REVISTA
O MUNDO DA
SAÚDE

Palliative care and advanced dementia: trajectory of hospitalized elderly people in their last 48 hours of life

Sergio Falcão Durão*
Márcia Carréra Campos Leal*
Ana Paula de Oliveira Marques*
Kimberly Mayara Gouveia Bezerra*

Abstract

This study aimed to analyze the last 48 hours of life of hospitalized elderly with advanced dementia and the profile of care over the 5 years analyzed. This is a retrospective cross-sectional study, through the analysis of electronic medical records of patients participating in the study, who died between January 1, 2013 and December 31, 2017. 328 medical records were analyzed in the defined period and 97 met the inclusion criteria. Ninety-three patients (95.9%) had records of advance directives of their wills, 73.2% were female, with a mean age of 88.7 years, 52.6% of deaths occurred in an apartment or infirmary, in the latter 48h of life, 64.9% were on an enteral diet, 28.9% were breathing by mechanical ventilation, 51% were using antibiotics, and 86.6% were prescribed fixed analgesia; however, 19% had a record of uncontrolled pain. Over the 5 years of observation, there were changes in the following aspects: reduction of deaths in the intensive care unit (60% vs. 36.4%), decrease in the use of tube feeding (87% vs. 32%), in the use of mechanical ventilation (53% vs. 18%); the use of central venous catheter (47% vs. 27%); the use of permanent urinary catheter (27% vs. 5%), and the presence of pressure injuries (87% vs. 45%). It is concluded that in the 5 years of analysis a palliative trend in care was characterized by the reduction of procedures considered invasive, in the last 48 hours of life, in patients with advanced dementia.

Keywords: Elderly. Advanced dementia. End of life care. Palliative care

---

INTRODUCTION

The aging of the world population and the change in the epidemiological profile, with a higher prevalence of chronic non-communicable diseases (CNCDs), have motivated changes in the health care profile, especially in hospital care for patients with advanced stage dementia.

The demographic and epidemiological transition is a global phenomenon. The combination of the sharp decrease in fertility rates and the increase in life expectancy has led to the rapid aging of populations around the world[1]. In Brazil, the increase in the elderly population has been happening at an accelerated pace. It is estimated that every year, 650,000 new elderly people are incorporated into the Brazilian population and already have an average life expectancy

DOI: 10.15343/0104-7809.202145413423

*Universidade Federal de Pernambuco – UFPE. Recife/PE, Brasil.
E-mail: sfalcaodurao@gmail.com

of 75.8 years[2]. The rapid demographic and epidemiological transitions in Brazil have had a profound repercussion on social, cultural, economic aspects, and especially on the population's health care.

Unlike acute processes that, for the health system, are less costly because they quickly culminate in cure or death, CNCDs imply decades of use of health services[3]. In 2015, costs for treating dementia alone were estimated at US$818 billion, equivalent to 1.1% of the global gross domestic product[4].

Dementia is a generic term, replaced in the DSM-V (Diagnostic and Statistical Manual of Mental Disorders - 5) by Major Cognitive Disorder, to denote various progressive and incurable neurodegenerative diseases that affect memory, other cognitive abilities, and behavior. They are understood to be associated with multiple risk factors throughout the course of life, varied symptomatic patterns, and a progression influenced by biopsychosocial and environmental factors[5].

Alzheimer's disease is the most common form of dementia, accounting for 60-80% of cases[6,7]. Other main forms include vascular dementia, Lewy body dementia, frontotemporal dementia, normal pressure hydrocephalus, and dementias derived from infections (Syphilis, HIV) as well as more rare causes.

In 2015, it was estimated that 47 million people (or approximately 5% of the world's elderly population) had dementia, a number that is expected to increase to 75 million in 2030 and 132 million by 2050. Recent assessments show that, globally, around 9.9 million people develop dementia each year, that is, a new case every three seconds. About 60% of people with dementia currently live in low and middle income countries and the majority of new cases (71%) are expected to occur in these countries[8].

In Brazil, the average prevalence of dementia patients is higher than in the world. Projections indicate that there will still be a small increase in the prevalence rate in the Brazilian population aged 65 and over, from 7.6% to 7.9% between 2010 and 2020, that is, 55,000 new cases per year[9]. The average survival after diagnosis varies from 3 to 12 years, with patients spending most of that time in the most severe stage of the disease[10].

There are several instruments and scales for cognitive assessments validated in the literature; however, the most widely used, both in practice and in clinical trials, is the MMSE (Mini Mental State Examination), which ranges from zero to thirty. Escores between 11 and 17 suggest a moderate stage of the disease, while scores less than or equal to 10 indicate an advanced stage[11]. Despite being the best known, this test has a floor effect for severely demented individuals, and new tools have been developed to better monitor these patients.

The Global Deterioration Scale - GDS and the Functional Assessment Staging - FAST are the most used scales in the literature as they are more accurate instruments for measuring the cognitive and functional performance of patients and for classifying advanced stage Alzheimer's Dementia patients[12]. In addition to these two, the Clinical Dementia Rating (CDR) is still frequently used, which allows for classifying the different degrees of dementia, as well as identifying questionable cases, that is, those that are not classified as normal[12].

GDS scores of 7 (1-7 scale), FAST 6 or 7 (1-7 scale), and CDR 3-5 (1-5 scale) are correlated with patients in advanced stages of dementia, when there are already profound memory deficits (e.g., inability to recognize family members), minimal verbal skills, inability to walk independently, inability to perform any activities of daily living, and urinary and fecal incontinence[13].

Hospital care for patients with advanced dementia has been a challenge. Unlike what happens with patients with cancer, the prognosis of patients with dementia is more difficult. Some studies have been done to understand the course of the disease and identify risk factors for a worse prognosis; however, the results are still not very consistent. Advanced age at diagnosis and low functional status are associated with higher mortality[14,15].

In this scenario, health teams are faced with difficult decisions that involve multiple actors (patient, family, team, among others). Discussing terminality, advance directives of will (ADW), end of life care, in the context of hospitalization of a patient with advanced dementia is a challenging task, and often involves suffering of the staff, patients, and families, especially when patients go to death in the hospital. In several countries, despite cultural differences, almost 50% of deaths occur in a hospital environment[16,17,18].

Although many physicians and family members of people with dementia do not consider dementia to be a progressive and fatal disease, in 2010, Alzheimer's dementia was the sixth leading cause of death in the United States and the fifth leading cause of death among the 65 year old and older population[19]. The institution of palliative care is recommended from the early stages of dementia[20]; however, it is uncommon for patients and caregivers to be familiar with the topic or have been approached by health professionals in the early stages of the disease regarding care planning in the advanced stage.

Palliative care is not synonymous with “there is nothing else to do” for the person who is at this stage of the disease. The care’s focus in this context needs to be changed from the search for a cure to the prevention and control of symptoms and implementation of care that reduces suffering, provides comfort, quality of life, and dignity for both the patient and their family, respecting their individual characteristics. In Brazil, this form of health care has been gaining prominence in the last decade due to the growing need of the population and the understanding of ethical and legal issues involving terminality and death and is already part of the care line of several Brazilians centers[21].

In the field of bioethics, there is a growing number of publications that deal with advance directives of will[22], which support a care plan with decisions shared between the physician’s assistant and the patient or legal guardian. This instrument is useful to guide the management of patients with advanced dementia. Despite being an approach guided by bioethical principles such as dignity, autonomy and non-maleficence, systematic reviews have not favored this approach in relation to usual health care[23].

Studies involving hospital care for patients with advanced dementia undergoing palliative care are still scarce in the literature. Therefore, based on the above and the aim of contributing to the improvement of care and the deepening of discussions on the topic, the present study aimed to analyze the last 48 hours of life of hospitalized elderly with advanced dementia and the care profile over the 5 year period analyzed.

MATERIAL AND METHODS

This is a descriptive, cross-sectional, retrospective, observational study conducted through the analysis of electronic medical records of patients admitted to a geriatrics and gerontology service of a private hospital in Recife, PE. Elderly people (60 years old or more) with advanced dementia who died in that service were selected from January 2013 to December 2017, according to the inclusion criteria. Data were collected from the hospital's digital file with informed consent from the institution's management.

Inclusion criteria were: age greater than or equal to 60 years old, death recorded in the peri-od between January 2013 and December 2017, and the diagnosis of "Advanced Dementia" or "Dementia Syndrome in advanced stage", "Advanced AD", "Advanced Alzheimer's Dementia", "Advanced Vascular Dementia", "Mixed (AD+DV) or Advanced Dementia (AD+HPN)", "Ad-vanced DFT", "Dementia of Advanced Parkinson's Disease", "CDR 03-05", "FAST 6 or 7", "GDS 6 or 7" recorded in the medical records. Incomplete medical records were excluded from the research.

To define the sample, 328 medical records were analyzed in the defined period, referring to all elderly patients who died and were monitored by the staff of the Geriatrics Department. Of these, 173 had Dementia Syndrome, and 97 completed the criteria for inclusion in the sample.

Information was collected by filling out a script designed for data collection. The dependent variable was the recording of ADW/PC (advanced directives of will/directives for palliative care) in the patient's therapeutic plan. The independent variables were socio-demographic data (gender, age); comorbidities reported in medical records (inactive stroke, Parkinson's Disease, Systemic Arterial Hypertension (SAH), Heart Failure (HF), Diabetes Mellitus (DM), Depression, Delirium, Chronic Liver Disease (CLD), Active Neoplasm, Chronic Kidney Disease (CKD), Chronic Obstructive Pulmonary Disease (COPD), Pressure Injury (PI), Immobility Syndrome). Moreover, the definition of ADW/PC described in the medical record; hospitalization time until death (days); PC time defined until the date of death (days); place of death; reports of the presence of pain in the last 48 hours of life; and use of medications, namely: prescription of analgesics/sedatives at fixed times, antibiotics, and vasoactive drugs were also recorded. Furthermore, therapeutic procedures in the last 48 hours of life like the use of tubes for feeding (naso-enteral tube (NET)/gastrostomy tube (GTT)); indwelling urinary catheters (IUC); central venous catheters (CVC); hemodialysis (HD); transfusion of blood components; use of invasive ventilatory assistance were also recorded.

The research project was registered and approved by the Ethics Committee for Research In-volving Human Beings of the Health Sciences Center of the Federal University of Pernambuco (CAAE No. 89505118.0.0000.5208), in compliance with Council Resolution 466/2012 National Health, referring to the development of research and tests involving human beings, safeguarding the ethical principles of justice, beneficence, and non-maleficence.

RESULTS

A total of 328 medical records were analyzed in the defined period, referring to all elderly patients who died and were monitored by the Geriatrics team. Of the total of 97 patients included in the study, 93 (95.9%) had advance care guidelines registered in the medical record before death, of which 73.2% were female, with a mean age of 88.7 years old.

The average length of hospitalization and the time of ADW-death were 60.6 and 18.6 days, respectively. Regarding the place of death, 47.4% occurred in the ICU and 52.6% in their apart-ment/infirmary.

Regarding the frequency of comorbidities, Table 1 shows higher percentages of SAH (63.9%), PI (63.9%), Immobility Syndrome (48.5%), stroke (34%), and DM (28.9%).

Table 2 describes the occurrence of procedures that patients underwent in the last 48 hours of life. It is noted that more than half of the individuals (68.1%) were on a tube diet (NET/GTT), 37.1% were using a central venous catheter (CVC), and 28.9% were breathing with the aid of mechanical ventilation (MVA).

In the studied population, a change in the care profile was observed over the 5 years. When comparing the first and fifth year evaluated, some changes in the care profile stand out, such as a reduction of about 24% of deaths in the ICU (60% vs. 36.4%), as shown in Figure 1. Also, there was a 42% decrease in the use of tube feeding (87% vs. 45%), a 35% reduction in the use of MVA (53% vs. 18%), a 20% decrease in the use of CVC (47% vs. 27%), an 22% reduction in the use of IUC (27% x 5%), as well as a 42% decrease in the presence of PI (87% vs. 45%).

The frequency of antibiotic use was 51%. Regarding pain control and the use of analgesics and/or opioids, 86.6% were using fixed analgesia; however, 19% had reported pain still present in the last 48 hours of life. With regards to the use of diet by feeding tubes, there was a reduction in frequency (87% vs. 45%) in the first and fifth year of analysis, respectively. The annual behavior of the last two variables mentioned above can be seen in Figures 2 and 3.

Regarding the association analysis, considering the dependent variable Palliative Care and the other variables, results with statistical significance were not obtained.

Table 1 – Frequency of comorbidities. Recife,PE, 2019.

Comorbidities	N	%
Systemic Arterial Hypertension	62	63.9%
Diabetes Mellitus	28	28.9%
Cancer	15	15.5%
Stroke	33	34%
Depression	6	6.2%
Chronic Liver Disease	5	5.2%
Heart Failure	17	17.5%
Chronic Kidney Disease	14	14.4%
Chronic Obstructive Pulmonary Disease	14	14.4%
Pressure Injury	62	63.9%
Parkinson D.	16	16.5%
Immobility Syndrome	47	48.5%

Table 2 – Frequency of procedures in the last 48 hours in a geriatric and gerontology service of a private hospital, Recife, PE, 2019.

Procedure	N	%
Tube feeding	63	64.9%
Indwelling urinary catheters	22	22.7%
Mechanical ventilation	28	28.9%
Hemodialysis	3	3.1%
Vasoactive Drugs	9	9.3%
Central venous catheter	36	37.1%
Blood Transfusion	0	0

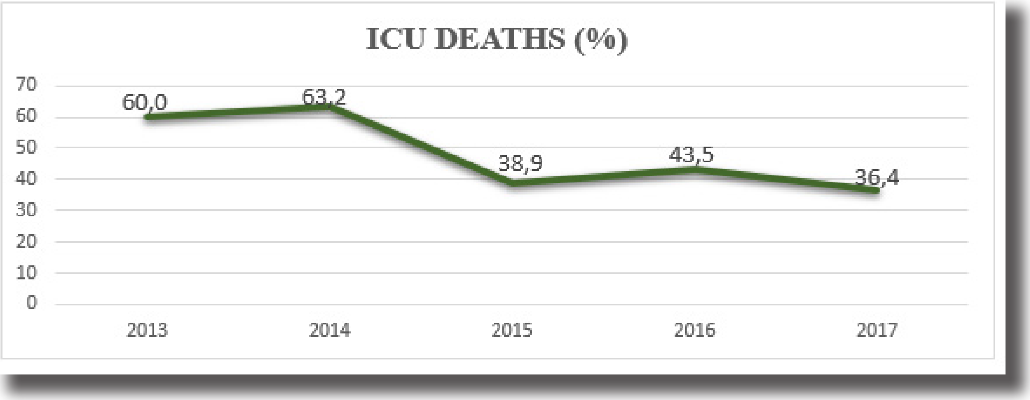

Figure 1 – Percentage of deaths in the ICU per year. Recife, PE, 2019.

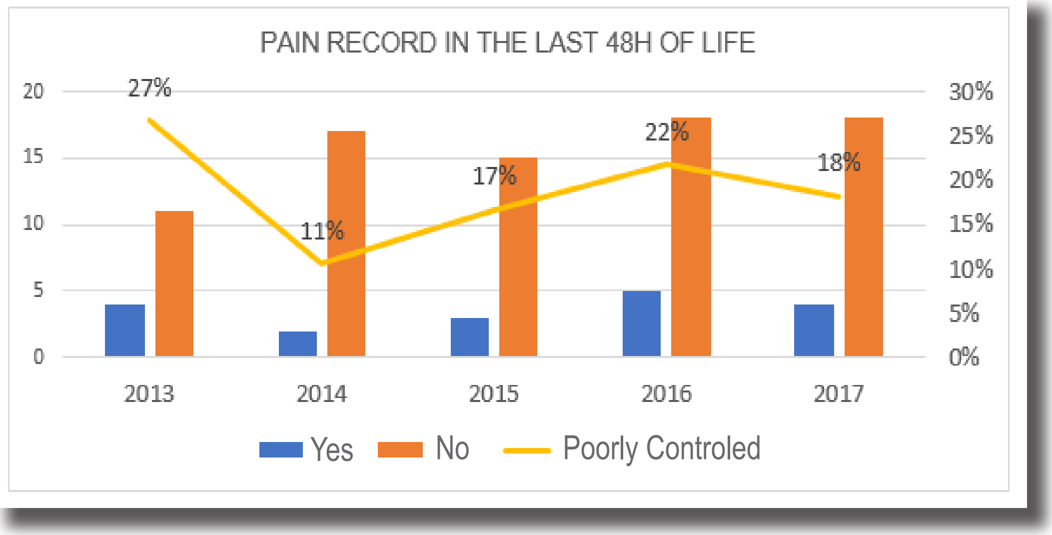

Figure 2 – Annual distribution of the sample regarding pain recording in the last 48 hours of life. Recife, PE, 2019.

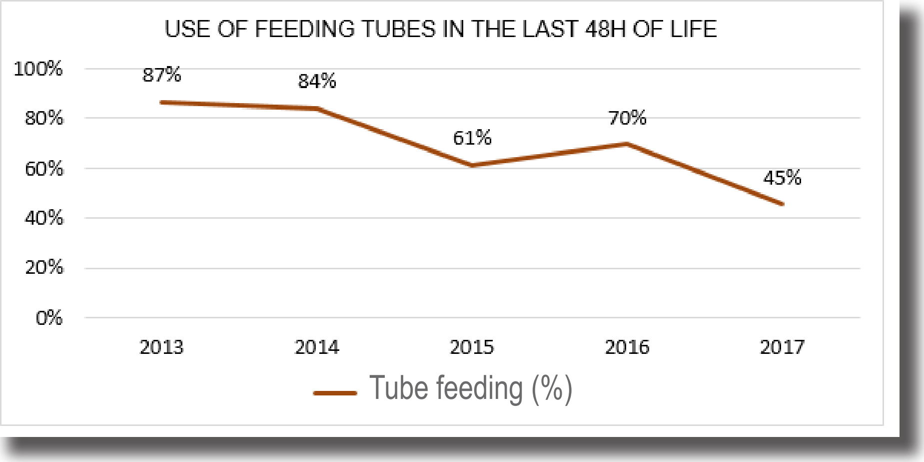

Figure 3 – Annual distribution of the sample regarding the use of tube feeding in the last 48 hours of life. Recife, PE, 2019.

DISCUSSION

The lack of publications in the literature addressing this group of patients in the hospital environment does not contribute to a more comprehensive discussion of the results. However, evaluating existing publications, it is interesting to note that the palliative care approach varies between services and is strongly influenced by cultural issues, as published by Yumoto[24], who compared the care profile in the United Kingdom with that in Japan. In Brazil, there is still no specific legislation that deals with palliative care, but there are ethical norms of the Federal Council of Medicine[25] and legal norms that guide the understanding of this matter, as well as a document from the Ministry of Health that supports this practice.

Regarding the place of death, just over half of them occurred outside the ICU environment (52.6%). Although there has not been a study of the impact of the continuous presence of caregivers and family members during the last 48 hours of life of patients at the bedside, it is understood that there is possibly a strong positive dimension. Hospices have been the most adequate care environment to treat patients with advanced dementia[23,24,] however, this category of service is not currently available in the State of Pernambuco and for this reason many patients with advanced dementia die in a hospital environment.

As for the procedures considered inappropriate for these patients, we found a high frequency of using tube feeding (68.1% vs. 20.5%) when compared to what was published by Di Giulio[26]. Literature shows together with publications from associations and medical societies that the use of feeding tubes in patients with advanced dementia are not recommended, either because of the lack of benefits in various health outcomes such as increased survival or the prevention of aspiration pneumonia[27,28]. In a recent systematic review, published by Lee[29], it was observed that tube feeding is associated with an increase in the mortality rate and possible complications related to the tube, as well as the absence of improvement in survival and nutritional status.

Despite this fact, in current practice, we accept severe dysphagia as part of the final stage of dementia, and that cachexia and dehydration are usually the reason for death for about 1/3 of these patients, as published by Koopmans[30]. This is a difficult matter for some family members and caregivers to accept. Among the reasons that justify this reality are the lack of better understanding of the evolution of dementia, the fear that the patient will suffer from hunger, the difficulty in predicting survival in patients with dementia, the lack of continuity in care, lack of training to communicate bad news among the health team, as well as the culture of denying that death is a natural phenomenon of human life[31].

Despite the decrease in the use of MVA, the disproportionality of its use was apparently more easily accepted by the patients' family members/legal guardians. The indication for the use of IUC is restricted in the last 48 hours of life and the reduction seems to be consistent with the improvement of the team in the management of care and the handling of cases in the environment outside intensive care units, where the use of these devices is more common.

The reduction in CVC performance should be perceived as a positive factor. Martinsson *et al.*[32] found that receiving fluids intravenously in the last 24 hours of life was strongly associated with in-hospital death. Despite not having been a studied variable, the use of the subcutaneous route (hypodermoclysis) to manage symptoms increased during the study period and may have influenced this finding, which requires further studies to test this hypothesis.

According to the results found by Aminoff[32], there was a slightly lower frequency of PI reports (63.9% vs. 70.4%) and similarity in relation to patients with uncontrolled pain (19% vs. 18.3%). Elderly people with advanced dementia who have PIs have an early mortality and significantly lower survival expectancy compared to similar patients without PIs. The development of these lesions is associated with the presence of comorbidities, including nutritional problems, in addition to immobility, which makes it essential to assess risk factors for the development of PI before the onset of more progressive stages of dementia[33,34]. Pressure injuries are very prevalent in this group of patients and although it was not possible to significantly correlate the care environment statistically with the frequency of these findings, there may be a correlation, suggesting that outside being the ICU environment, when subjected to fewer probes and tubes, less hydration there is a tendency for a lower prevalence of this type of injury.

Regarding the use of antibiotics, a frequency of 51% of use was found. Di Giulio[26] in his study, evaluated the last 30 days of life of patients, and found a higher frequency of antibiotic use (71.6%), a result probably influenced by the longer observation time (2 days vs. 30 days). The use of antibiotics as a symptom management strategy in advanced dementia has been a matter of debate in palliative care.

There is no standardization of conduct nor professional practice. Decisions have been centered on the wishes of the patient/family and agreed upon with the physician's assistant. In the service studied, the principle is adopted that the use of antibiotics reduces discomfort in patients with advanced dementia and pneumonia[35]. There is no consensus on this topic, as exemplified by a prospective American study conducted by Givens[36], in which there was a greater survival yet discomfort in the group of patients who used antibiotics. Moreover, the use of these medications was also associated with reduced comfort for people with advanced end of life dementia[37].

In a systematic literature review, Higginson[38], despite the low quality of the studies found, observed a small but positive effect on care when assessing patients, family members, and staff in all care environments. Herein, there was no qualitative analysis, nor was the benefit of palliative interventions among caregivers, family members and staff addressed; however it is believed that the positive effect in reducing invasive procedures was very relevant.

The results found in the present study probably reflect the maturity and training of the hospital teams in relation to palliative care, also influenced by the creation in 2016 of a Palliative Medicine committee composed of geriatricians, oncologists, and intensivists. It is possible that the research field, comprised of a private hospital with an international accreditation certificate, multidisciplinary teams, medical and multidisciplinary education programs, was also a factor that influenced these results.

Among its limitations, the most relevant factors were the retrospective design of the study, the omissions of information from the sociodemographic profile, the absence of the assessment of the impact of palliative care among caregivers, as discussed by Kucmanski[39]. No national publications were found with the same methodology as this study and there was the bias of not being able to pair groups proportionally with and without the definition of ADW in order to assess the impact of this tool on care.

CONCLUSION

The change in the care profile over the 5-year period of analysis represented the most rele-vant data of this work. When comparing the first and fifth year of analysis, it is possible to observe an important change in the profile of care, in relation to the following aspects: reduction of deaths in the ICU, use of tube feeding, MVA, CVC, and IUC, as well as decreased presence of PI.

The results found suggest an invasive treatment profile, in many cases disproportionately; however, there seems to be a strong palliative care trend in the period studied. Among the factors that can justify this change are the growth of teaching in palliative medicine over the last 5 years, the presence of a graduate program in geriatrics in the department, the support of an interdisciplinary hospital team, and doctors (geriatricians, oncologists, intensivists) specialized in palliative medicine who provided assistance in the last year of the analysis.

Communication barriers are one of the important frontiers for research with patients with advanced dementia and there is still no strong evidence to guide clinical management. The studies we used to compare the findings were methodologically the closest, but it is clear that the differ-ences certainly limit comparative analyses.

Therefore, there is a need to carry out other studies in this same thematic line, especially lon-gitudinally, addressing the benefits of ADWs in care, as well as other variables such as caregiver/relatives, health team, communication, and grief, as they are necessary for there to be progress in the search for a smoother, more transforming and ritualized process of death – the model of beautiful death – called *kalothanasia*, while doing so in a challenging medical scenario of therapeutic obstinacy.

REFERENCES

1. Cortez ACL, Silva CRL, Dantas EHM. Aspectos gerais sobre a transição demográfica e epidemiológica da população brasileira. Enfermagem Brasil. 2019; 18(5):700-709. DOI: https://doi.org/10.33233/eb.v18i5.2785
2. IBGE. Tábuas de Mortalidade por sexo e idade – Brasil, Grandes Regiões e Unidades de Federação - 2010. Rio de Janeiro: IBGE; 2013.
3. Kalache A. The Longevity Revolution: Creating a society for all ages. Adelaide Thinker in Residence 2012-2013. Adelaide: Government of South Australia; 2013.
4. Alzheimer's disease international. World Alzheimer Report 2015: The Global Impact of Dementia, An analysis of prevalence, incidence, cost & trends. 2015.
5. Spector A, Orrel M. Using a biopsychosocial model of dementia as a tool to guide clinical practice, Intern. Psychoger. 2010; 22(6): 957–965. DOI: 10.1017/S1041610210000840.
6. Souza RK, Barboza AF, Gasperin G, Garcia HD, Barcellos PM, Nisihara R. Prevalência de demência em pacientes atendidos em um hospital privado no sul do Brasil. Einstein. 2020; 18, 1-7. DOI: 10.31744/einstein_journal/2020AO4752
7. Karantzoulis S, Galvin J. Distinguishing Alzheimer's disease from other major forms of dementia. Expert Rev Neurother. 2011; 11; 1579–1591. DOI: 10.1586/ern.11.155
8. Prince M, Wimo A, Guerchet M, Al G-C, Wu Y-T, Prina M. World Alzheimer Report 2015. The global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International; 2015. Disponível em: https://www.alzint.org/u/WorldAlzheimerReport2015.pdf
9. Burla C, Camarano AA, Kanso S, Fernandes D, Nunes R. Panorama prospectivo das demências no Brasil: um enfoque demográfico. Ciência & Saúde Coletiva. 2013; 18 (10):2949-2956. DOI: 10.1590/S1413-81232013001000019
10. Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: a revi-ew. Int J Geriatr Psychiatry. 2013; 28(11): 1109-1124. DOI: 10.1002/gps.3946
11. Folstein MF, Folstein SE, McHugh PR. "Mini-Mental State": practical method for grading the cogni-tive state of patients for the clinician. J Psychiatr Res. 1975; 12 (3):189-198. DOI: 10.1016/0022-3956(75)90026-6
12. Reisberg B. Functional Assessment Staging (FAST). Psychopharmacol Bull. 1988; 24 (4):653-659.
13. Morris J. The Clinical Dementia Rating (CDR): current version and scoring rules. Neurology. 1993;43 (11):2412-2414. DOI: 10.1212/WNL.43.11.2412-a
14. Mitchell SL, Miller SC, Teno JM, Kiely DK, Davis RB, Shaffer ML. Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. JAMA. 2010; 304(17): 1929-1935. DOI: 10.1001/jama.2010.1572
15. Jayes RL, Arnold RM, Fromme EK. Does this dementia patient meet the prognosis eligibility requirements for hospice enrollment? J Pain Symptom Manage. 2012; 44 (5):750-756. DOI: 10.1016/j.jpainsymman.2012.08.004.
16. Cassel CK, Vladeck, BC. ICD-9 code for palliative or terminal care. N Engl J Med. 1996; 335 (16):1232–1234. DOI: 10.1056/NEJM199610173351612
17. Fins JJ, Miller FG, Acres CA, Bacchetta MD, Huzzard LL, Rapkin BD. End-of-life decision-making in the hospital: current practice and future prospects. J Pain Symptom Manage. 1999; 17 (1):6-15. DOI: 10.1016/s0885-3924(98)00109-2.
18. Broad J, Gott M, Kim H, Boyd M, Chen H, Connolly MJ. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. J Public Health. 2013; 58 (2):257-267. DOI: 10.1007/s00038012-0394-5.
19. Merel S, DeMers S, Vig E. Palliative Care in Advanced Dementia." Clin Geriatr Med. 2014; 30 (3):469-492. DOI: 10.1016/j.cger.2014.04.004.
20. Hashimie J, Schultz SK, Stewart JT. Palliative Care for Dementia: 2020 Update. Clinics in Geriatric Medicine. 2020; 36 (2): 329-339. DOI: 10.1016/j.cger.2019.11.011
21. BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde Departamento de Ações Programáticas e Estratégicas. Orientações técnicas para a implementação de Linha de Cuidado para Atenção Integral à Saúde da Pessoa Idosa no Sistema Único de Saúde – SUS [recurso eletrônico] / Ministério da Saúde, Secretaria de Atenção à Saúde, Departamento de Ações Programáticas e Estratégicas. – Brasília : Ministério da Saúde, 2018.
22. Conselho Federal de Medicina (BR). Resolução do CFM número 1995 de 9 de agosto de 2012. Brasília- DF, 2012. Disponível em: http://www.portalmedico.org.br/resolucoes/CFM/2012/1995_2012.pdf.
23. Murphy E, Froggatt K, Connolly S, O'Shea E, Sampson EL, Casey D, et al. Palliative care interventions in advanced dementia. Cochrane Database Syst Rev. 2016; 12 (12):CD011513. DOI: 10.1002/14651858.CD011513.pub2
24. Yumoto Y, Kernohan WG, Morioka N, Ogata Y. International reflections on caring for people with advanced dementia Public Health Nurs. 2019; 36 (2):192-198. DOI: 10.1111/phn.12572.
25. Conselho Federal de Medicina (BR). Resolução do CFM número 1805 de 28 de novembro de 2006. Brasília-DF, 2006. Disponível em: https://sistemas.cfm.org.br/normas/visualizar/resolucoes/BR/2006/1805.
26. Di Giulio P, Toscani F, Villani D, Brunelli C, Gentile S, Spadin P. Dying with Advanced Dementia in Long-Term Care Geriatric Institutions: A Retrospective Study. J Palliat Med. 2008; 11(7): 1023-1028. DOI: 10.1089/jpm.2008.0020
27. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Patients dying with dementia: experience at the end of life and impact of hospice care. J Pain Symptom Manage. 2008; 35: 499-507. DOI: 10.1016/j.jpainsymman.2007.06.011
28. Van Bruchem-Visser RL, Mattace-Raso FUS, Beaufort ID, Kuipers EJ. Percutaneous Endoscopic Gastrostomy in Older Patients with and without Dementia: Survival and Ethical Considerations. J Gastroenterol Hepatol. 2018; 34 (4):736-741. DOI: 10.1111/jgh.14573
29. Lee Y-F, Hsu T-W, Liang C-S, Yeh T-C, Chen T-Y, Chen N-C, et al. The Efficacy and Safety of Tube Feeding in Advanced Dementia

Patients: A Systemic Review and Meta-Analysis Study. Journal of the American Medical Directors Association. 2021; 22 (2):357–363. DOI: 10.1016/j.jamda.2020.06.035

30. Koopmans R, Van der Sterren KJMA, Van der Steen JT. The 'natural' endpoint of dementia: death from cachexia or dehydration following palliative care? Int J Geriatr Psychiatry. 2007; 22: 350–355. DOI: 10.1002/gps.1680

31. Chou HH, Tsou MT, Hwang LC. Nasogastric tube feeding versus assisted hand feeding in-home healthcare older adults with severe dementia in Taiwan: A prognosis comparison. BMC Geriatrics. 2020; 20 (1):1–8. DOI: 10.1186/s12877-020-1464-9

32. Aminoff B, Adunsky A. Dying dementia patients: Too much suffering, too little palliation. Am J Hosp Palliat Care. 2005; 22 (5):344-8. DOI: 10.1177/104990910502200507.

33. Jaul E, Meiron O, Menczel J. The Effect Of Pressure Ulcers On The Survival In Patients With Ad-vanced Dementia And Comorbidities. Experimental Aging Research, 2016; 42: 382–389. DOI: 10.1080/0361073X.2016.1191863

34. Jaul E, Barron J, Rosenzweig JP, Menczel J. An overview of co-morbidities and the development of pressure ulcers among older adults BMC Geriatrics, 2018; 18:305. DOI: 10.1186/s12877-018-0997-7

35. Miller SC, Lima JC, Looze J, Mitchell SL. Dying in U.S. nursing homes with advanced dementia: how does health care use differ for residents with, versus without, end-of-life Medicare skilled nur-sing facility care? J Palliat Med. 2012; 15 (1):43-50. DOI: 10.1089/jpm.2011.0210

36. Givens JL Jones RN, Shaffer ML, Kiely DK, Mitchell SL. Survival and comfort after treatment of pneumonia in advanced dementia. Arch Intern Med. 2010; 170:1102–1107. DOI: 10.1001/archinternmed.2010.181

37. Eisenmann Y, Golla H, Schmidt H, Voltz R and Perrar KM. Palliative Care in Advanced Dementia. Front. Psychiatry, 2020; 11: 699. DOI: 10.3389/fpsyt.2020.00699

38. Higginson IJ, Finlay I, Goodwin DM, Edwards AGK, Douglas HR, Norman CE, et al. "Do Hospital-Based Palliative Teams Improve Care for Patients or Families at the End of Life?" Journal of Pain and Symptom Management. 2002; 23 (2):96–106. DOI: 10.1016/S0885-3924(01)00406-

39. Kucmanski LS, Zenevicz L, Geremia DS, Madureira VSF, Silva TG, Souza SS. Alzheimer's desease: challenges faced by family caregivers. Rev. bras. geriatr. Gerontol. 2016; 19 (6):1022-1029. DOI: 10.1590/1981-22562016019.150162.

Received in september 2020.
Accepted in september 2021.