



## Decisions at the end of life made by relatives of institutionalized patients with dementia



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### ABSTRACT

**Background:** The wishes and preferences of patients with dementia should inform the decisions made about their future care. However, the decision-making that occurs at the end of life is a difficult experience for the families of patients. With regard to decision-making in the terminal stages, few studies have explored the experiences and feelings of caregivers of persons with dementia who are institutionalized.

**Aim:** To describe the processes of decision-making used by families regarding treatments at the end of life of institutionalized patients with advanced stages of dementia.

**Methods:** Five focus groups were conducted in five nursing homes in Spain, representing a total of 84 familiars. **Results:** Five categories that describe the context for decision-making were identified: the emotional effect, the “living death,” the two faces of death, the values and objectives regarding treatments at the end of life, and the lack of knowledge about the progression of dementia.

**Conclusions:** The participants have unresolved emotional needs resulting from both the disease and the institutionalization of a member of their family. The participants were unprepared to make end-of-life treatment decisions, and they lacked a consistent healthcare provider to provide informational and emotional support that would have helped with decision-making. The carers' own wishes and preferences were shaped by their perceptions and experiences of the dementia illness.

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## 1. Introduction

When communication occurs surrounding preferences and treatments at the end of life, it has the potential to improve both the quality of care and the attention received by the patient and their family, especially in the nursing home setting (Elliott et al., 2014; Lovell & Yates, 2014). The proponents of improving end-of-life care at the institutional level have suggested that early planning in patient care begins with a process of communication. This communication occurs between patient, family and care center and is maintained throughout institutionalization (Penders et al., 2014; Silveira, Kim, & Langa, 2010).

The advance directive, or living will, is a step beyond informed consent in that it provides context and respect for patient autonomy. As a document, it responds to the need to reflect wishes that cannot be communicated directly because of a disability (Kwak, De Larwelle, Kesler, & O'Connell Valuch, 2015; van der Steen et al., 2013). In nursing homes,

advance directives typically include directions regarding resuscitation, hospitalization, nutrition, hydration, and the use of medications. However, advance directives are only one indicator of communication about end-of-life treatments. An advance directive itself does not improve communication about important decisions made at the end of life, nor is it enough to serve as a practical guide for specific decisions. Instead, it merely provides general guidelines (van der Steen et al., 2014).

Unlike advance directives are often protocolled in many homes, true planning for end-of-life care of any patient is indicative of excellence. It is a dynamic and continuous communication process and is not limited to the advance directive (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014).

The planning of end-of-life care, or advanced care planning, is a way to explore and communicate the preferences and goals for end-of-life care, occurs over time, and may or may not include an advance directive. Advance care planning is a process of discussion that usually takes place in anticipation of a future deterioration of an individual's condition, and the discussion occurs between the individual in question and a care worker, usually from a health-care background (Teno, 2010). It is a process of communication that involves individuals in decisions about their future care, particularly in making plans to ensure that their preferences

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can be met when their mental capacity is lost. The purpose of planning end-of-life care is to guide end-of-life treatments, especially for those who are cognitively impaired, as occurs in the case of dementia.

The planning of end-of-life care for nursing home residents with dementia-related illnesses is of special importance. Dementia is a slow and gradual process that evolves over many years (Batsch & Mittelman, 2012). The terminal stages of dementia lead to dependence in activities of daily living, a bedridden lifestyle, and eventually to death. Given that it is a long-term illness resulting in an inability of the person to make decisions, the responsibility often falls on the families and on the institutions themselves (De Roo et al., 2013). Family carers' involvement in the medical decision-making process increases as the patient's involvement declines (Hirschman, Xie, Feudtner, et al., 2004). Insufficient information about the course of the disease, together with feelings of guilt and failure, often leave family carers unprepared to make end-of-life decisions on behalf of their relative (Robinson, Dickinson, & Rousseau, 2012). It remains unknown whether the decisions that carers make are influenced by their own wishes or if they accurately reflect the decisions that the patient with dementia would have made themselves (Ryan & Scullion, 2000). Family carers often suffer significant distress, in particular 'anticipatory' or 'pre-death' grief, and they are expected to act as 'proxies', making difficult and emotionally demanding decisions (Denning, Jones, & Sampson, 2011). Given the lack of residents' cognitive capacity and the low prevalence of advance directives, this population is especially vulnerable to either over- or under-treatment at the end of life (Aw, Hayhoe, Smajdor, et al., 2012).

Addressing this reality with family and establishing a dialogue regarding decision-making at the end of life could enable a more fluid communication channel that could satisfactorily solve many of the problems currently observed (Gaugler, Reese & Sauld, 2015). Therefore, the purpose of this study was to describe the decision-making used by families regarding treatments at the end of life of institutionalized patients with advanced stages of dementia. For the purposes of this study, we focused on the treatment decisions regarding resuscitation, hospitalization, artificial feeding by gavage, and the use of treatments or techniques that do not have a clear benefit in the final stages of life.

## 2. Method

The study used naturalistic principles of research study design, data collection, and analysis of the data (Leech & Onwuegbuzie, 2008). The naturalistic approach facilitates the exploration of the underlying complexities and processes that influence decision-making. The Krueger method (Krueger, 2000) for performing qualitative focus groups was used, which is based on creating interactive and dynamic groups that respond to specific open questions about decision-making at the end-of-life, in the presence of several researchers. Data analysis occurred at the level of the responses of the participants, this is, analysis stayed true to participant responses as possible, and reflective notes were taken by the researchers.

### 2.1. Participants

Five long-term care nursing homes were selected and belonged to the same religious order in three cities of northern Spain. The selected participants were familiars of residents with dementia. Inclusion criteria: the residents with dementia had moderate to severe dementia (GDS in stages 6–7) and the familiar was also required to be familiar with an ability to make legal decisions about the health of the patient. There weren't specific exclusion criteria; we recruited all familiars who wanted to participate, independently of the grade of knowledge about the wishes of their familiar with dementia, respect to make decisions at the end-of-life. A total of five focus groups were created out of the family members who agreed to participate.

### 2.2. Data collection procedure

The researchers obtained approval for the study from the bioethics committee, the religious congregation and the five nursing homes. The relatives of the family who met the inclusion criteria were invited by letter to participate. The letter explained the nature of the study and referenced the team of nurses who were conducting the study. The nurses also called each family member to explain the study in more detail and to invite them to participate in the focus groups. Overall, 135 letters were sent, and 84 families ultimately participated. The reasons for non-participation included other commitments, bad weather and poor health.

Each focus group had between 10 and fifteen participants, with a maximum of sixteen participants. The four researchers attended all of the focus groups, and each focus group was led by a principal investigator who had previous training and experience with focus group methodology. The same open questions were used in all groups, for example: *What is the hardest decision that I had to make as a member of the family?; What does quality of end of life mean to you?; As dementia progresses, please describe under what conditions you would consider being hospitalized and consider if it's better to leave the residence.* The lead researcher also made use of spontaneous probing and follow-up questions to explore any new major themes that arose. The focus groups lasted approximately two hours and were videotaped with the permission of the participants.

### 2.3. Data analysis

The collection and analysis of the data were both simultaneous and continuous. Namely, the analysis began with the first focus group and continued with each subsequent group. To facilitate qualitative content analysis, qualitative analysis software (Atlas.ti 6.0) was used for the process of identifying, coding and classifying measurement standards of the data. The data analysis occurred in three phases. First, after transcription, each focus group interview was read among all of the researchers to obtain a "sense of the whole" (Kidd & Parshall, 2010). Codes, words or phrases to organize the data were established and identified directly from the data (Leech & Onwuegbuzie, 2008). The definitions for each identified code were then described and categories were developed to organize the codes into meaningful groups, with detailed descriptions provided for each category. A total of 129 codes and 16 categories were ultimately identified. For the process of decontextualization and recontextualization, the Tesch (1990) method was used to secondarily evaluate patterns and themes. The data were divided and organized to allow comparisons between all of the focus groups. Lastly, the third phase involved interpretation of the data towards the generation of temporary relations and working hypothesis (Leech & Onwuegbuzie, 2008).

## 3. Results

### 3.1. Description of the sample

Overall, 84 familiars participated, including 22 daughters, 9 sons, 12 wives and husbands, 11 sisters, 5 brothers, 11 nieces and five grandchildren of patients with dementia. The ages ranged between 36 and 87 years ( $M = 66$ ). The age of dementia-affected residents ranged from 72 to 98 years ( $M = 84$ ). The time from loss of decision-making capacity to the time of study of the residents was 1 to 8 years ( $M = 4$ ). The total time of institutionalization in the center ranged from 7 months to 8 years ( $M = 3.1$  years).

There were five major issues identified surrounding the experience of decision-making: the emotional effect, the "living death" of the person with dementia, the two faces of death, values and objectives regarding treatments at the end of life, and lack of knowledge about the

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