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End-of-life care of elderly patients with dementia: A cross-sectional study of family carer decision-making

Rafaella I. Peixoto[a,*], Vera M. da Silveira[b], Rogério D. Zimmermann[b], Adriana de M. Gomes[c]

[a] *Department of Geriatrics, Hospital das Clínicas, Universidade Federal de Pernambuco, Brazil*
[b] *Programa de pós-graduação em Gerontologia, Universidade Federal de Pernambuco, Brazil*
[c] *Hospital Oswaldo Cruz, Universidade de Pernambuco, Brazil*

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ABSTRACT

Background: Dementia syndromes pose a major worldwide challenge to public health. In terminal stage of dementia, carers are responsible for decision making in end-of-life treatment and there may be multiple factors that contribute to the choice of a palliative or invasive treatment.
Aim: To identify possible factors that influence the decision-making of family caregivers on implementing invasive or palliative interventions for people with end stage dementia.
Design: A structured interview with family caregivers of elderly patients addressing aspects of the following categories: elderly with dementia, caregiver, medical treatment history. Statistical analysis was performed to test whether there was a significant association between the carer's decision (invasive or palliative treatment) and the collected variables.
Settingand participants: The study was conducted in three hospitals in Brazil. Participants were family caregivers of inpatients with end stage dementia
Results: Most of caregivers chose not to perform invasive procedures. The factors with the greatest association with the decision for invasive care were: elderly with tracheostomy, dementia diagnosis for less than 2 years, caregiver's age less than 50 years, history of hospital admission in the last year, affirmation that interviewee would be surprised with the death of the elderly within 1 year and the denial that health care team has already explained about treatment options.
Conclusion: There were identified several factors related to the carer, the elderly person and their medical treatment that may influence the choice between palliative and invasive care for the elderly person with dementia.

1. Introduction

Dementia syndromes have progressively increased in prevalence and are currently incurable, which presents a major global challenge to public health. In 2015, a document published by Alzheimer's Disease International estimated that approximately 46.8 million people were living with dementia. This number is expected to double every 20 years to 74.7 million in 2030 and 131.5 million in 2050. The global cost of patient care and treatment in 2015 was 818 billion dollars, which represented a considerable increase compared to 2010 (604 billion dollars). Therefore, investment in research in the fields of prevention, treatment, cure and palliative care for advanced cases is needed (Alzheimer’s Disease International, 2015).

The advanced stage of Alzheimer's disease, which is the most common cause of neurodegenerative dementia, is characterised by serious deficits in memory and language, urinary and faecal incontinence, loss of balance and coordination, immobility syndrome and full dependency for the instrumental and basic activities of daily living. As a chronic, progressive and incurable disease, dementia may be considered a terminal condition (Kuhn & Forrest, 2012).

A prospective study conducted with residents of long-term institutions in the United States described the prognosis for people with advanced dementia criteria. This study showed a high mortality rate among these individuals, with mean survival of 1.3 years and mortality of 25% at 6 months (Mitchell et al., 2009). The described life expectancy is comparable to conditions commonly recognised to have a poor prognosis, such as metastatic breast cancer and stage IV congestive heart failure (Alzheimer’s Disease International, 2014; Barber &

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* Corresponding author at: Department of Geriatrics, Hospital das Clínicas, Universidade Federal de Pernambuco, Av. Prof. Moares Rego, 1235-Cidade Universitária, Recife, PE, CEP 50670-901, Brazil.
E-mail address: rafaellaip@gmail.com (R.I. Peixoto).

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Murphy, 2011).

Although studies of palliative care have historically focused on the treatment of individuals with cancer, the current literature advocates the need to extend palliative care to the elderly, particularly those living with dementia (Harrison, Cavers, Campbell, & Murray, 2012; Kellehear, 2009).

Qualitative studies indicate that families have little understanding of the natural course of dementia (Gessert, Forbes, & Bern-Klug, 2000; Caron, Griffith, & Arcand, 2005). An awareness that dementia is a progressive and terminal disease is fundamental to allow focus on comfort in the advanced stages of the disease (Mitchell et al., 2009; Van Der Steen, 2013). Decision making in end-of-life treatment is complex and there may be multiple factors that contribute to the choice of a palliative or invasive treatment. Caron et al. describes five dimensions that can be involved in decision making: dimensions of the person, dimensions of the caregiver, context of interaction with the medical team, family context, and the treatment itself (Caron et al., 2005).

Specialists from the European Association for Palliative Care met in 2013 to formulate palliative care guidelines for the elderly with dementia. The topic “communication and shared decision-making in palliative care” was chosen as a research priority (Van Der Steen, 2014).

With greater knowledge of the decision-making process and strategies for better communication and support, these families can be guided to improve the carers’ acceptance and understanding of the prognosis of dementia.

The aim of this study was to analyse the decision-making of carers of the elderly with advanced dementia syndrome and to identify possible factors that affected decisions regarding patient care.

2. Methods

2.1. Setting

The study was conducted in three hospitals in the state of Pernambuco, in Brazil: the *Real Hospital Português de Beneficência em Pernambuco*, the Miguel Arraes Hospital and the Getúlio Vargas Hospital. The study was submitted and approved by the ethics committee of UFPE (CAAE: 52239715.7.0000.5208).

2.2. Participants

The study population was family carers of elderly patients (aged over 60 years) with advanced dementia criteria. The following criteria were used to classify the stage of dementia as advanced: deep deficits in language, faecal and urinary incontinence, complete functional dependence and loss of the ability to walk. These features are part of the stage 7 classification of the Global Deterioration Scale (GDS) (Reisberg, 1982; Scot & Pace, 2009). Similarly, the items described above categorise the patient as stage 7 on the Functional Assessment Staging of Alzheimer's Disease (FAST) scale (Reisberg, 1988). A clinical examination was undertaken to assess meeting of inclusion criteria.

The inclusion and exclusion criteria for participation in the study are enumerated in Table 1.

2.3. Sample calculation

We calculated that 136 participants were required to obtain an 80% chance of detecting an effect size (W) of 0.3 using a Chi-square test with 4 ° of freedom with a 5% significance level and a change in the carer’s decision frequency of 12% to 32% (odds ratio 3.4) in a logistic regression model with an R^2 of 0.03. For this calculation, we considered an expected frequency of the decision to provide invasive care of 12%, as described by Hickman et al. (Hickman, Tolle, Brummel-Smith, & Carley, 2004).

2.4. Questionnaire development

A questionnaire was developed for data collection that took into account articles published on the subject, particularly the study of Caron et al., that describes five dimensions involved in decision making: dimensions of the person, dimensions of the caregiver, context of interaction with the medical team, family context, and the treatment itself (Caron et al., 2005; Long, Sowell, Hess, & Alonzo, 2012; Raymond et al., 2014; Van Der Steen, 2013). The following variables were considered:

- Elderly patient with dementia: use of a nasogastric tube or gastrostomy, presence of tracheostomy (TCT), stroke sequelae (SS), time bedridden, approximate time since onset of dementia symptoms, place of residence (long term institution or home) and the individuals with whom the patient lives (formal carers, the respondent or other family members);
- Caregiver: age, gender, relationship to the elderly, whether the caregiver lives with the elderly person, whether the caregiver is the primary carer, religion, civil status, education, family income, opinion as to whether the patient's financial burden is worrying, quality of the relationship with the patient before dementia, whether the caregiver is receiving help with the care and opinion as to whether dementia is a disease that leads to death;
- Medical history of the dementia patient: hospital admissions in the last year (excluding the current admission), admissions to the intensive care unit (ICU) in the past year, perception of quality of life after hospital stay, carer's evaluation of the elderly patient's quality of life, response to the question “would it be surprising if the elderly person passed away within 1 year” and expressed wishes of the patient regarding their end-of-life care (written or not);
- Medical treatment: whether regular follow-up is performed with a doctor, quality of relationship and confidence in the doctor, whether the doctor informed the family of the estimated survival time, expected future complications (pressure ulcers, feeding problems and recurrent infections) and treatment options (invasive measures versus palliative care).

The researcher developed a standardised script to ask the question “in the event of cardiac arrest, should cardiopulmonary resuscitation (CPR) be administered?" and “in case of a deterioration in respiratory pattern, should mechanical ventilation (MV) be used?". The script was inspired by the one used in the Physician Orders for Life-Sustaining Treatment (POLST) project and explained these procedures impartially.

Table 1
Inclusion and exclusion criteria.

Inclusion	Exclusion
• age of patient with dementia > 60 years, • age of the carer interviewed over 18 years, • the carer was a relative, spouse or legal guardian of the patient, • the elderly patient must have the advanced dementia syndrome criteria as described above and • the respondent must agree to participate and sign the informed consent form.	• elderly patient on mechanical ventilation, • elderly patient currently hospitalised in the ICU, • carer with cognitive impairment hindering him/her from answering the questions on the form and • elderly patient institutionalised without an accessible family carer.