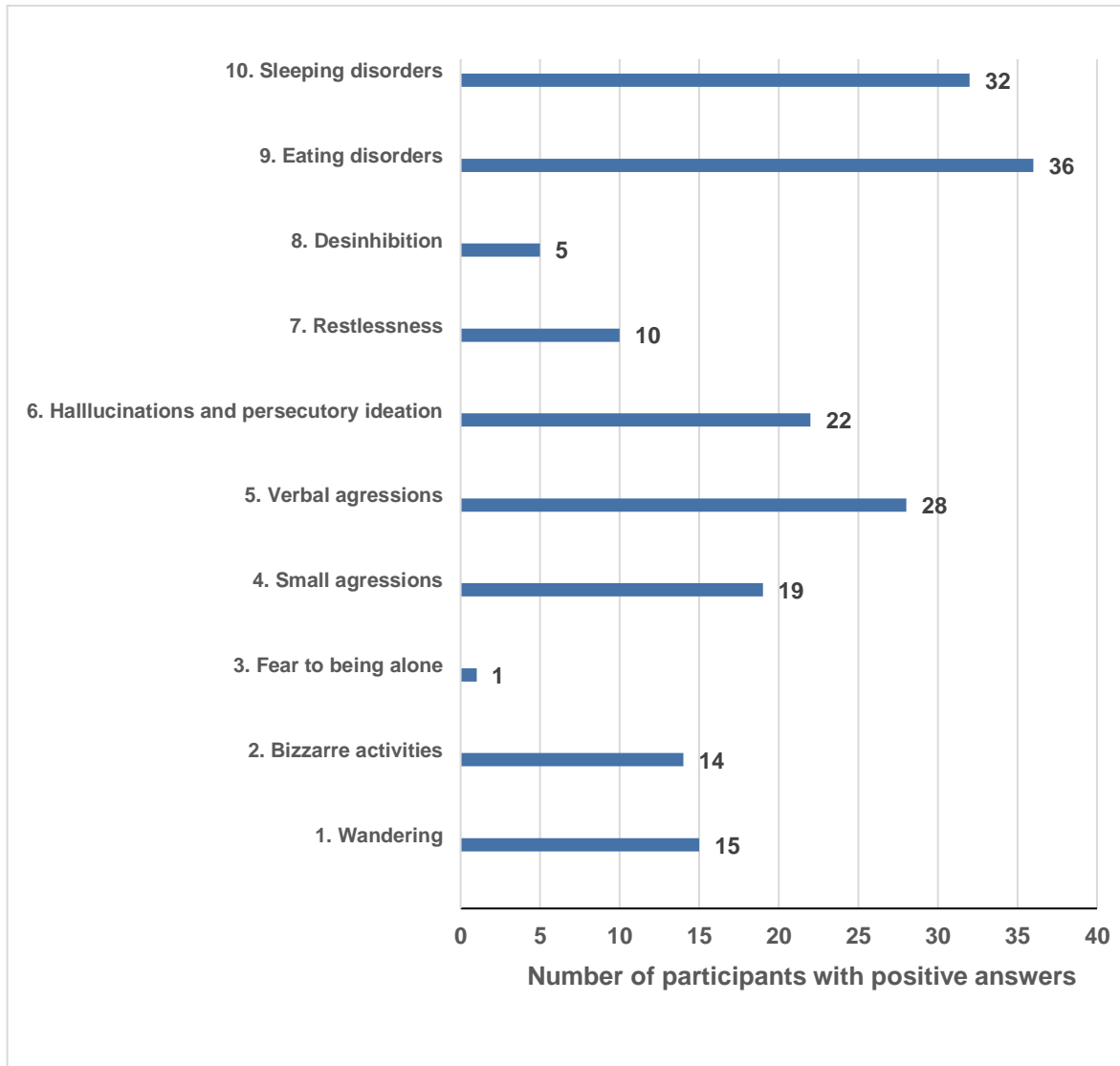
The prevalence of all events is exposed in the graphic below.

Graphic 04. Prevalence of events



Regarding the most prevalent domain, that is, **BPSD**, with **84.7%** positive responses, the main event reported was eating disorders, with 36 (61%) participants answering they had gained or lost weight due to eating disorders five years prior to diagnosis. Secondly, sleeping disorders were reported by 32 (54%) of participants. Verbal aggressions were third, mentioned by 28 (47%) of caregivers. Hallucinations and persecutory ideas were reported by 22 (37%) patients or caregivers. The graphic below resumes the behavioral and psychological symptoms found in our study.

Graphic 05. Behavioral and psychological symptoms results



Each item shown in the graphic above agrees with each question performed in the questionnaire, and the frequency can be observed the Table 6 – Appendix 2.

Regarding possible associations, the researchers analyzed all domains searching for a significant statistical association concerning age, gender, schooling, marital status, dementia subtype and MMSE score. These analyses did not find significant associations. The tables below summarize the results found.

Table 07. Domains of events and age (p-value: Chi-Square Test)

	Age				(p-value)
	N	Mean(SD)	Median	Min - Max	
Total	59	78.85 (7.61)	79	61-91	-
RTA					
No	56	78.75 (7.71)	79.5	61-91	0.6912
Yes	3	80.67 (6.43)	78	76-88	
Falls					
No	22	78.09 (8.06)	78.5	64-89	0.6210
Yes	37	79.3 (7.41)	80	61-91	
UHI					
No	44	78.3 (8.15)	78	61-91	0.4431
Yes	15	80.47 (5.67)	81	70-89	
IFC					
No	19	78.21 (6.76)	79	64-88	0.5533
Yes	40	79.15 (8.05)	79,.	61-91	
ME					
No	18	80.28 (8.52)	83	64-89	0,486
Yes	41	78.22 (7.2)	77	61-91	
BPSD					
No	9	76.33 (6.93)	73	70-87	0.1542
Yes	50	79.3 (7.7)	80	61-91	
SN					
No	41	78.49 (8.13)	79	61-91	0.6563
Yes	18	79,67 (6.42)	80	68-90	
LIO					
No	41	79,02 (8,21)	80	61-90	0.6326
Yes	18	78,44 (6.23)	78.5	68-91	
Total					
No	1	72 (0)	72	72-72	0.767
Yes	58	78.97 (7.62)	79.5	61-91	

The following graphic summarizes the relative frequency distribution of domains of the events by age:

Graphic 06. Frequency Distribution of the Domains of Events by Age

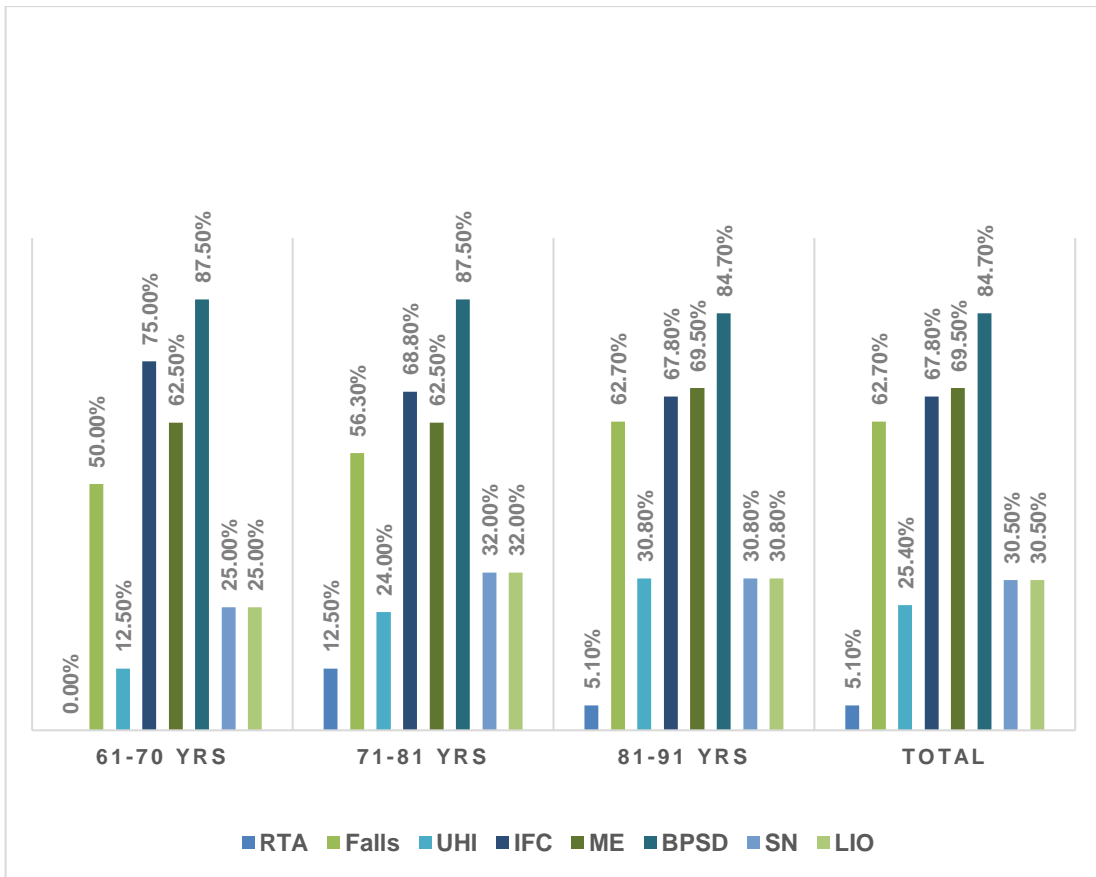


Table 08. Domains of events by gender

	Gender			(p-value)
	Women	Men	Total	
RTA				
No	42 (97.7%)	14 (87.5%)	56 (94.9%)	0.760*
Yes	1 (2.3%)	2 (12.5%)	3 (5.1%)	
Total	43 (100%)	16 (100%)	59 (100%)	
Falls				
No	15 (34.9%)	7 (43.8%)	22 (37.3%)	0.5579*
Yes	28 (65.1%)	9 (56.3%)	37 (62.7%)	
Total	43 (100%)	16 (100%)	59 (100%)	
UHI				
No	29 (67.4%)	15 (93.8%)	44 (74.6%)	0.0476*
Yes	14 (32.6%)	1 (6.3%)	15 (25.4%)	
Total	43 (100%)	16 (100%)	59 (100%)	
IFC				
No	14 (32.6%)	5 (31.3%)	19 (32.2%)	1.0000*
Yes	29 (67.4%)	11 (68.8%)	40 (67.8%)	
Total	43 (100%)	16 (100%)	59 (100%)	
ME				
No	12 (27.9%)	6 (37.5%)	18 (30.5%)	0.5330*
Yes	31 (72.1%)	10 (62.5%)	41 (69.5%)	
Total	43 (100%)	16 (100%)	59 (100%)	
BPSD				
No	7 (16.3%)	2 (12.5%)	9 (15.3%)	1.0000*
Yes	36 (83.7%)	14 (87.5%)	50 (84.7%)	
Total	43 (100%)	16 (100%)	59 (100%)	
SN				
No	30 (69.8%)	11 (68.8%)	41 (69.5%)	1.0000*
Yes	13 (30.2%)	5 (31.3%)	18 (30.5%)	
Total	43 (100%)	16 (100%)	59 (100%)	
LIO				
No	30 (69.8%)	11 (68.8%)	41 (69.5%)	1.0000*
Yes	13 (30.2%)	5 (31.3%)	18 (30.5%)	
Total	43 (100%)	16 (100%)	59 (100%)	
Total				
No	1 (2.3%)	0 (0%)	1 (1.7%)	1.0000*
Yes	42 (97.7%)	16 (100%)	58 (98.3%)	
Total	43 (100%)	16 (100%)	59 (100%)	

*Fisher Test

The following graphic summarizes the frequency distribution of domains of the events by Gender:

Graphic 07. Frequency distribution of events domains by gender

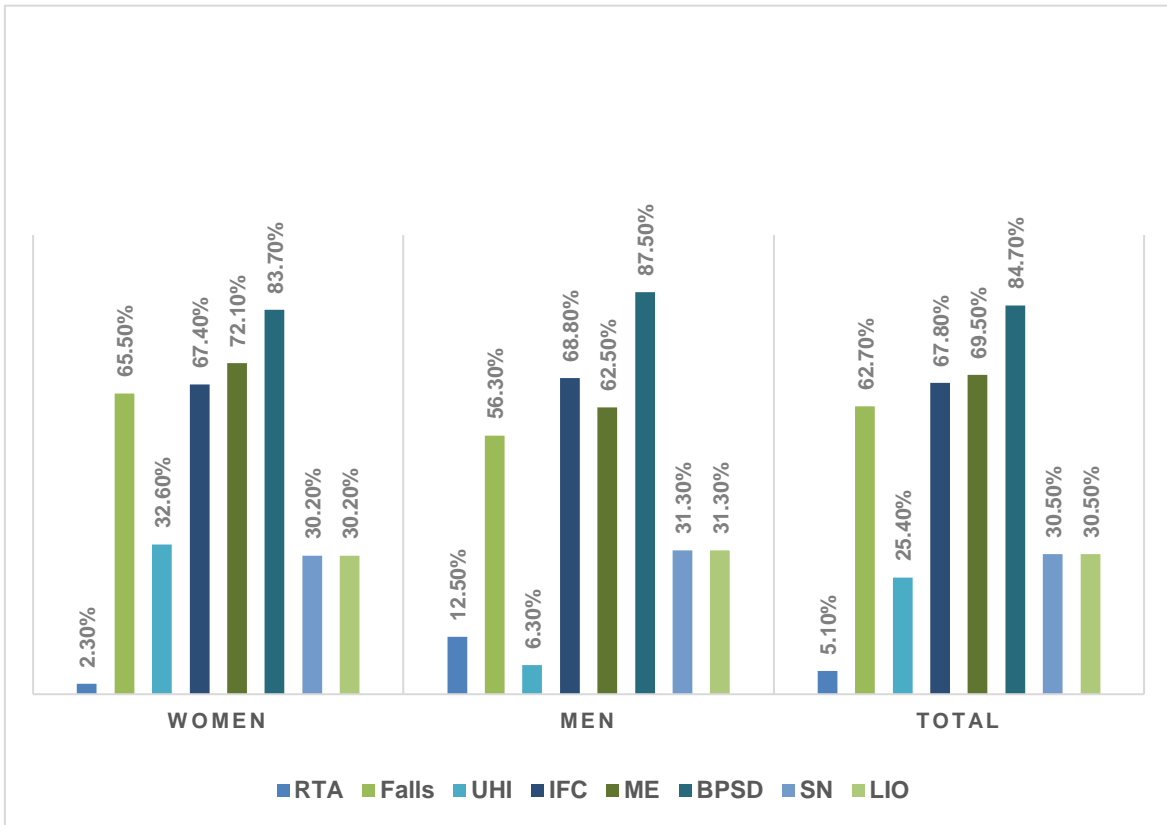


Table 09. Domains of events by marital status

	Marital status			(p-value)
	Married	Single/Widow/Other	Total	
RTA				
No	28 (90.3%)	28 (100%)	56 (94.9%)	0.2390*
Yes	3 (9.7%)	0 (0%)	3 (5.1%)	
Total	31 (100%)	28 (100%)	59 (100%)	
Falls				
No	15 (48.4%)	7 (25%)	22 (37.3%)	0.0636
Yes	16 (51.6%)	21 (75%)	37 (62.7%)	
Total	31 (100%)	28 (100%)	59 (100%)	
UHI				
No	25 (80.6%)	19 (67.9%)	44 (74.6%)	0.2600
Yes	6 (19.4%)	9 (32.1%)	15 (25.4%)	
Total	31 (100%)	28 (100%)	59 (100%)	
IFC				
No	10 (32.3%)	9 (32.1%)	19 (32.2%)	0.9925
Yes	21 (67.7%)	19 (67.9%)	40 (67.8%)	
Total	31 (100%)	28 (100%)	59 (100%)	
ME				
No	9 (29%)	9 (32.1%)	18 (30.5%)	0.7955
Yes	22 (71%)	19 (67.9%)	41 (69.5%)	
Total	31 (100%)	28 (100%)	59 (100%)	
BPSD				
No	5 (16.1%)	4 (14.3%)	9 (15.3%)	1.0000*
Yes	26 (83.9%)	24 (85.7%)	50 (84.7%)	
Total	31 (100%)	28 (100%)	59 (100%)	
SN				
No	20 (64.5%)	21 (75%)	41 (69.5%)	0.3825
Yes	11 (35.5%)	7 (25%)	18 (30.5%)	
Total	31 (100%)	28 (100%)	59 (100%)	
LIO				
No	20 (64.5%)	21 (75%)	41 (69.5%)	0.3825
Yes	11 (35.5%)	7 (25%)	18 (30.5%)	
Total	31 (100%)	28 (100%)	59 (100%)	
Total				
No	1 (3.2%)	0 (0%)	1 (1.7%)	1.0000*
Yes	30 (96.8%)	28 (100%)	58 (98.3%)	
Total	31 (100%)	28 (100%)	59 (100%)	

* Fisher test

The following graphic summarizes the frequency distribution of domains of the events by marital status:

Graphic 08. Frequency Distribution of events domains by marital status

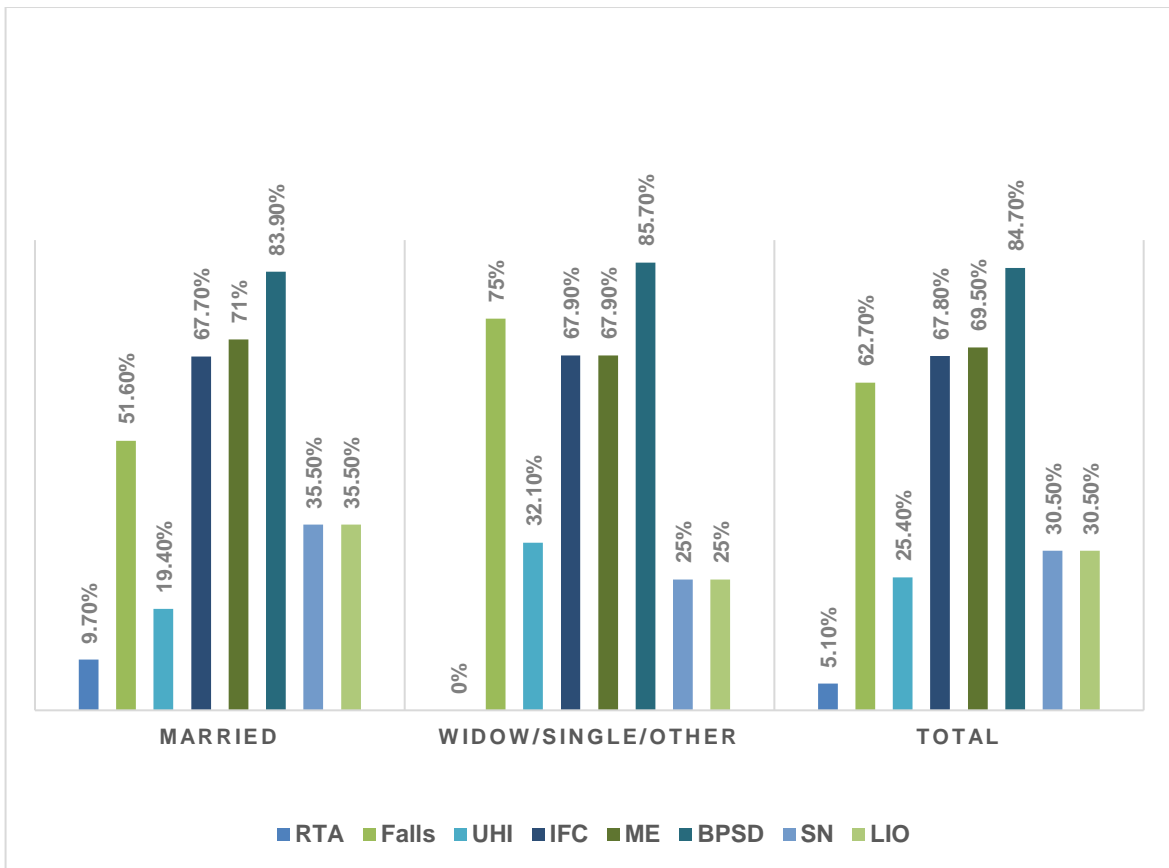


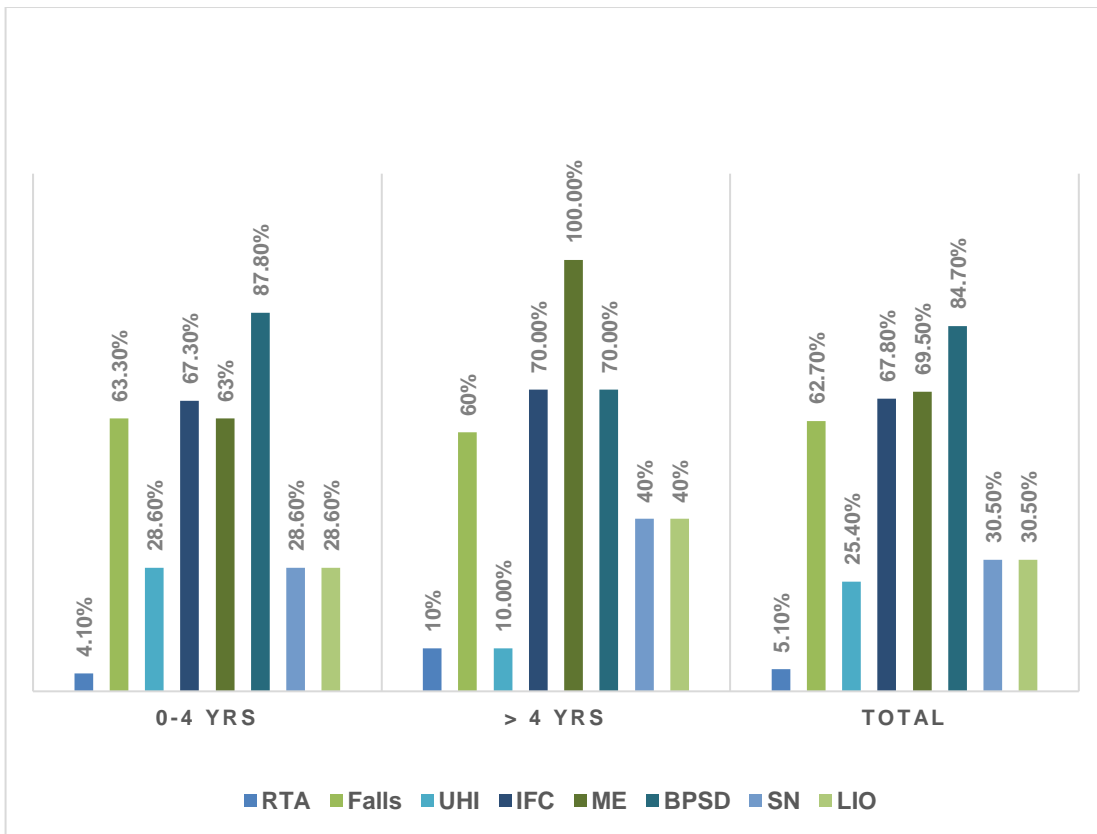
Table 10. Domains of events by schooling

	Schooling			(p-value)
	0-4 yrs	>4 yrs	Total	
RTA				
No	47 (95,9%)	9 (90%)	56 (94,9%)	0,4333*
Yes	2 (4,1%)	1 (10%)	3 (5,1%)	
Total	49 (100%)	10 (100%)	59 (100%)	
Falls				
No	18 (36,7%)	4 (40%)	22 (37,3%)	1,0000*
Yes	31 (63,3%)	6 (60%)	37 (62,7%)	
Total	49 (100%)	10 (100%)	59 (100%)	
UHI				
No	35 (71,4%)	9 (90%)	44 (74,6%)	0,4263*
Yes	14 (28,6%)	1 (10%)	15 (25,4%)	
Total	49 (100%)	10 (100%)	59 (100%)	
IFC				
No	16 (32,7%)	3 (30%)	19 (32,2%)	1,0000*
Yes	33 (67,3%)	7 (70%)	40 (67,8%)	
Total	49 (100%)	10 (100%)	59 (100%)	
ME				
No	18 (36,7%)	0 (0%)	18 (30,5%)	0,0238
Yes	31 (63,3%)	10 (100%)	41 (69,5%)	
Total	49 (100%)	10 (100%)	59 (100%)	
BPSD				
No	6 (12,2%)	3 (30%)	9 (15,3%)	0,1700*
Yes	43 (87,8%)	7 (70%)	50 (84,7%)	
Total	49 (100%)	10 (100%)	59 (100%)	
SN				
No	35 (71,4%)	6 (60%)	41 (69,5%)	0,4753*
Yes	14 (28,6%)	4 (40%)	18 (30,5%)	
Total	49 (100%)	10 (100%)	59 (100%)	
LIO				
No	35 (71,4%)	6 (60%)	41 (69,5%)	0,4753*
Yes	14 (28,6%)	4 (40%)	18 (30,5%)	
Total	49 (100%)	10 (100%)	59 (100%)	
Total				
No	1 (2%)	0 (0%)	1 (1,7%)	1,0000*
Yes	48 (98%)	10 (100%)	58 (98,3%)	
Total	49 (100%)	10 (100%)	59 (100%)	

*Fisher test

The following graphic summarizes the frequency distribution of domains of the events by schooling:

Graphic 09. Frequency Distribution of Events by Schooling



Due to the statistical significance found, we summarize the outcomes of Medication Errors by Schooling below:

Graphic 10. Medication errors by schooling

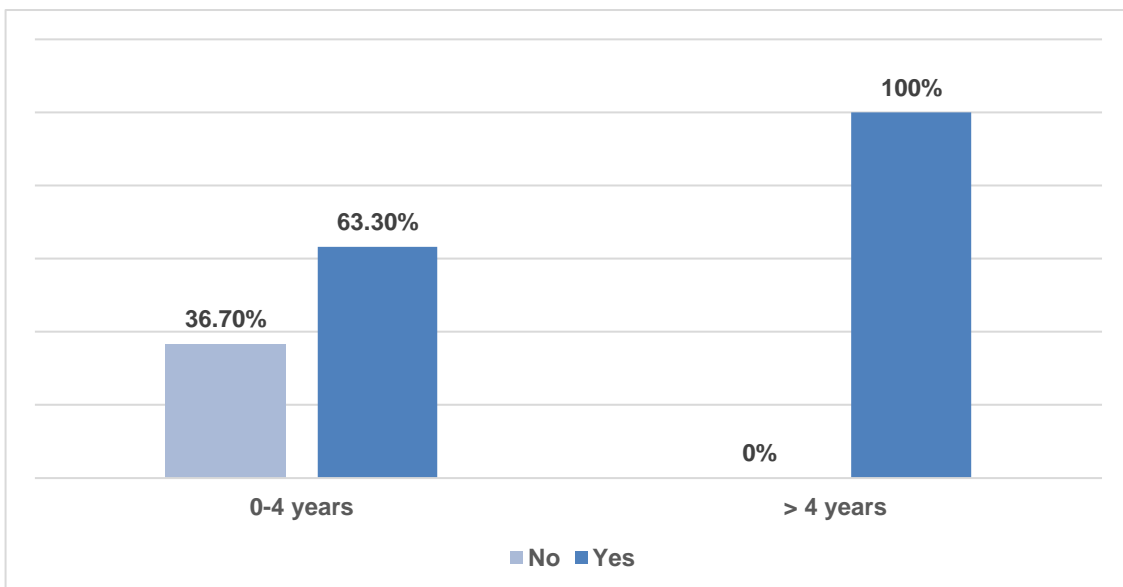


Table 11. Domains and Diagnosis (p-value: Chi-Square Test)

	Diagnosis			Total	(p-value)
	Alzheimer's Disease	Mild Cognitive Impairment	Other Dementias		
RTA					
No	31 (93,9%)	5 (100%)	20 (95,2%)	56 (94,9%)	0,745*
Yes	2 (6,1%)	0 (0%)	1 (4,8%)	3 (5,1%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
Falls					
No	12 (36,4%)	2 (40%)	8 (38,1%)	22 (37,3%)	0,983*
Yes	21 (63,6%)	3 (60%)	13 (61,9%)	37 (62,7%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
UHI					
No	26 (78,8%)	3 (60%)	15 (71,4%)	44 (74,6%)	0,626*
Yes	7 (21,2%)	2 (40%)	6 (28,6%)	15 (25,4%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
IFC					
No	11 (33,3%)	1 (20%)	7 (33,3%)	19 (32,2%)	0,8176 *
Yes	22 (66,7%)	4 (80%)	14 (66,7%)	40 (67,8%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
ME					
No	9 (27,3%)	2 (40%)	7 (33,3%)	18 (30,5%)	0,800*
Yes	24 (72,7%)	3 (60%)	14 (66,7%)	41 (69,5%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
BPSD					
No	4 (12,1%)	1 (20%)	4 (19%)	9 (15,3%)	0,753*
Yes	29 (87,9%)	4 (80%)	17 (81%)	50 (84,7%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
SN					
No	21 (63,6%)	4 (80%)	16 (76,2%)	41 (69,5%)	0,531*
Yes	12 (36,4%)	1 (20%)	5 (23,8%)	18 (30,5%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
LIO					
No	23 (69,7%)	4 (80%)	14 (66,7%)	41 (69,5%)	0,835*
Yes	10 (30,3%)	1 (20%)	7 (33,3%)	18 (30,5%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
Total					
No	0 (0%)	0 (0%)	1 (4,8%)	1 (1,7%)	0,350*
Yes	33 (100%)	5 (100%)	20 (95,2%)	58 (98,3%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	

*Likelihood Ratio Test

Graphic 11. Frequency distribution of events by diagnosis

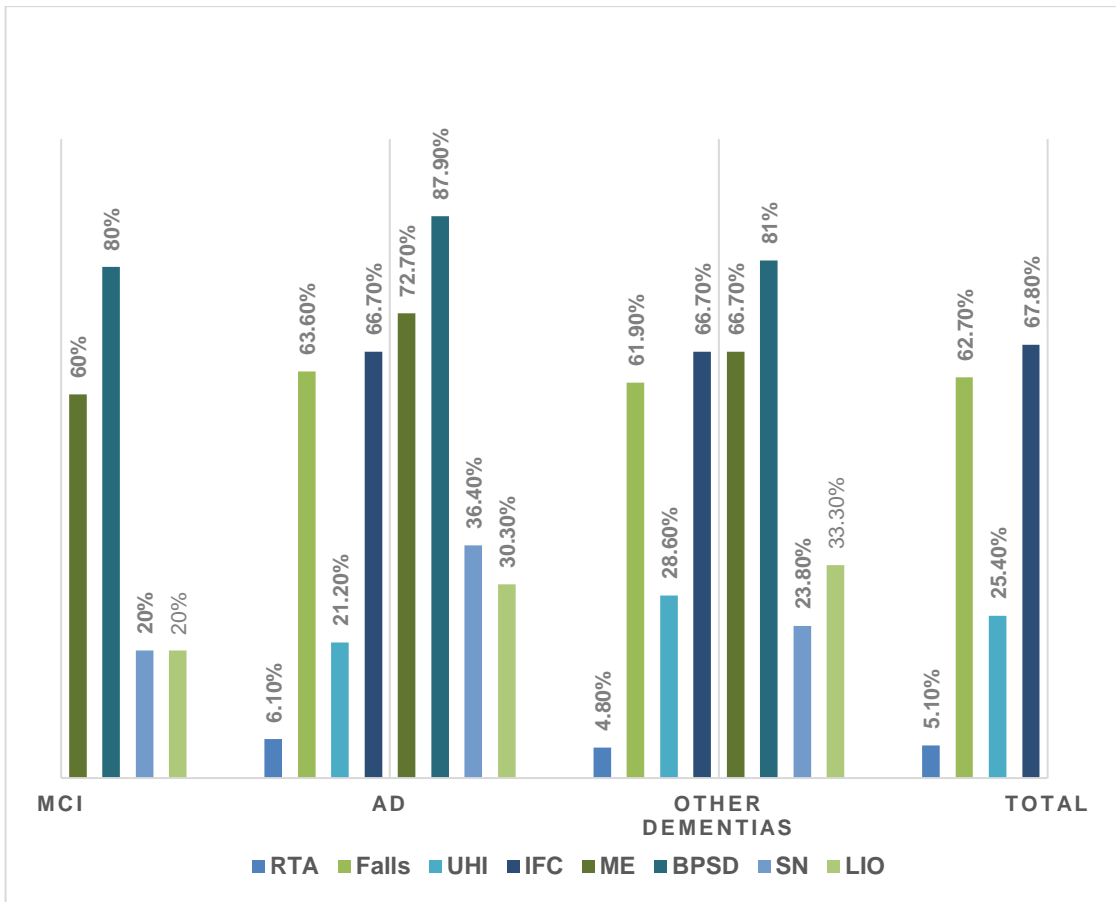


Table 12. Domains and MMSE (p-value: Chi-Square Test)

	MMSE			(p-value)
	MCI /Mild Stage	Moderate /Severe Stage	Total	
RTA				
No	30 (53.6%)	26 (46.4%)	56 (100%)	0.5995*
Yes	1 (33.3%)	2 (66.7%)	3 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
Falls				
No	12 (54.5%)	10 (45.5%)	22 (100%)	0.8122
Yes	19 (51.4%)	18 (48.6%)	37 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
UHI				
No	25 (56.8%)	19 (43.2%)	44 (100%)	0.2600
Yes	6 (40%)	9 (60%)	15 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
IFC				
No	11 (57.9%)	8 (42.1%)	19 (100%)	0.5704
Yes	20 (50%)	20 (50%)	40 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
ME				
No	9 (50%)	9 (50%)	18 (100%)	0.7955
Yes	22 (53.7%)	19 (46.3%)	41 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
BPSD				
No	6 (66.7%)	3 (33.3%)	9 (100%)	0.4770*
Yes	25 (50%)	25 (50%)	50 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
SN				
No	23 (56.1%)	18 (43.9%)	41 (100%)	0.092
Yes	8 (44.4%)	10 (55.6%)	18 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
LIO				
No	21 (51.2%)	20 (48.8%)	41 (100%)	0.7588
Yes	10 (55.6%)	8 (44.4%)	18 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	
Total				
No	0 (0%)	1 (100%)	1 (100%)	-
Yes	31 (53.4%)	27 (46.6%)	58 (100%)	
Total	31 (52.5%)	28 (47.5%)	59 (100%)	

* Fisher Test

2. Discussion

Firstly, it is relevant to characterize the type of adverse events and which factors determine the respective prevalence in the period that precedes a correct diagnosis of dementia. The results of these questions have epidemiological and clinical relevance and they were addressed and analyzed in this study.

Besides that, the characterization of this type of events in a given social and economic context also improves the capacity to assess the potential value associated with an earlier diagnosis and the possibility of implementing preventive strategies aimed at the specific problems identified.

The study applied a questionnaire with objective and straightforward questions to patients and their families or caregivers in order to survey the main significant events that occurred five years before the diagnosis related to dementia.

To our knowledge, the study is unique in Portugal, and no similar study has been carried out using the same methodology. The results are significant because they can influence directly and indirectly public health policies for the elderly in Portugal. Furthermore, it is interesting to note that Portugal has the fifth oldest population in the world, giving priority to elderly care. Besides, studies exposed an estimated prevalence of 5.91 % cases of dementia in Portugal (90).

Even in other countries, no study was found with the same questions. *Bature* and colleagues, 2017, performed a systematic review of literature to evaluate signs and symptoms preceding AD diagnosis. However, in this systematic review, all studies selected only AD dementia, and the signs and symptoms sought did not cover all events that were searched in our study (56).

The results can be analyzed from three perspectives. The first was to assess the prevalence of some of the most dementia observed relevant events years before diagnosis. The second was if the events' frequencies in our study were similar to other studies in other countries. Finally, and perhaps the most outstanding was to discuss if these events could have been avoided with a more accurate and early diagnosis.

Concerning the participant's sociodemographic characteristics, our sample presented a high average age (79 years) and a large majority were women 43 (73%). The remarkable difference between genders is similar to that found in other dementia studies in a Population-Based Cohort from Northern Portugal (68 Participants: 47 women and 21 men) (22). The sample's low educational level (83.1% of participants had up to 4 years of education) was also surprising, but it is comparable to the average found in other research

on the elderly carried out in Portugal, in which 77.3% of participants had up to 4-year of formal education (91).

Regarding the date of diagnosis, most participants 31 (52.5%) reported that the first symptoms appeared between 1 and 3 years before the interview date, and 28 (30,5%) started symptoms more than 3 years before the date of diagnosis. This is a relevant and worrying result, as it suggests a long period between the onset of symptoms and the beginning of specific care and treatments.

MMSE score was another significant result regarding public health since almost 50% were already in moderate or severe stage of dementia just a few months after the diagnosis. These outcomes may demonstrate that the diagnosis of dementia in Portugal is late.

However, there was no significant difference in events prevalence between patients with MCI/mild dementia vs. moderate/severe dementia regarding the MMSE score (Table 12). This outcome can be considered positive, as it may indicate that once symptoms, signs, and events concerning dementia are beginning, in some way, the families or even the caregivers increase the care for the patient, avoiding an increase in these harmful events. Without this intervention, maybe the outcomes in this study were worse.

Concerning the neurological diagnosis, we found results slightly different from those found in two current studies in northern Portugal because while we found 55% of AD, 10.2% of MD and 8.5% of VaD in our study, *Nunes and colleagues, 2010*, found equal proportions of AD and VD (92) and *Ruano and colleagues, 2019*, found 52% of VD and 36.1% of AD in their study (22). However, the finding is compatible with a memory clinic based study (low rates of referral due to VaD) and European epidemiological data about dementia, in which AD is the main diagnosis. The possible explanation for this variation is the high prevalence of women in our study (73%) because AD is more frequent in women.

Regarding the frequency of events, the results showed a high prevalence of events related to dementia. Examining the eight domains analyzed, 4 showed prevalence above 50%; ASB, IFC, ME and Falls, three presented a high prevalence: 30.5% for self-neglect, 28,8% for loss of Important Objects and 25,4% for unintentional Home Injuries. Concerning road traffic accidents, only 3 (5.1%) participants reported some accident involving means of transportation.

Concerning BPSD with 84.7% of positive responses, it is significant to note that from ten questions asked, three (eating disorders, sleep disorders and verbal aggressions) had more than 50% of the participants reporting frequent events before diagnosis (Appendix 2).

The main result in BPSD domain was eating disorders with 36 positive responses in which 24 (40.6%) patients informed significant weight loss. Concerning sleep disorders, with a total of 32 (84.7%) positive responses, 30 (50.8%) patients reported frequent sleep disturbance. Twenty-eight caregivers mentioned verbal aggressiveness, and 23 reported frequent attacks (Appendix 02).

The main sub-diagnosis of dementia found in the BPSD domain was AD, with 87.9% of prevalence, and although very high, this prevalence is compatible with the literature (51).

The BPSD prevalence of 84.7% was similar to other studies, particularly a population-based prevalence study performed by *Steinberg M. and colleagues, 2003*, in which the researchers found the cumulative prevalence of mental or behavioral disturbances during 18 months as 88.6% (78). The symptoms informed by our questionnaire have also been described by other studies that evaluated symptoms of dementia.

Studies frequently described the relationship between neuropsychiatric symptoms in dementia and caregiver's burden, demonstrating a significant correlation between the high prevalence of symptoms and increasing caregiver's burden(79)(93).

Furthermore, these BPSD outcomes found were at least partially avoidable because nowadays there are many pharmacological therapies for treating neurological symptoms in dementia and reduce the social burden of these symptoms (94).

Medications errors on self-administration has a high prevalence (69.5%), and a high frequency (Table 4. Appendix 2), or rather, 33 of 59 participants reported that they often forgot to take their medication before dementia diagnosis. Our study depicted a higher prevalence than that found by *Lui and colleagues, 2012*; however, the results were perhaps influenced by low health literacy among the study participants. Nevertheless, this statistic is worrisome because errors in taking medicines may indicate a high risk for adverse events with severe consequences as hospitalizations and deaths.

The literature is rich in studies with coping strategies to improve medicines management in dementia (71)(95). However, these policies can only achieve the outcomes if there are early diagnosis and correct identification of the difficulty.

Particularly noteworthy was the 67.8% prevalence of impairment in financial capacity, which was similar to what *Chiong and colleagues* found in their study (65).

The domain Impairment financial capacity was an interesting result, because as we can observe in the questions/responses (Table 5 - Appendix 02), although 67.8% already had

some difficulty in managing finances, in some questions such as for: “*Did you have difficulties in using bank cards or writing checks?*” the answers, “*I never did it, because someone always did it for me and I never used this payment system*” were highly prevalent. Three sociodemographic characteristics of our sample could have influenced these responses:

1. the high mean age of the sample that are perhaps culturally more familiarized to dealing with cash;
2. high prevalence of women in the sample (72%), from a generation more economically dependent on their husbands,
3. The sample’s low education level (83.1% of sample had up to 4 years of schooling).

Although we found these issues on certain questions, the prevalence of problems in managing finances was very high, which indicates that even before diagnosis almost 70% of patients already had difficulties in having an independent life. *Martin RC and colleagues, 2018*, have investigated financial capacity as a critical clinically-relevant IADL closely linked to personal autonomy and disability and successful independent living, and this research group has found significant declines in multiple financial skills in people with MCI, validating the results found in our study (45).

In this subject, or rather, financial capacity, the clinicians have a crucial ethical responsibility to inform, aware, and assess patients, families and caregivers. *Widera and colleagues, 2011*, describe 5 important roles for clinicians in order to help patients and families (38)(40):

1. Educating patients and families about the need for advanced financial planning;
2. Recognizing signs of possible impaired financial capacity in their elderly patients;
3. Assessment of financial Impairment or Financial Abuse, and the authors highlight: “Physicians have an ethical and professional obligation to assess for and address elder financial abuse”;
4. Suggesting practical interventions to help patients to maintain financial independence;
5. Making referrals for financial capacity assessment.

Falls were the fourth most prevalent domain. In fact, falls in cognitively healthy elderly are a major public health concern, and in Portugal, the prevalence in 2017 was 21.87% among the elderly over 70 years old (58). Considering falls in dementia, the situation is more severe since they are a significant cause of morbidity and mortality in people with cognitive decline (26)(27)(96).

Our study found 62.7% of falls prevalence, and 23 (38%) of participants informed that they had frequent falls before dementia diagnosis (Appendix 2). Even patients who at the questionnaire date still had an MMSE compatible with MIC or Mild Dementia (52.5%) presented a high prevalence of falls (32%).

The most prevalent subtype of dementia found in falls was AD, with 63.3% of prevalence. Our outcomes are in agreement with other studies (27)(97). *Allan and colleagues, 2009*, in a prospective study of predictors of falls in dementia had demonstrated that older people with dementia, experience eight times more incident falls than those without, and the prevalence of falls in AD was 47% (27).

The prevention of falls in dementia patients is unclear because it is not evidenced that interventions identified to reduce the risk of falls in a cognitively normal population can help patients with dementia (28). *Shaw, 2007*, summarized that “despite individual positive studies in populations including participants with dementia, systematic review and meta-analysis does not demonstrate generalizable benefit from multifactorial or individual intervention strategies in this population group”(28). Despite this conclusion, falling prevention should be a goal in the elderly in order to try to find a reduction in risks.

Self-neglect was also well reported among study participants (30.5%). The majority (25%) of self-neglect was related to personal care. Self-neglect in the elderly is frequent, and the studies show that self-neglect can increase mortality in the elderly (83). In our study, even patients with MCI and mild dementia (13.5%), had reported by their caregivers, some self-neglect events.

Although studies refer memory loss as one of the first symptoms of dementia(15)(57), we did not find a specific prevalence of loss of important and valuable objects in literature. However, the majority of participants that informed losses (18), mentioned as a frequency event (14) (Appendix 2. Table 08).

In a study review performed by *Gagnon-Roy and colleagues, 2018*, regarding unintentional home injuries and avoidable incidents in older adults with cognitive impairment, burns appeared as the third cause of emergency department visits following an incident in USA (2-3%).

Considering the severity of consequences, we believe that the UHI outcomes were worrisome in our study because 25% of participants reported some UHI event being that, 23% described mild fire accidents, and 3 (5.1%) informed mild burns (Appendix 2). The

literature is insufficient regarding the prevalence of burns in dementia disease. Perhaps, the presence of caregivers and institutionalizations can change this event rate.

Road traffic accidents (RTA) had a low prevalence in our study (5.1%), but is important to note that 43 (72%) of participants of our research informed that they never drove or stopped driving more than 5 years ago (Appendix 2), which limited our assessment of this domain. However, recent studies show that older adults with impaired cognitive actually drive less than healthy.

Petersen and colleagues, 2018, in a population-based nested case-control study in Danish, found a 57% RTA risk in people with dementia compared to their matched controls, and concludes that the results may instead relate to lower rates of daily outdoor activity among the population of dementia patients living at home. In the same way, *Fraade-Blonar and colleagues, 2019*, in a retrospective cohort study in the USA, observed that lower crash risk in their study might result from protective steps to limit driving among older adults' diagnosis and their impact on reducing crash risk.

Regarding the high prevalence of events and sign with a social and economic impact in the 5 years before diagnosis that our study found, it is important to discuss some words about capacity and autonomy because some domains like impairment financial capacity and road traffic accident involves ethical and legal questions about the patient's autonomy.

Our study's outcomes may lead to the impression that early diagnosis is necessary to establish more restrictive measures to protect patients and thirds. However, the proposition is the opposite. Dementia has a long progression, and the loss of capacity is slow and not for all daily living decisions or activities. *Fernandes L, 2008*, summarize "mental capacity is not universal. The absence of this capacity in a given situation may not suppose its non-existence for other situations, being susceptible to change"(98). Preserving the patient's autonomy and decision is one of the goas of care for dementia patients.

The outcomes showed that in a Portuguese dementia population, events with social or economic impact associated with the disease could be observed years before the diagnosis with a similar prevalence found after neurological diagnosis. In addition, we realized that there are some important and relatively unexplored social, ethical and legal issues about these events and their consequences.

Finally, in our opinion, health professionals must monitor the first signs and symptoms of dementia in the elderly to inform patients and their families how to treat or avoid these undesirable symptoms and events and possibly enroll them in early pharmacological therapy and/or non-pharmacological interventions of cognitive stimulation such as cognitive

stimulation therapy (CST), cognitive training programs and other therapies in order to reduce the progression of the disease.

Limitations

The main limitation of this work was the limited number of patients that were available with the inclusion criteria of the study, resulting in a not very extensive sample. Furthermore, it was hospital based, depending on the type of patients referred to the neurology clinic by family physicians. Another limitation was the possible information bias, because it is possible that the current caregivers have not lived with the patient in the last 5 years, not knowing all the events and symptoms that occurred some years before.

Conclusion and Key Messages

This study carried some spotlights concerning events and signs found before dementia diagnosis, that are summarized below:

1. Dementia is a social and economic public health challenge in Portugal
2. The prevalence of dementia signs and symptoms seen in patients attended a neurology outpatient clinic with the disease up to 5 years before the diagnosis is high
3. The study indicates that in Portugal the dementia diagnosis is performed late
4. There are a lot of symptoms and signs in dementia that could be avoided or reduced with an early diagnosis
5. The health professional must be prepared to recognize and inform patients and families about dementia first signs and disease progression.
6. Not only pharmacological interventions, but also non-pharmacological interventions can help reduce disease progression. It is crucial to disseminate and access all therapies.
7. The assessment of capacity in dementia should aim to protect patients and their families, and above all, maintain the patient's autonomy.

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Appendix 1: The Questionnaire

Sociodemographic Information

Date:

Name - Initials:

Marital Status:

Age:

Gender: F M Other

Schooling:

Occupation:

Do you work? Yes No

CP:

Phone Number:

Caregiver's Name:

Adverse events with social and/or economic impact in patients with dementia attended at a neurology outpatient clinic - Prevalence study in the five years prior to diagnosis

Caregiver Information

Degree of Kinship of the Caregiver

Does the caregiver live with the patient?

Clinic Information's

Neurological Diagnosis:

Date of diagnosis:

Estimated date of first symptoms:

Physician:

MMSE:

Date:

Other neurological assessments:

The Questionnaire:

1- Road traffic accidents – Last 5 years

1.1 Did the patient get involved in an accident while driving a car?

Yes: How many times: No: I don't remember:

1.2 Did the patient get involved in an accident while driving a motorcycle?

Yes: How many times: No: I don't remember:

1.3 Did the patient get involved in an accident while driving a bike?

Yes: How many times: No: I don't remember:

1.4 Did the patient get involved in an accident as a pedestrian?

Yes: How many times: No: I don't remember:

2- Unintentional Injuries – Last 5 years

2.1 Did the patient have a fall episode?

Yes: How many times: No: I don't remember:

2.2 Did the patient have an accidental poisoning episode?

Yes: How many times: No: I don't remember:

2.3 Did the patient cause an episode of the fire principle?

Yes: How many times: No: I don't remember:

2.4. Did the patient have an accidental burn?

Yes: How many times: No: I don't remember:

3. Impaired Financial Capacity – Last 5 years

3.1 Did the patient have a difficulty to recognize coins?

Yes: How many times: No: I don't remember:

3.2 Did the patient have a difficulty in writing checks (except visual difficulties)?

Yes: How many times: No: don't remember:

3.3 Did the patient have a difficulty or forgetting with bill payments?

Yes: How many times: No: I don't remember:

3.4 Did the patient have a difficulty in managing bank accounts, not being able to use bank services as usual?

Yes: How many times: No: I don't remember:

3.5 Did the patient make purchases in a wrong way or not characteristics with his/her habits?

Yes: How many times: No: I don't remember:

3.6 Did the patient make withdrawals in the cash in a wrong way or not characteristics of his/her habits?

Yes: How many times: No: I don't remember:

3.7 Did the patient make strange or mistaken donations?

Yes: How many times: No: I don't remember:

3.8 Was the patient a victim of scams?

Yes: How many times: No: I don't remember:

4. Medication Errors (self-administration) – Last 5 years:

4.1. Did the patient forget to take medications?

Yes: How many times: No: I don't remember:

4.2 Did the patient take wrong medication or a visibly deteriorated medication?

Yes: How many times: No: I don't remember:

4.3 Did the patient take medication with the wrong dose?

Yes: How many times: No: I don't remember:

4.4. Did the patient take medication at the wrong time?

Yes: How many times: No: I don't remember:

5. BPSD (not severe) – Last 5 years

5.1 Did the patient have a wanderings episode?

Yes: How many times: No: I don't remember:

5.2 Did the patient start to perform strange or purposeful activities, different from normal habits?

Yes: How many times: No: I don't remember:

5.3 Did the patient start to be afraid of being alone?

Yes: How many times: No: I don't remember:

5.4 Did the patient have any episode of small aggression, such as kicks, bites, grips?

Yes: How many times: No: I don't remember:

5.5 Did the patient have any episode of verbal aggression or hostility?

Yes: How many times: No: I don't remember:

5.6. Did the patient have persecutory ideas or hallucinations?

Yes: How many times: No: I don't remember:

5.7. Did the patient have irritability or motor disturbance episodes?

Yes: How many times: No: I don't remember:

5.8. Did the patient have a episode of disinhibition?

Yes: How many times: No: I don't remember:

5.9. Did the patient have an eating disturbance?

Yes: How many times: No: I don't remember:

5.10. Did the patient have a sleep disturbance?

Yes: How many times: No: I don't remember:

6. Self-Neglect – Last 5 years:

6.1 Did the patient have self-neglect episodes - personal hygiene failures?

Yes: How many times: No: I don't remember:

6.2 Did the patient have self-neglect episodes - refuse of medical treatments?

Yes: How many times: No: I don't remember:

7. Loss of important or value objects – Last 5 years

7.1 Did the patient have episodes of loss of valuables or money or assets?

Yes: How many times: No: I don't remember:

Observation - Frequency of events:

1-2 events: rarely

3-5 events: sometimes

> 5 events: often

APPENDIX 2 – Questionnaire responses

Table 01. Domain 1 - Road Traffic Accident

Questions	Never	Rarely	Stopped Driver ≥5 years	Sometimes	Often	Never Drive	I.D.R.*
R.T.A 1.1	14	1	1	-	-	43	-
R.T.A 1.2	14	1	1	-	-	43	-
R.T.A 1.3	15	-	1	-	-	43	-
R.T.A 1.4	58	1	-	-	-	-	-

Table 02. Domain 2 – Falls

Questions	Never	Rarely	Sometimes	Often	I.D.R.*
U.H.I. 2.1	22	12	2	23	0

Table 03. Domain 2 - Unintentional Home Injuries

Questions	Never	Rarely	Sometimes	Often	I.D.R.*
U.H.I. 2.2.	57	2	-	-	-
U.H.I. 2.3	45	10	1	3	-
U.H.I. 2.4	56	1	-	2	-

Table 04. Domain 3 - Impaired Financial Capacity

Questions	Never	Rarely	Sometimes	Often	Never Performed*	Never used the service*	I.D.R.*
I.F.C. 3.1	41	-	2	14	2	-	-
I.F.C. 3.3	4	-	-	1	20	34	-
I.F.C. 3.3	25	5	-	10	16	1	2
I.F.C. 3.4	25	-	-	21	10	1	2
I.F.C. 3.5	29	4	-	20	4	-	2
I.F.C. 3.6	45	2	-	5	5	2	-
I.F.C. 3.7	52	-	-	5	-	-	2
I.F.C. 3.8	50	5	1	3	-	-	-

Table 05. Domain 4 - Medications Errors

Questions	Never	Rarely	Sometimes	Often	Never Performed*	I.D.R.*
M.E. 4.1	20	4	1	33	1	-
M.E. 4.2	32	2	-	16	2	7
M.E. 4.3	32	1	-	20	2	4
M.E. 4.4	26	2	2	27	1	1

Table 06. Domain 5 – Abnormal Social Behaviors

Questions	Never	Rarely	Sometimes	Often	Weight Gain	Weight loss	I.D.R.*
A.S.B. 5.1	44	7	1	7	-	-	-
A.S.B. 5.2	55	-	-	2	-	-	1
A.B.S. 5.3	58	-	-	1	-	-	-
A.B.S. 5.4	50	2	-	7	-	-	-
A.B.S. 5.5	31	5	-	23	-	-	-
A.B.S. 5.6	37	3	-	19	-	-	-
A.B.S. 5.7	49	-	-	10	-	-	-
A.B.S. 5.8	52	2	-	5	-	-	-
A.B.S. 5.9	23	-	-	2*	10	24	-
A.B.S. 5.10	27	-	2	30	-	-	-

*Gain and Loss

Table 07. Domain 6 – Self-Neglect

Questions	Never	Rarely	Sometimes	Often	I.D.R.*
S.N. 6.1	42	1	-	15	1
S.N. 6.2	53	-	1	5	1

Table 08. Domain 7 – Loss Important Object

Questions	Never	Rarely	Sometimes	Often	I.D.R.*
L.I.O 7.1	41	4	-	14	-

†.D.R: I don't remember

Appendix 3

STROBE Statement—Checklist of items that should be included in reports of **observation studies**

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	a, Title, and abstract b, Abstract
Introduction Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Introduction, paragraph 1-9 State of the art
Objectives	3	State specific objectives, including any prespecified hypotheses	Objectives of the study
Methods Study design	4	Present key elements of study design early in the paper	Methods, paragraph 1
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Methods, paragraph 3-7 The questionnaire
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (b) For matched studies, give matching criteria and number of exposed and unexposed	a. Methods, paragraph 3-7 criteria for participation in the study b. Not applicable
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Methods, Tables 03 Variables
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Methods, Variables The questionnaire
Bias	9	Describe any efforts to address potential sources of bias	Objective of the study paragraph 4

Study size	10	Explain how the study size was arrived at	Methods, sample size
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Methods, variables statistical analyzes
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	a, Methods, statistical analyzes
		(b) Describe any methods used to examine subgroups and interactions	b, Not applicable
		(c) Explain how missing data were addressed	c, Not applicable
		(d) If applicable, explain how loss to follow-up was addressed	d, Not applicable
		(e) Describe any sensitivity analyses	e, Not applicable
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	Not Applicable.
Descriptive data	14*	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	a, Results, paragraph 1, Table 05, 06
		(b) Indicate number of participants with missing data for each variable of interest	b, Not applicable
		(c) Summaries follow-up time (e.g., average and total amount)	c, Not applicable
Outcome data	15*	Report numbers of outcome events or summary measures over time	Graphic 01, Tables 05,06,07, 08,09,10,11
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which	Not applicable

		confounders were adjusted for and why they were included	
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	Not Applicable
Discussion			
Key results	18	summarize key results with reference to study objectives	Discussion,
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Limitations
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Discussion
Generalisability	21	Discuss the generalisability (external validity) of the study results	Discussion, paragraph 36
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Not applicable

Appendix 4 - Article

Adverse events with social and/or economic impact in patients with dementia attended at a neurology outpatient clinic - Prevalence study in the five years prior to diagnosis

Delineau, VMEB; Cruz VTR

ABSTRACT

Dementia gives rise to a great social burden, forcing family members and caregivers to bear economic burden and stress, and increasing public health challenges. **Objectives:** To investigate the prevalence of events with social or economic implications for the patients, the caregivers and other third parties, related to dementia disease in the 5-year period preceding the diagnosis of dementia. **Methods:** 59 participants were recruited from the neurologic outpatient clinic of Pedro Hispano Hospital in Matosinhos - Portugal. The participants and their caregivers answered a standardized survey regarding the eight domains of events and signs related to dementia that occurred 5 years before the disease diagnosis. Some days after the questionnaire interview, calls were made to caregivers to find out any other events that might not have been reported. Hospital admissions, episodes of recourse to hospital emergency services or other consultations with specialists were investigated. **Results:** The mean age of participants was 78.85 (SD 7.61) years and the majority of the sample were women 43 (72.9%). The main diagnoses found were AD (55%), MD (10.2%), and VaD (8.5%). The most prevalent domain of event found was BPSD (Behavioral and Psychological Symptoms in Dementia) with 84.7%. Secondly, it was Medication errors on self-administration with 69.5% of prevalence. Impaired Financial Capacity presented 67.5% of prevalence. Most participants 31 (52.5%) reported that the first symptoms appeared between 1 and 3 years before the survey. **Conclusions:** The high prevalence of these events emphasizes how relevant this could be to establish public health policies to reduce dementia's consequences.

Acronym

Key-words: dementia; mild cognitive impairment, social and economic impact;

Introduction

The rising number of people with dementia has become a serious public health issue. In 2015, the global cost of dementia was estimated at \$ 818 billion, equivalent to 1.1% of the world's Gross Domestic Product (GDP), ranging from 0.2% in low and middle income countries to 1.4% in countries with high income (1). 85% of these costs were related to family and social (2). In 2018, the global cost was further increased and it was estimated in \$1 trillion annually (3). However, these numbers will be much higher in the coming years, as it is estimated that in 2030 this cost would likely reach \$ 2 trillion (1)(4).

Portugal is the 3rd country with most cases of dementia in Europe and the 4th among the OECD countries (5). A study in the North of the country established prevalence rates of 2.7% for dementia affecting individuals older than 55 (6) .

As a consequence of dementia progression, the patient's dependence and incapacity rise and quality of life declines (2)(7). In addition, due to difficulties with managing finances, medications, shopping, and for advanced levels of the disease: hygiene, dressing, eating, bathing and other basic activities, a caregiver would ultimately become required (8). The other side of the progression of the disease is a social problem in which we found caregivers frequently stressed and depressed as result of the high burden they have to carry (9)(10).

Furthermore, the onset of dementia usually corresponds to a slowly progressive process of this loss of capacity, which makes difficult for patients and family members to recognize the initial symptoms (11). It is therefore common that initial diagnosis occurs after a sentinel event or only after a series of adverse events with a social or economic impact that surprises patients and their families and forces them to seek specific care.

Hence, it is relevant to characterize the type of adverse events, when they appear, and which factors determine their prevalence. The responses of these questions are of epidemiological and clinical relevance and they are addressed and analyzed in this study.

Our main objective is to analyze a prevalence of events with social or economic implications for the patient, caregivers and other third parties potentially associated to dementia disease.

The study was limited to the 5-year period preceding the diagnosis of dementia and focused on serious, but preventable events through the implementation of earlier pharmacological and non-pharmacological interventions.

Methods:

This study is reported as per the “Strengthening the Reporting of Observational Studies in Epidemiology” guideline (STROBE Checklist).

This is an observational study of prevalence, based on standardized survey (Appendix n. 02) prepared by the researcher considering all events defined in table 01. This study was approved by the Ethics Committee of Hospital Pedro Hispano (HPH) – Matosinhos - Portugal.

Patients were recruited among the neurology service users at the outpatient clinic of HPH, after their consultations. The inclusion criteria for assessing the patients were: prior determination of a diagnosis of dementia or MCI; pre-established Mini-mental State Examination (MMSE); the presence of the caregiver on the date of interview and the complete data on the patient. The exclusion criteria were: reversible dementia; psychiatric pathology before dementia (except depression) and serious visual or hearing impairment.

After patients and their caregivers consented to participate in the study by signing an informed consent form approved by the local ethics committee, the objectives of the study were presented to them. Afterwards, they answered the questionnaire through an interview carried out by the researcher.

One week later the questionnaire interview, the researcher called to the participants to find out if any other events were identified and not reported in the questionnaire, since some of events may have been recognized after a family discussion about the study. Hospital admissions to HPH, episodes of recourse to hospital emergency services or other consultations with specialists were investigated in the search the other events.

The targeted events found in the literature and objective of this study are the following:

Table 01. Events

Domains	Definitions	Events Investigated
Road traffic accidents (RTA)	Events involving a moving vehicle and resulting in victims and/or material damage (12)(13)(14)	Car; motorcycle; bicycle and pedestrian accidents
Falls	Tinetti, 1988, fall is "an event which results in a person coming to fall unintentionally on the ground or other lower level, not as a result of a major intrinsic event (such as stroke) or overwhelming hazard" (15)	Falls
Unintentional home injuries (UHI)	Physical injuries to self or others, property loss or property damage at home	Poisonings, fires, burns
Impaired financial capacity (IFC)	Financial Capacity, is "the ability to independently manage money and financial assets in a manner consistent with personal self-interest and values" (16)	Inability to recognize or count coins; non-payment of bills or rentals; confusions in bank account management; mistaken purchases, unusual withdrawals or donations; scams
Medications errors (self-administration)	The United State National Coordinating Council for Medication Error Reporting and Prevention defines a medication error as: "any preventable event that may cause or lead to inappropriate medication use or patient harm while the medication is in the control of the health care professional, patient, or consumer" (17)	Drugs errors; dose errors; frequency errors (self-administration)
Behavioral and psychological symptoms in dementia (BPSD)	Behavior with signs of psychological or psychiatric changes with social implication (except mood symptoms)(18)(19)(20)(21)	Delusions; hallucinations; agitation/aggressions, disinhibition; Irritability; motor disturbance/ wandering; sleep disturbances; eating disturbances
Self-neglect (SN)	A self-neglector is a person who exhibits ≥ 1 of the following: 1) Persistent inattention to personal hygiene and/or environment; 2) Repeated refusal of some/all indicated services which can reasonably be expected to improve quality of life; 3) Self-endangerment through the manifestation of unsafe behaviors (22)	Consciously neglecting chronic medical problems; unexplained lapses in recommended health maintenance activities; lack of personal hygiene; disheveled appearance (22)
Loss of Important Objects (LIO)	Loss of important or valuable objects that result in injury to the patient or third parties	Loss of important or valuable objects

In order to avoid potential bias, the researchers decided not to include the mood symptoms in the BPSD domain because there is a debate whether depression is a prodromal symptom or an independent risk factor for dementia. In addition, depression is a very frequent diagnosis for elderly people that can occur many years before the onset dementia (23).

Sample Size Calculation

The sample size calculation used the prevalence of each events researched in this study. We took the prevalence presented in the previous studies for each event in MCI, and we calculated the sample size in **epi info statcalc online**. In the literature the domains of events that have the highest prevalence are Falls (24) and BPSD (18)(20)(25). They were chosen to establish the ideal sample. In order to calculate the sample size, we used the information report regarding the number of dementia patients attended at HPH in 2016 (26).

Statistical Analysis:

All Statistical Analyses were performed using the Statistical Package for the Social Sciences (SPSS version 24 and 26 for Windows). For the descriptive analysis of continuous variables, mean, standard deviation, median and average were calculated. For categorical variables, frequency and percentage were calculated. To compare the scores by Diagnosis, the Chi-Square test was performed. The threshold of significance was set at $p < 0.05$.

The results:

The table 02 shows demographic and clinic characteristics of the participants. In our study 59 patients with eligibility criteria performed the questionnaire. The mean age of participants was 78,85 years (SD 7,61), median of 79 and range of 61-91 years old. Most of the participants were women 43 (72.9%). The main marital status was married with 31 (52%), followed by widows 24 (40.7%). Most of the participants (83.1%) had up to 4 years of study, with only one participant having more than 12 years of study. Only 3 (5.1%) participants were still professionally active at the time of the interview.

The main diagnosis found was AD with 33 patients and 55% of the sample. Mixed Dementia (MD) was the second most prevalent diagnosis (10.2%), and the third was Vascular Dementia (VaD) (8.5%). There were 05 (8.5%) participants with MCI diagnosis. Most participants (52.5%) reported that the first symptoms appeared between 1 and 3 years before the date of the interview.

The MMSE carried out up to 6 months before the questionnaire date, revealed that 05 (8.5%) of the participants scored above 26 points (MCI), 26 (44.1%) scored between 20-25 points (Mild Dementia), 17(28.8% scored between 10-19 (Dementia Moderate) and 11 participants scored below 09 points (Dementia Severe).

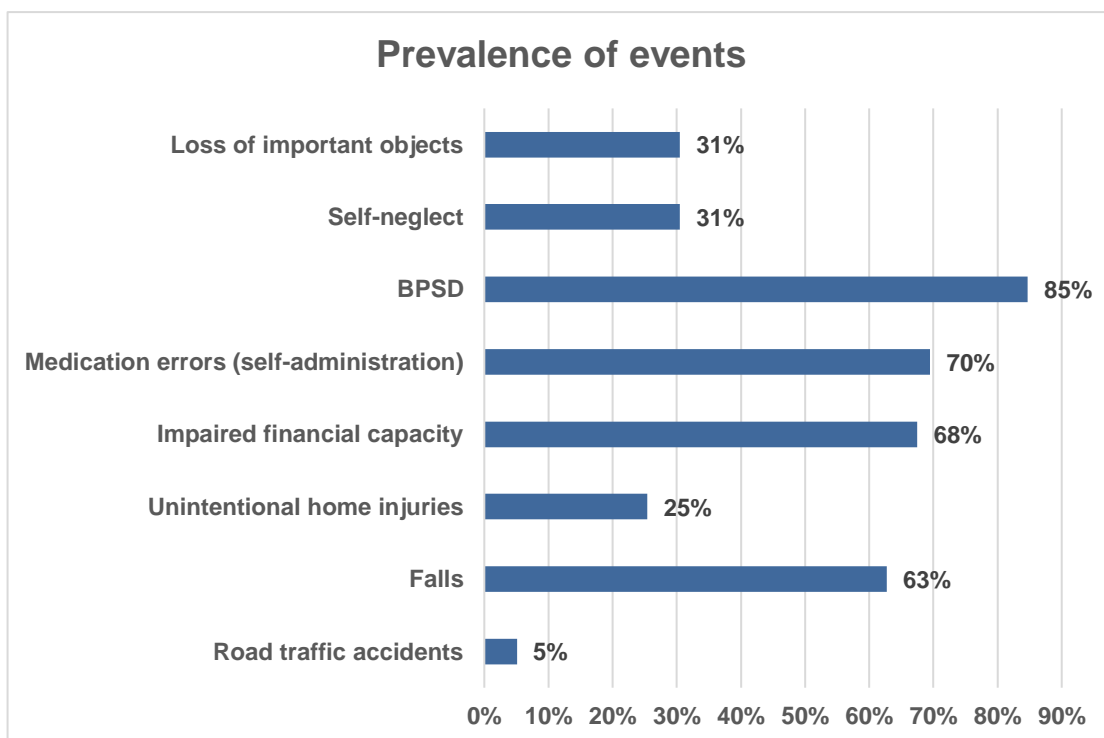
Table 02. Socio-demographic and clinical information

Socio-demographic and clinical information's	Total N=59
Age, years	
Mean (SD)	78.85 (7.61)
Median	79
Range	61-91
Gender	
Women	43 (72.9%)
Men	16 (27.1%)
Marital status	
Maried	31 (52.5%)
Widow	24 (40.7%)
Single	03 (5.1%)
Other	01 (1.7%)
Schooling	
0-4 yrs	49 (83.1%)
5-9 yrs	09 (15.3%)
> 9 yrs	01 (1.7%)
Neurological Diagnosis	
Alzheimer's disease (AD)	33 (55%)
Mixed type dementia (MD)	06 (10.2%)
Vascular dementia (VD)	05 (8.5%)
Mild cognitive impairment (MCI)	05 (8.5%)
Parkinson's disease dementia (PDD)	04 (6.8%)
Dementia with Lewy Body (DLB)	03 (5.1%)
Frontotemporal dementia (FTD)	03 (5.1%)
Data of the first symptom	
0-1 yrs	10 (16.9%)
1-3 yrs	31 (52.5%)
3-5 yrs	10 (16.9%)
> 5 yrs	08 (13.6%)
MMSE (Mini Mental State Examination)	
≥ 26 (MCI)	05 (8.5%)
20-25 (Mild dementia)	26 (44.1%)
10-19 (Moderate dementia)	17 (28.8%)
0-9 (Severe dementia)	11 (18.6%)

The most prevalent event found was BPSD with 84,7% of positive response by participants. Secondly, it was Medication Errors on Self-Administration with 69,5% of prevalence. Impaired Financial Capacity presented 67,5%. Falls presented a prevalence of 62,7%. Self-neglect had the same prevalence as Loss of Important Objects, that is, 30,5% of participants referred had at least one event. Unintentional home injuries were reported by 25,4% of participants. Only 03 (5,1%) participant reported had road traffic injuries.

The prevalence of all events is exposed in the graphic below.

Graphic 1. Prevalence of events



Regarding possible outcome associations, all domains were analyzed statistically in order to seek an association of results in relation to the different Sub-Diagnoses of dementia. The results are exposed below in the table attached (Table 03), but our study did not find a statistical significance in these associations.

Table 03.Diagnosis and Events

	Diagnosis			Total	(p-value)
	Alzheimer's Disease	MCI	Other Dementias		
RTA					
No	31 (93.9%)	5 (100%)	20 (95.2%)	56 (94.9%)	0.745*
Yes	2 (6.1%)	0 (0%)	1 (4.8%)	3 (5.1%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
Falls					
No	12 (36.4%)	2 (40%)	8 (38.1%)	22 (37.3%)	0.983*
Yes	21 (63.6%)	3 (60%)	13 (61.9%)	37 (62.7%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
UHI					
No	26 (78.8%)	3 (60%)	15 (71.4%)	44 (74.6%)	0.626*
Yes	7 (21.2%)	2 (40%)	6 (28.6%)	15 (25.4%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
IFC					
No	11 (33.3%)	1 (20%)	7 (33.3%)	19 (32.2%)	0.8176 *
Yes	22 (66.7%)	4 (80%)	14 (66.7%)	40 (67.8%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
ME					
No	9 (27.3%)	2 (40%)	7 (33.3%)	18 (30.5%)	0.800*
Yes	24 (72.7%)	3 (60%)	14 (66.7%)	41 (69.5%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
BPSD					
No	4 (12.1%)	1 (20%)	4 (19%)	9 (15.3%)	0.753*
Yes	29 (87.9%)	4 (80%)	17 (81%)	50 (84.7%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
SN					
No	21 (63.6%)	4 (80%)	16 (76.2%)	41 (69.5%)	0.531*
Yes	12 (36.4%)	1 (20%)	5 (23.8%)	18 (30.5%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
LIO					
No	23 (69.7%)	4 (80%)	14 (66.7%)	41 (69.5%)	0.835*
Yes	10 (30.3%)	1 (20%)	7 (33.3%)	18 (30.5%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	
Total					
No	0 (0%)	0 (0%)	1 (4.8%)	1 (1.7%)	0.350*
Yes	33 (100%)	5 (100%)	20 (95.2%)	58 (98.3%)	
Total	33 (100%)	5 (100%)	21 (100%)	59 (100%)	

*Likelihood Ratio – Chi-Square Test

Discussion

As far as we know, this study is unique in Portugal, and there is no similar study carried out using the same methodology. The results are important because they can influence directly and indirectly public health policies for the elderly in Portugal. Furthermore, it is interesting to note that Portugal has the fifth oldest population in the world.

The results of sociodemographic characteristic presented a high average age (79 years) among the participants being most of them women (72%). The remarkable difference between the genders is similar to the one already found in another study of dementia in a Population- Based Cohort from Northern Portugal (27). The low educational level of the sample (83.1% of the participants had up to 04 years of study) was also surprising but it is similar to the average found in another study of elderly carried out in Portugal, in which 77,3% of participants had up to 4 years education level.

Regarding the date of diagnosis, most participants 31 (52.5%) reported that the first symptoms appeared between 1 and 3 years before the date of the interview, and 28 (30,5%) have recalled symptoms more than 03 years before the date of diagnosis. This is a relevant and worrying result demonstrating a long period between the onset of symptoms and the beginning of specific care and treatments.

MMSE score presented another significant outcome from the perspective of public health, in which 28 (47,4%) were already in moderate and severe dementia just a few months after the diagnosis. This result might demonstrate the occurrence of a late dementia diagnosis in Portugal.

However, there was no significant difference in events prevalence between patients with MCI/mild dementia vs. moderate /severe dementia regarding the MMSE score (Table 12). This outcome can be considered positive, as it may indicate that once symptoms, signs, and events concerning dementia are beginning, in some way, the families or even the caregivers increase the care for the patient, avoiding an increase in these harmful events.

Concerning the neurological diagnosis, we found results slightly different from those found in two current studies in northern Portugal, because while we found 55% of AD, 10,2% of MD and 8,5% of VD in our study, Nunes *and colleagues*, 2010, found equal proportions of AD and VD(28) and Ruano *and colleagues*, 2019, found 52% of VaD and 36,1% of AD in their study (27). However, the finding is compatible with the world epidemiological data on dementia, in which AD is the main diagnosis (2)(29). We have raised two hypotheses for this outcome variation: firstly, is the high prevalence of women in our study (AD is more

frequent in women), and secondly, perhaps our study population has fewer risk factors for vascular disease. Although, this second hypothesis should be better investigated.

Regarding the frequency of events, the outcomes showed a high prevalence. Examining the eight domains analyzed, 04 showed prevalence above 50%, they are BPSD (84,7%), Medication Errors (69,5%), Impaired Financial Capacity (67,8%) and Falls (62,7%), three presented an important prevalence, that is, Self-neglect (30,5%), Loss of Important Objects (30,5%) Unintentional Home Injuries (25,4%). Concerning Road Traffic Injuries only 03 (5,1%) participants reported some type of accident involving means of transportation.

The BPSD prevalence of 84,7% was similar to other studies, particularly for a population-based prevalence study performed by *Steinberg M. and colleagues, 2003*, in which the researchers found the cumulative prevalence of mental or behavioral disturbances during 18 months at 88.6% (78). The main sub-diagnosis of dementia found in BPSD domain was AD, with 87,9% of prevalence. Although high this prevalence is in line with the literature findings and it might indicate a great burden for family members and caregivers (25)(31) .

Medication errors on self-administration has high prevalence (69,5%) and perhaps the results were influenced by low health literacy among the participants of the study. This outcome is a concern, because errors in taking medicines may give rise to adverse events with severe consequences such as hospitalizations and ultimately possible deaths.

Impaired financial capacity was 67,8% of prevalence concerning total participants, which meets what *Chiong and colleagues* found in their study (32). Regarding MCI participants the prevalence was higher (80%), but the small sample would not allow to draw a conclusion on this outcome.

Falls were the fourth most prevalent domain (62,7%). In fact, falls in cognitively healthy elderly are a major public health problem, and in Portugal the prevalence in 2017 was 21,87% among elderly over 70 years old. Considering falls in dementia, the situation is even more serious as they are a significant cause of morbidity and mortality in people with cognitive decline. The most prevalent sub-diagnosis of dementia found in falls was AD with 63,3% of prevalence. Our outcomes agree with other studies (33)(34). *Allan and colleagues, 2009*, in a prospective study of predictors of falls in dementia demonstrated that older people with dementia experience 8 times more incident falls than those without the disease, and the prevalence of falls in AD in their study was 47% (33).

The prevention of falls in dementia patients is unclear, once it has not been evidenced that interventions to reduce the risk of falls in cognitively normal population can help patients with dementia. *Shaw, 2007* summarized that “despite individual positive studies in

populations including participants with dementia, systematic review and meta-analysis does not demonstrate generalizable benefit from multifactorial or individual intervention strategies in this population group”(35). Despite this conclusion, the preventions of falls should be a goal in the elderly population, especially with dementia disease. Despite this conclusion, falling prevention should be a goal in the elderly in order to try to find a reduction in risks.

Self-Neglect presented a worrisome prevalence (30,5%), because studies showed that self-neglect can increase mortality in elderly (36).

Although memory loss is known in studies as one of the first symptoms of dementia, we did not find in literature a specific prevalence of losing important and valuable objects. However, our study found a prevalence of 30,5%.

In a study review performed by *Gagnon-Roy and colleagues*, 2018, regarding unintentional home injuries and avoidable incidents in older adults with cognitive impairment, burns appeared as the third cause of Emergency Department visits following an incident in USA (2-3%) (37). In our study the outcome was frequent, because 15% of participants reported unintentional home injuries (poisoning or mild burns). Considering the seriousness of the consequences this outcome is another concern. Perhaps the presence of caregiver or institutionalization could do help to prevent or limit these occurrences.

Road traffic accidents (RTA) was a low prevalence in our study (5,1%), but it is important to note that 43 (72%) of our participants informed us that they never drove or have stopped driving more than 05 years before the survey, which really limited our assessment.

In summary, the outcomes showed that in a Portuguese population events with social or economic impact associated to dementia disease can be observed years before the diagnosis with the similar prevalence got found after neurological diagnosis. In addition, we realized that there are some important and relatively unexplored issues about these events and their consequences.

Finally, in our opinion, health professionals must monitor the first signs and symptoms of dementia for elderly in order to inform patients and their families how to avoid these undesirable events and possibly enroll them in early pharmacological therapy and/or non-pharmacological interventions of cognitive stimulation such as Cognitive Stimulation Therapy (CST), Web Cognitive Training (38) programs and other therapies in order to reduce the progression of the disease.

Limitations

The main limitation of this work was the reduced numbers of patients that were available with the inclusion criteria, resulting in a rather small sample. The second limitation is a possible information bias, as the caregivers may not have lived with the patient the whole time in the last 05 years, so they might not know all the events and symptoms that occurred these years before the diagnosis.

Conflict of interest:

There is no conflict of interest to declare.

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