Palliative medicine and care

Palliative care in dementia

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ABSTRACT

Objectives: To analyze the current literature on the various aspects of palliative care in advanced dementia (AD).

Material and methods: A narrative review focused on the literature available regarding the final stages of dementia: prognosis, decision-making, assessment of patient needs, support/alleviation of symptoms and the integration of palliative care into the comprehensive care of AD.

Results: AD is a terminal disease associated with extensive suffering and having to make difficult decisions in its most severe stages. Estimating prognosis is difficult, which may explain why most patients are not included in palliative care programs. The decision-making process is characterized by uncertainty due to the lack of scientific evidence backing the efficacy of treatments and the need to reconcile conflicting points of view, as well as due to the difficulty of understanding patient wishes. Caring for these patients is difficult; for them, non-verbal communication is essential and careful attention to the presence of symptoms is required. It is also necessary to take into consideration the suffering of caregivers. The few studies that have developed specific tools for guiding the final phase of life in AD and the specific measurements of outcomes have demonstrated what can be achieved and the significant work ahead.

Conclusions: Further research on end-of-life care for persons with dementia is needed in order to develop interventions that address the particular challenges of dying with this disease and to be able to improve the end-of-life care provided to these patients in the environments where the majority of them live and die.

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1. Introduction

Dementia is an organic, acquired syndrome characterized by a permanent impairment of certain cognitive functions, including memory, as compared to the patients’ previous level of performance. These deficits are compounded by an alteration in abstract thought and in the ability to reason, which allow for the classification of dementia as a cognitive disorder. In addition, there are also usually psychiatric, personality and behavioral symptoms present. All dementia syndromes share the following characteristics: present a normal level of consciousness, be acquired and long-lasting, affect various functions and be of a sufficient severity to have repercussions on personal, work and social performance. The diagnosis and classification of dementia must be carried out using consensus documents, such as the DSM-IV classification, a guide developed by the American Psychiatric Association [1] or the CIE-10 of the World Health Organization [2], which are the most internationally used classifications.

Delphi consensus study on the global prevalence of dementia published in 2005, estimated that 24.3 million people suffer from dementia and that 4.6 million new cases are reported each year [3]. Dementia has always been associated with aging; thus, the progressive increase of life expectancy is one of the factors that has contributed to the rise in its incidence and prevalence in recent years, and will continue to do so in the coming decades. This has led the WHO to place the number of cases in the year 2040 at 81,100,000 [3].

There are various diseases and pathological processes that cause dementia. Primary degenerative dementia [Alzheimer’s disease, Lewy Body dementia and frontotemporal dementia] represents 60–70% of all cases. Vascular dementia (VD) stands at approximately 15% and mixed dementia (degenerative and vascular) represents 20–25% [4].

Dementia syndromes are processes with devastating consequences based on their repercussions on the affected patient (in terms of mortality, morbidity, disability, quality of life, etc.), on family members (physical, psychological, social-economic repercussions, etc.) and on society in general (use of social-healthcare funds, preferentially). Alzheimer’s disease is among the ten primary causes of mortality [5], and accounts for 98.8% of deaths in individuals over 85 years of age [4].

Despite the fact that in the last two decades a large part of patients’ relatives and healthcare professionals have begun to
believe that palliative care is an effective response in the final stage of dementing diseases, in 1996 only 1.5% of patients with dementia used the Medicare Hospice programs in the US, while a large number of patients were hospitalized and treated invasively, even though their life expectancy was short [6]. Since 1998, a gradual change has been occurring in the trend toward an increase of hospital admissions for dementia patients in Medicare centers for patients with terminal illness (from 12,829 in 1998 to 60,488 in 2008) [7] such that, in 2009, the National Hospice and Palliative Care Organization reported that 11.2% of its admissions had a primary diagnosis of dementia [8]. Political interest in the needs of individuals with dementia is currently on the rise [5,9,10]. The professional and political recommendations for the care of individuals with dementia at the end of their lives emphasize the importance of anticipated planning of the care, coordinated efforts between healthcare and social care, and the adaptation of the framework and tools for palliative care for these patients [11]. The challenge for healthcare professionals and politicians is to guarantee that high-quality palliative care be accessible to the growing number of individuals dying with dementia; this effort could require the extension of comprehensive palliative care services.

The objective of this study is to review the literature on the different aspects involved in the application of palliative care in advanced dementia (AD) to define the patients susceptible to receiving this care, the needs of patients, the complexity involved with the care and the decision-making and the most important measures to be adopted for their treatment from a quality of life improvement standpoint.

2. Natural history of dementia. Advanced stage

Although the initial symptoms of each of the dementia diseases are different and not all follow the clearly defined stages covered in the Global Dementia Staging (GDS) [12] like Alzheimer’s disease, the final phases of all dementias present similar problems and characteristics. Patients with an AD who suffer severe cognitive impairment are characterized by having lost all verbal capabilities and only emitting single syllables or grunts, are incontinent and require help when bathing and eating. Basic psychomotor skills (walking, posture control) are lost as this advanced phase, and at the end, the patient is bedridden for the majority of the time due to the difficulty of being able to sit up without proper support. There are often neurological and cortical signs and symptoms. Moreover, in this final stage of the disease, patients are very susceptible to develop other pathologies, with the primary cause of death being pneumonia and cardiovascular diseases. Pneumonia occurs with greater frequency in patients with Alzheimer’s disease, while heart failure and stroke occur more commonly in patients with VD [13]. The majority of these data are obtained, however, from death certificates that may not be sufficiently reliable. In this phase, nutrition and eating problems also arise [14], and the presence of severe symptoms that disturb the patient’s comfort is common and increases as death approaches.

During the last 18 months of life, the probability of an AD patient to suffer at least one episode of pneumonia is over 40%, and that of a febrile episode is over 50%. Eating problems appear in more than 85% of patients [14]. Mortality at 6 months following the patient’s development of pneumonia, a febrile episode or eating problems stands at nearly 46.7%, 44.5% and 38.6%, respectively [14]. Dementia is also associated with malnutrition due to reduced food intake and skin lesions [15]. The impact of dementia on patient life expectancy is important as it reduces the survival rate [16,17], thus making the probability of dying at a certain age two to four times greater than that of patients of the same age without dementia [18–20]. The mean survival time of patients with dementia has been analyzed in cohort studies and case series, ranging from 3 to 11 years [17,21,22] based, primarily, on the age at diagnosis, gender and the presence of comorbidity [23]. One Italian study indicated that the relative risk (RR) of death in patients with dementia (RR = 3.61 [CI 2.55–5.11]) was greater than that of patients with cancer (RR = 2.01 [CI 1.20–3.38]) or with heart failure (RR = 1.87 [CI 1.27–2.76]) [24] and that institutionalization is shown to be more life-threatening for the patient (RR = 4.17 [CI 2.20–7.94]) than any other pathological process considered separately (including dementia). Therefore, demented patients, who are often institutionalized at the final stages of their disease, have a very high risk of dying [24].

The mortality rate in AD is very high [6,25–27] (25% at 6 months) [14] and mean survival is 1.3 years. These figures are similar to the most commonly recognized end-of-life situations like metastatic breast cancer or stage IV congestive heart failure [14].

Understanding the clinical trajectory of the final stage of dementia is a fundamental requirement for improving the care for patients suffering this disease and helps both the physician and the patient’s family to be realistic regarding what to expect as the disease progresses and the patient’s death nears [14].

2.1. Prediction of the proximity of death for individuals with dementia

Recognizing when a person stops living with dementia and starts dying from it, and the prediction of survival time, may influence the decision to use services specializing in palliative care and the application of certain resources. It may also affect decisions about the benefits of transferring patients to an acute care unit or starting certain treatments. The lack of recognition that someone is dying may lead to hospital admissions that are unnecessary, and potentially bothersome, to the patient and his or her family [28]. Some studies suggest that healthcare professionals are not trained to recognize the final stages of this disease. Mitchell, in 2004, compared two groups of patients: one with dementia (1,609) and another with cancer (883), both at severe phases of the disease and living in nursing homes in New York. Six months after admission, 92% of cancer patients and 71% of dementia patients had died, but upon admission, only 1.1% of the latter group were considered to have a prognosis of fewer than 6 months [27,29]. The lack of consensus about the value of different prognostic indicators in AD and the uncertainty of the course of potential complications that compromise the lives of these patients and that may appear at any time during the disease further hinder this situation. These acute events have a major influence on the prognosis, and our ability to predict their onset is poor. Furthermore, the inability of some scoring systems to discriminate between underlying morbidity and the different courses of the disease support the concept that the existing tools and guidelines need further validation and refinement [27,29,30]. This is all compounded by the fact that few studies have described the natural course of dementia after palliative care has been started.

Many factors have been associated with variations in survival. There is a significant interaction between patient age and mortality [16,18,27,31], as an independent predictive factor of mortality at 1 year (RR: 1.06; 95% CI: 1.04 to 1.09) [32]. Gender is less related [33], though the majority of studies report a shorter survival in men in all age groups as compared to women [23,27,31]. The more severe the dementia, the greater the risk of long-term mortality [31]. An advanced GDS stage is associated with high mortality at 1 year [32] (RR: 1.98; 95% CI: 1.41–2.77). The etiology of the dementia must also be considered. VA has a risk of mortality at 5 years greater than that of Alzheimer’s disease, while Lewy Body dementia has the same risk of mortality at 3 years as Alzheimer’s
disease [13]. In Alzheimer’s disease, a greater duration of the disease (RR 1.07, 95% CI 1.04–1.10), presence of tactile hallucinations (RR 1.74; 95% CI 1.08–2.78), wandering (RR 1.89, 95% CI 1.18–3.02) and depression (RR 1.07, 95% CI 1.02–1.10) are associated with an increased mortality at 1 year [32]. Another important aspect is comorbidity: the presence of cardiovascular disease, diabetes mellitus or malnutrition all have an impact on mortality [27].

Regardless of medical factors, the type of social care appears to significantly affect the survival of patients with dementia. Participation in daycare centers, as well as the active support by family members, appear to significantly decrease mortality [13]. The aforementioned Italian study that established the association between mortality and institutionalization reinforces this idea [24]. However, the situation may differ in different countries. In another study conducted in Korea [32] whose hypothesis was that mortality in patients with Alzheimer’s disease was greater in nursing homes than in the community, overall mortality at 1 year was found to be 18.7%, and there were no statistically significant differences in the mortality rates among patients who received care in their homes versus those who resided in nursing homes.

Many of these factors that, in different studies, have shown an association with mortality in patients with dementia have been integrated into various prognostic models that intend to identify those patients with an elevated probability of death in the coming 6 months. In the mid-1990s, Medicare and the National Hospice Organization (NHO) [34] developed criteria to identify a survival period of 6 months or less for patients with terminal non-oncological diseases (including dementia). Since then, these criteria have been used extensively but have never been validated in a prospective study or with a large sample. These guidelines were introduced without empirical data demonstrating their validity and without an apparent plan for validation immediately after their publication. Retrospective studies have shown that their capacity to predict mortality at 6 months is poor [27,35,36]. Later, other studies have tested and validated scales that attempt to predict survival. In 1997, Luchins proposed a set of criteria (a study was designed to verify them) that were primarily based on the characteristics of AD and on its associated medical complications, and compared them to those of the NHO [26]. A review of the records of 165 individuals with dementia admitted to a hospice program documented that patients who complied with the Medicare prognostic criteria and those who did not had a similar survival [37], and that only 64% of individuals who satisfied the NHO criteria died within 6 months of admission. It was concluded that advanced age, anorexia and limitations in the performance status are more useful prognostic factors than the existing criteria [37], and that the NHO guidelines should be modified to include validated empirical predictors. In 2004, Susan Mitchell [27] published a 12-item scale for the risk of mortality at 6 months that included demographic data (age and sex), comorbidity (cancer, heart failure, need for oxygen therapy), symptoms like dyspnea, malnutrition data, presence of intercurrent acute processes and performance data such as fecal incontinence or bed rest, which then provided an estimated risk of death at 6 months according to the score obtained. In 2010, this same author [35] revised this scale and published another 12-item prognostic tool: the Advanced Dementia Prognostic Tool (ADEPT), which was subsequently validated through a prospective study [36] comparing it against the NHO guidelines in a cohort of 606 patients with AD residing in nursing homes. This study revealed that the ADEPT scale’s capacity to identify patients at a high risk of death in the next 6 months was modest, but better than the NHO guidelines. One of the potential advantages of the ADEPT score is that, since it is a continuous measurement, it provides the flexibility to select cut-off points with different functional characteristics (balance between sensitivity and specificity).

Each of these results highlights the challenges encountered in measuring prognosis in patients with AD and suggests that developing criteria to predict short-term mortality in demented patients with any degree of certainty could be an unrealistic objective. Therefore, considering access to palliative care based on the estimation of life expectancy limits the possibilities of being able to benefit from such care [29,38]. The care provided to those patients should be guided, therefore, by the needs of the patient and by the objectives of care instead of by estimated life expectancy [36]. If we continue to use survival as the only criteria to granting dementia patients access to the resources of palliative care, many patients will continue to be deprived of care that has been proven to be beneficial to patients dying with dementia [14].

2.2. Special circumstances. Complexity

An individual with AD should be considered in the same way as those at the final phase of other diseases, and the treatment of the medical complications, which appear during this phase of the disease, should be designed to provide maximum patient comfort rather than maximum survival at any cost. This approach is beneficial, not only to the patient suffering dementia, but also to his or her family members. However, palliative care for patients with dementia may be far more complex. As had been mentioned previously, for these patients, it is difficult to establish a prognosis, there is a significant difficulty in recognizing and evaluating pain and other symptoms, and the patient, if he or she did not do so at the beginning of the disease, will not be able to express his or her preferences regarding the type of care he/she wishes to receive (hospital admission, artificial nutrition [AN], antibiotic treatment, etc.).

Various studies have compared the care received by demented patients and cancer patients. In dementia aggressive interventions are performed more often than in cancer patients [29,39]. The nature of the symptoms presented by both types of patients is similar, but their frequency is different [29,40]. Indicators of poor quality of care in nursing homes (pressure ulcers [PU], restraints and antipsychotic drugs) are more common in patients with severe dementia. A total of 25% of patients with dementia receive antipsychotic treatment immediately before death and physical restraints are used in 10% of them. Even after statistical adjustment for behavioral disorders, the probability of receiving antipsychotic treatment was significantly greater among patients with AD [29]. It is possible that in many cases, antipsychotic drugs are administered to control the agitation secondary to a misdiagnosed symptom [41].

3. How to address comorbidity in advanced dementia

Patients with dementia often die after pneumonia or prolonged food intake problems. They usually also present febrile episodes. In autopsies on these patients, the primary causes of death are pneumonia, cardiovascular diseases, pulmonary embolism, cachexia and dehydration [42]. According to the death certificates, pneumonia could be the cause of death in one to two-thirds of all patients with dementia [43]. In the last 3 months of life, 37% of patients suffer from pneumonia, 32% from febrile processes and 90% have nutrition issues [14]. Survival after any of these complications is reduced [14]. Other problems that regularly appear, though with lesser frequency, during the final phase of dementia are epilepsy, gastrointestinal hemorrhages, and hip and other fractures [14]. These data could be used to inform families and healthcare professionals that infection and nutrition problems are to be expected and that their presence usually indicates that the end of the patient’s life is near [14]. It must also be understood that, though these complications are the main cause of death, like
they are in other terminal diseases, the primary disease, dementia in this case, is the underlying cause of death for the patient.

Patients with dementia who suffer intercurrent acute diseases are normally transferred to hospitals to be administered aggressive treatments (parenteral treatments, tubes, etc.) without evaluating the repercussions these treatments could have on cognition, the onset of behavioral disorders or comfort [44,45]. Recent studies have highlighted the lack of evidence and even the existence of contradictory data on the efficacy of these treatments in achieving comfort and other outcomes at the end of the life of patients with dementia [46]. Furthermore, some interventions that could be uncomfortable for the patient may be necessary to reduce suffering, such as hospitalization due to a hip fracture. This creates a great degree of uncertainty among physicians regarding the optimal treatment to carry out to achieve their objectives: patient comfort, maintaining functionality and prolonging life.

3.1. Intercurrent infections

Infections, particularly pneumonia, are common in patients with AD [14,47,48]. The percentage of patients suffering from pneumonia has been observed to be relatively constant during the last 6 months of life and stands slightly above 10%, but increases to 50% in the last month of life. This finding supports the idea that pneumonia is a predictor of patient death [47], as it is associated with an elevated mortality and, moreover, has a great morbidity. Survival after a pneumonia episode is poor [6], and the prognosis worsens with the severity of cognitive impairment [49]. Pneumonia is also a very distressing experience in this fragile population due to the severity of the symptoms it causes [50] and the uncomfortable interventions commonly used to treat the infection [6]. When the dementia patient develops pneumonia, he or she is normally treated with antibiotics (primarily parenterally) and many are hospitalized [14,47,48,51–54]. However, the benefits of antibiotic treatment and hospitalization are not well established in this population [51,53], and there is substantial variability in clinical practice [53,54]. The current literature provides limited and, at times, contradictory information on the capacity of antimicrobial agents to influence two fundamental objectives: prolonging survival [55,56] and achieving patient comfort [50,57].

Approximately one of every four decisions faced by the families of patients institutionalized with AD deals with the treatment of infections [58]. It would be ideal for these decisions to be guided by information on the possibilities that each therapeutic option has of achieving treatment objectives (prolongation of life, patient comfort). The discomforts involved with more invasive treatments (hospitalization, inserting an intravenous line, intramuscular injections) could be acceptable if this approach had a greater efficacy for patient survival and the reduction of symptoms. But the scarce data available with respect to the outcomes of antibiotic use constitute an obstacle for decision-making. Even though a randomized study is the best method for assessing the efficacy of the different treatment options, conducting a trial on pneumonia in AD would be ethically difficult and, therefore, improbable. Thus available studies are limited by the difficulty of randomization, and some observational studies are not adjusted for the factors associated with the probability of receiving treatment [50,53,57].

With respect to survival, a recent multicenter, prospective cohort study conducted with the CASCADE study population found that antibiotics were commonly prescribed (91%) for pneumonia episodes. Survival (unlike what was found in previous studies) was prolonged among residents who received antimicrobial treatment (mean increase of 273 days) as compared to those who were not treated [59]. There were no statistically significant differences in survival among the three administration routes for antibiotics (P = 0.58). Moreover, this study revealed that for institutionalized patients with dementia who suffered pneumonia, the order to not hospitalize was associated with greater mortality [59].

Comfort is often the primary objective of care in AD and is a fundamental factor to keep in mind when considering the possible treatment options. Pneumonia is one of the main causes of discomfort in the terminal phase of dementia [50]. Interventions like parenteral therapy and transfer to a hospital could be an added burden for the comfort of these patients [39]. However, few empirical studies have investigated discomfort in dementia patients, and there are few validated instruments available for measuring discomfort in these patients who cannot verbalize their feelings. Recent projects, like that of van der Steen [57], suggest that treatment with antibiotics reduces the discomfort of patients even when death is imminent. Other studies, like the very recent one by Givens, have obtained the opposite result, indicating that comfort was better during the pneumonia episodes not treated with antibiotics and that it decreased with increasing aggressiveness of care [59].

The lack of evidence on the efficacy of treatments for achieving the objectives for which they were implemented complicate decision-making, with respect to which treatment to choose in patients with dementia. Further studies are needed, which would ideally be conducted on a population with similar characteristics to those to be treated, to be able to make decisions with a more appropriate scientific basis.

3.2. Nutritional problems

Deficient food intake is common among dementia patients. During various phases of the disease, the patient shows indifference to food or resists being fed. The causes of this scarce intake include the fact that the patient may not recognize food or the loss of normal physiological regulators of appetite and satiation due to changes in limbic and/or hypothalamic function. In AD, physical difficulties appear in the act of swallowing, such as the impossibility of adequately managing the bolus in the mouth (oral phase dysphagia), or while swallowing (pharyngeal phase dysphagia) [60]. These difficulties normally appear when the patient is already dependent for all other basic activities of daily living (BADL) and is often bedridden [60] (they may appear earlier in VD). In the last 3 months of life, 90.4% of patients with dementia have feeding problems and mortality in the 6 months after the development of feeding problems stands at 38.6% [14].

The decision to intervene by implementing AN with an enteral feeding tube is most often taken in AD. Starting AN is an emotive, controversial decision influenced by complex ethical [61], religious, cultural and legal questions. It also depends on other factors, such as clinical needs, local practices, physician and caretaker preferences, if there is a living will and if there was a previously-developed plan for care. It is, therefore, a complex decision that, in many cases, must be made by the patient’s relatives and that, with the aging population and increased prevalence of dementia, will have to be addressed with increasing frequency. There are many arguments for starting AN (Table 1). However, on many occasions, when those arguments are used, they do not take into consideration whether there is any evidence that any of the results pursued are achieved with AN or if, on the other hand, it could actually cause harm. There are no relevant randomized clinical trials comparing the use of feeding tubes (of any type) with oral nutrition in patients with AD. Despite an extensive search for studies that would contribute evidence to either side of this argument conducted in a Cochrane review in 2009 [62] (452 studies were reviewed), no randomized studies were found. Thus, the conclusions obtained were only based on observational studies that, to compare results, used a control group; that is, compared AN with no intervention or “standard care or treatment”, in any healthcare
context. Previously, in 1999, Finucane [60] conducted an excellent review of that published between 1966 and 1999 in search of data regarding if any type of feeding tube nutrition achieved the objectives it proposed in this type of patient.

Below, with the limitations of the type of studies on which it is based, is a concise presentation of our current knowledge of whether enteral nutrition provides any benefit to AD patients, as one of the bases for making an ethically correct decision is to do so with a scientific basis that supports it. Therefore, each of the potential objectives of enteral nutrition in patients with AD is analyzed below.

3.2.1. Does it prevent aspiration pneumonia?

The evidence available to date, though of low quality, indicates that the use of feeding tubes does not prevent the aspiration of oral secretions, does not prevent reflux of gastric content and could be a risk factor for aspiration pneumonia since various studies have demonstrated elevated rates of pneumonia in patients fed in this manner [63–66]. Therefore, AN through nasogastric tubes does not appear to be a satisfactory solution for preventing the pneumonia secondary to aspiration in patients with AD.

3.2.2. Does it prevent malnutrition and its consequences?

Dementia patients with feeding problems often lose weight and develop other alterations of nutritional markers, such as a decrease in body mass index (BMI), plasma albumin, cholesterol, hematocrit, lymphocytes and the tricipital skin-fold. The little data available [62] have failed to show that AN improves weight or the majority of nutritional parameters: albumin [67–69], hematocrit, cholesterol [68] and hemoglobin [67]. Patients with severe dementia generally do not benefit from enteral nutrition for two fundamental reasons: they no longer have any possibility of neurological or physical recovery, and they are not “hungry” [70]. Individuals who reach the advanced phase of dementia, when food intake is reduced, have a low metabolic rate since the loss of muscle mass reduces their lean mass, the brain is atrophied and are physically inactive. Individuals with severe dementia may be lean and eat less food than may appear adequate, but in many, if not most, cases, it does not indicate they are “starving to death” unless they are in a state of impaired physiological homeostasis. When initiating a nutritional treatment, the objective is not so much to correct the nutritional parameters, but to prevent and treat the consequences of malnutrition, like the appearance of pressure ulcers (PU), infections, weakness and even death. Symptoms resulting from malnutrition also include changes in the sense of taste, anorexia, asthenia or delayed healing of wounds [71], and AN, in dementia patients, has not been proven to revert all these adverse outcomes related to malnutrition.

3.2.3. Does it increase survival?

Perhaps one of the most commonly used arguments to start AN is the intent to prolong patient life, and it is widely believed that AN will prevent death by starvation. Nevertheless, the evidence available presents four arguments to the contrary. First, survival for AD patients with very low weight fed orally “by hand” may be high [60,72]. Second, the insertion of feeding tubes presents an associated morbidity and mortality [73–77] even though it is low. Third, the mortality of patients fed by tubes is significant [68,78]. Finally, the few studies on the impact of the mode of feeding in mortality of AD did not find that AN improves survival [25,62,67,79]. This fact is possibly due to the fact that the loss of appetite and inability to eat have been described as something normal in the final stages of diseases like dementia whose course towards death could be independent of medical interventions like AN.

3.2.4. Does it prevent or improve the progress of pressure ulcers?

Evidence shows that AN does not improve the course of PU or prevent the appearance of new pressure sores, but that it may actually increase the risk of their formation [9,17,60]. This may be due to the fact that, often, to prevent the patient from removing the feeding tube, physical or pharmacological restraints are used and AN gives way to an increase of diuresis and stools, which lead to humidity in the diaper area, thus contributing to the appearance of ulcers.

3.2.5. Does it reduce the incidence of infections?

Aspiration pneumonia and PU (which may be infected) have been mentioned above. The insertion of feeding tubes could lead to local infection. The most recent reviews do not show that AN reduces the risk of other infections (urinary tract, viral, ophthalmological, etc.) though this fact could very possibly be due, in large part, to the fact that the study objectives did not include seeking their presence; that is to say, we have little information in that regard.

3.2.6. Does it improve performance status?

On some occasions, the objective of AN in undernourished AD patients is to improve their strength and performance status. Studies on the consequences that nutrition has on the progress of AD patients have not found an impact on their performance status. Functional impairment is a marker of dementia progress and, therefore, it could possibly be irreversible through nutritional treatment.

3.2.7. Does it provide comfort (to prevent hunger and thirst) and improve quality of life?

It is thought that insufficient consumption of food leads to distressing hunger and thirst. It is practically impossible to obtain data on the subjective experience of AD patients who stop eating. Data on thirst and hunger can only be extrapolated from cognitively intact patients who have reached the final phase of other diseases. Many elderly patients do not feel discomfort due to dehydration because they present an impaired thirst mechanism [75] and may, even, be more comfortable when they do not initiate treatment with AN since dehydration reduces the production of bodily fluids that reduce the volume of phlegm and the need for diaper changes and bathing. Moreover, AN does not reduce, but may increase, the presence of symptoms like coughing and nausea. When AN is used as a permanent substitute for oral feeding, patients are deprived of the pleasure of tasting food and of the social interaction that takes place at mealtimes since manual feeding involves close contact between the caretaker and patient. A 2009 Cochrane review did not find any studies that measured quality of life of patients, but it did find one study that observed that in a period of 6 months, 71% of patients with a feeding tube versus the 55% without one required physical restraint. It is possible that quality of life of AD patients may be negatively affected by AN if physical restraints must be used to administer it. The experience of feeling “tied down” is unpleasant and may make

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Evidence they may be achieved</th>
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<tbody>
<tr>
<td>Prevent aspiration pneumonia</td>
<td>None</td>
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<tr>
<td>Prevent malnutrition and its consequences, including death by starvation</td>
<td>None</td>
</tr>
<tr>
<td>Increase survival</td>
<td>None</td>
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<tr>
<td>Prevent or treat pressure ulcers</td>
<td>None</td>
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<td>Reduce infections</td>
<td>None</td>
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<tr>
<td>Improve performance status</td>
<td>None</td>
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<tr>
<td>Provide comfort (prevent hunger and thirst) and thus improve quality of life</td>
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behavioral symptoms increase and often give way to the use of sedating drugs. All these data seem to suggest that AN treatment may not improve quality of life, but could actually increase patient suffering and discomfort.

An alternative to starting AN is to review and correct all those factors that, in some way, have made the patient stop ingesting food. The presence of other diseases should be evaluated since it is not uncommon for this problem to arise during a hospital admission for an acute pathology. Moreover, the patient could reject eating simply because he or she does not like the food or because he or she is not feeling hungry. We must, therefore, take into consideration if the taste and texture of the food we are offering is adequate, and seek foods that have strong flavors and that are cold or hot, instead of at room temperature. The poor state of the patient’s mouth could also be the reason behind the patient not eating. The patient may present candidiasis, painful teeth or defective or poorly adjusted dental prostheses, ulcers, xerostomia, etc. Mouth pain is a very important reason for patients to reject food. Therefore, a proper review and treatment of mouth problems could help, to a great extent, to improve the nutrition of said patients. Poor control of symptoms could be another reason explaining why the patient does not eat. Constipation and secondary abdominal pain are among the most common symptoms. Some drugs cause anorexia, nausea and constipation; drug treatments must thus be reviewed and any unnecessary drugs should be discontinued.

Patients with AD may also present dysphagia. One possible solution for this problem could be to administer soft foods that are semi-solid and thick in consistency. It is also important to change the size and frequency of meals. Techniques, such as reminding them often to swallow with each food bolus, encouraging them to cough softly after each swallow, administering teaspoon size or smaller bolus, placing food and liquids well inside the mouth and facilitating techniques should be used.

Of equal importance is the attention to the environment in which the patient is fed: noise, company of other patients that cause a change in mood, distracting television, etc. A quiet place should be chosen, and the person doing the feeding should do so in an unhurried manner and without forcing the patient. Verbal or physical contact has been shown to improve food intake at each meal. Some punctual actions have been observed to encourage this: reorienting the patient to food, hugging and kissing, maintaining contact with the patient and responding to all sounds issued by the patient.

4. Needs of patients with dementia. Control of symptoms

Carrying out an adequate evaluation of suffering is extremely important in patients with AD, who cannot communicate their physical needs, understand the treatments they are receiving or report the symptoms that make them uncomfortable. Despite that, studies on AD rarely make specific reference to the assessment of patient suffering [26,80]. In an attempt to measure suffering, scales like the Quality of Life in late-stage Dementia scale (QUALID), End Of Life in Dementia (EOLD), Mini Suffering State Examination (MSSE), Discomfort Scale-Dementia of Alzheimer-Type (DS-DAT) [41] scales were developed. There are three types of EOLD scales: (1) Satisfaction With Care (SWC-EOLD), which assesses the satisfaction of family members with the care received by the patient; (2) Symptom Management (SM-EOLD), which assesses the control of symptoms; and (3) Comfort Around Dying (CAD-EOLD), which assesses comfort during the dying process [81].

In 1997, McCarthy claimed that patients with dementia, as compared to those who suffer other diseases, also experience a broad variety of symptoms, including persistent pain, but they are less likely to be treated for it in the last 6 months of life [82]. More recently [83], a retrospective study conducted in Japan compared the last 48 hours of life of individuals with dementia with those of other patients without dementia and concluded that dementia was a significant independent predictor of uncontrolled pain.

As mentioned previously, pneumonia can be the cause the death in half of the patients suffering from dementia. The pre-death suffering experienced by the patient dying from pneumonia is more severe (up to 30% greater) than that suffered by those dying of other causes [50] and may be 50% greater at the time the decision is made whether to start an antibiotic treatment than 2 weeks before [50]. Pneumonia produces symptoms like general discomfort, fever, cough, dyspnea, tachypnea, reduced level of consciousness and sudden changes in patient behavior, who may become confused and agitated [50].

Regardless of the coexistence or not of pneumonia, patients with AD present dyspnea (≥ 5 days per month) 46.0%, pain (≥ 5 days per month) 39.1%, PU (stage II or higher) 38.7%, agitation 53.6% and aspiration 40.6%. The frequency at which these symptoms appear, increases as the time of death nears [14].

4.1. Pain

Research on pain assessment for individuals suffering the final stages of dementia is limited and has been focused on the capacity of caregivers to predict it [84], and on the validity and perceived value of different pain assessment tools for end of life care [85].

Even though patients with mild–moderate cognitive impairment may be evaluated with simple questions, this option disappears as the dementia advances, manifestations of pain tend to decrease and the patient loses the ability to answer questions. At that time, the only way to determine the presence and characteristics of pain is through what is revealed through their behavior. The observational methods are evaluation tools based on pain-associated behaviors. Indicators of pain include behavioral symptoms (agitation, posture changes, noisy breathing, etc.), non-verbal vocalizations (screams, grunts, etc.), facial expressions or changes in usual behavior (aggressiveness, refusal to eat, alteration of sleep rhythm, changes in level of activity, etc.). An understanding of these patterns is important in pain management, and to identify them, information needs to be provided by the family or caregiver. These patterns have been used to develop various observation scales for pain-related behavior that vary in terms of number of items (5–10, the short scales or over 10 for long scales), the format of administration (Yes/No questions; points scale) or if an informant is needed or if they can be administered by an observer who is not familiarized with the patient (Table 2) [86–88].

Once the presence of pain has been determined, the treatment should not differ from that used in any other type of patient, except for a special care in the use of drugs with CNS side effects.

4.2. Behavioral symptoms

Some of the most bothersome complications of the advanced phase of dementia are behavioral symptoms like physical aggression, hallucinations, wandering, agitation, sleep disorders and anxiety [89]. “Behavioral and Psychological Symptoms of Dementia” (BPSD) is a term used to describe this broad range of non-cognitive symptoms appearing in patients with dementia of any etiology [90]. These symptoms lead to emotional suffering for both, the patient and his or her family, and increase the risk of mortality and institutionalization.

Before starting any specific treatment, it is important to perform a complete clinical evaluation of the patient. Physical problems such as infections, pain or dehydration are very frequent and often the triggers for BPSD; thus, their treatment normally corrects BPSD. Most clinical practice guidelines indicate that a
non-pharmacological approach should be the first step in BPSD treatment, and there is growing evidence, including randomized studies, that psychological and social interventions and patient-focused care are effective [91,92]. Neuroleptics are the most commonly used drugs for the treatment of BPSD. Though there is a large arsenal of antipsychotic and antidepressant drugs for attempting to control these symptoms, none of them, with the exception of risperidone, has been specifically approved for this purpose. A Cochrane review concluded that the analysis of outcomes was not able to demonstrate that haloperidol had any significant general effect on the control of agitation as compared with placebo and, that, therefore, it could not be recommended for the routine treatment of these symptoms [93]. Another review conducted recently indicated that some atypical neuroleptic drugs (risperidone and aripiprazole) carbamazepine, memantine and citalopram may be useful in the treatment of these symptoms [92]. The evidence available mostly has been obtained makes in Alzheimer’s disease, as there are very little data regarding other dementias.

5. Planning of care

Various elements contribute to complicating the decision-making process in AD. It is difficult for patients to participate in treatment planning since many of them may have not been informed of the diagnosis or prognosis when they are still competent to do so. As the dementia advances, the individual loses his or her capacity to decide, and it is usually at this time when difficult decisions need to be made regarding end of life care, such as hospital admission, treatment of systemic infections with antibiotics and AN.

Another factor that complicates decision-making in these patients is the nature of the interventions needed to treat the acute episodes. In patients with metastatic cancer, aggressive treatments like cardiopulmonary resuscitation or mechanical ventilation are not generally effective. Some treatments for severe exacerbations of heart failure (admission to the intensive care unit, cardiac catheterization or mechanical ventilation) could be effective but are invasive, uncomfortable and expensive. In AD, treatments for intercurrent processes like infections (intravenous antibiotics, serum therapy and electrolyte adjustment) are fairly standard, not overly uncomfortable, relatively inexpensive and frequently effective. Therefore, if a decision is made to only take comfort measures, both the treating physician and the dementia patient’s family must refuse routine treatments that are used daily, are minimally invasive, may be relatively not uncomfortable for the patient and potentially effective. This may be emotionally and psychologically difficult both for caregivers and health care providers. In refusing treatments like antibiotics, families may feel that they are directly responsible for the patient’s death. This situation demands open communication and support from the physician to help families address the emotional and psychological challenges, including guilt, involved in the making of end of life decisions in dementia [94].

Each of the intercurrent processes that mark the course of dementia requires a “decision-making” process, given that the attitude taken towards them could affect both the survival and quality of life of the patient. These are complex decisions that should be made as a team and with the participation of the family (given that the patient is no longer able to decide in this phase) but that can be simplified if a proper advance directives have been developed and the patient’s wishes are known. The ideal case would be for the patient to have chosen the person he or she wishes to decide for him or her and with whom the patient has been able to talk about his or her wishes and philosophy before developing AD. Under these circumstances, the representative may decide based on what he or she believes the patient would have wanted by placing him or herself in the role of the patient and helping to interpret the previous instructions he or she may have left.

Decisions regarding future treatments must be made outside of the time of crisis, at a meeting with the primary caretaker and other members of the family, together with the treating team. This family meeting is a good opportunity to address any concerns regarding the patient’s clinical situation and treatment, as well as to clarify the prognosis and explain the options for handling the complications and intercurrent diseases. The risks and benefits of all therapeutic strategies according to the known scientific evidence should also be explained at this time. The presence or absence of prior instructions made by the patient should be taken into consideration at the beginning of the conversation. Decisions regarding the therapeutic limitations are very difficult to make. Family members may feel overwhelmed and guilty if a decision is made to stop any therapeutic modality [58], and they need a guide to help them in this process. To reach a consensus, many factors must be weighed, including the severity of the dementia, the frequency of acute events (first pneumonia versus third or fourth), the family’s ability to address the situation, their cultural and religious background and the resources available in the place where the patient lives.

6. Care for the family

For individuals with AD who live at home or in environments in which the family members maintain constant contact with the patient, the role and contribution of the caregivers are crucial. Studies indicate that people who care for their family members with AD have different, but equivalent, needs from those caregivers of patients dying from other diseases [95]. Care for an AD patient can be physically and mentally exhausting given that these patients require constant care at all hours of the day, and often, the caregivers themselves are often old and have their own health problems. The
experiences of caregivers and their responses are shaped, more so than by the physical aspects in the final stage of dementia, by the dementia-related behavioral alterations and the experience of prolonged loss, including the loss of control and ability to decide when the patient should be admitted to a nursing home or a hospital [82,96]. Some studies reveal the feelings of caregivers upon the death of the person with dementia, including the importance of the “goodbye moment” and the mistake of thinking that mourning is over at the time when a person with dementia dies [97]. Others, on the contrary, found that when care has been provided over a prolonged period of time, relief is a significant emotion when the person with dementia dies and only the minority (14%) require attention to mourning [95]. When the elderly person with dementia is in a nursing home, the factors that improve the caregivers experience and their satisfaction, specifically as it regards decision-making about end-of-life care, are: giving structured time for communication, addressing questions about the resident’s comfort, avoiding feeding pumps and care in a specialized unit [98].

7. Specific programs

Despite the cultural differences, studies in North America, Europe and Australia indicate that individuals with dementia normally receive worse quality of care than those without dementia. As compared to other patient groups, individuals with dementia receive less pain relief and fewer medical services, and decisions to avoid hospital admission are not made until death is imminent [28,82,99,100]. A study conducted by Aminoff [101] found that 63.4% of patients with AD presented elevated suffering, 29.6% moderate suffering and only 7% presented mild suffering. These data are maintained despite the proper use of analgesics; thus, the authors believe that other factors unrelated to pain must be contributing to patient suffering. Several studies have described interventions that could improve this situation. Individuals with dementia who live in nursing homes experience fewer adverse symptoms and better levels of comfort when there is a specific, structured approach in place for providing the care needed with the support of specialists and trained personnel [102]. A series of studies that developed and tested a discomfort in dementia scale (ADD) in individuals with AD living in nursing homes used analgesics and non-pharmacological interventions designed to improve comfort as outcome measures [103–105], and found that the use of the tool could improve the recognition of the symptoms and administration of analgesics. Later, another study conducted by the same team [106,107] tested a protocol with five clinical steps to promoting comfort and reducing behavioral disorders. Though the therapeutic response to the positive evaluation was effective in 86% of participants, 70% of them received a positive assessment but no treatment. Non-pharmacological interventions were effective in reducing discomfort in 62% of participants, and analgesics were effective in 75% of patients. The study demonstrated a more effective use of analgesics and less discomfort in the intervention group. This study and that conducted by Abbey [85] highlight the importance of structured operating procedures that combine educational support for professionals with the development of specific interventions for the end of life care for individuals with dementia. These studies were conducted in nursing homes and were based on efficient interdisciplinary work. The obstacles to providing quality care to patients with dementia at the end of their life include the lack of any validated measure of the quality of care or quality of life, as well as the lack of appropriate interventions [108].

8. Conclusions

End of life care of the highest possible quality must be attained for patients with AD. To do so, this care must be adequate, ethically adjusted and timely, and take into consideration the complex circumstances of the patient, the wishes and concerns of the family and the diverse environmental conditions (some live at home, but many are institutionalized). Also, greater evidence is needed to help the decision-making process when faced with the complications arising at the end of their life, and careful attention must be paid to the presence of symptoms that significantly alter the quality of life of these patients, which go unnoticed on many occasions or, often, whose manifestations are confused with the behavioral symptoms common in AD. The families of patients with AD require special attention given the peculiarities of these patients, who have lost all possibilities of communicating, require constant care and, moreover, for whom very complex decisions need to be made.

Disclosure of interest

The author declares that she has no conflicts of interest concerning this article.

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