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## Desire to institutionalize in Alzheimer's caregivers: An empirical analysis on Italian data

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## ABSTRACT

**Objective:** Families choice to institutionalize an Alzheimer's disease (AD)-affected relative is hard and possibly painful. Recent literature contributions have investigated the causes of the emergence of desire to institutionalize (DI) who is affected by AD. This paper contributes to the topic by providing an Italy-based empirical analysis of factors correlated with DI in primary informal caregivers of patients affected by AD.

**Methods:** Data were drawn from an original survey carried out over 2009. 171 primary informal caregivers of patients followed in two Italian outpatients AD Care Units, located in two of the major Italian cities, Naples (46.78%) and Rome (53.22%), were interviewed. The caregiver desire to institutionalize AD affected patients was observed and its heterogeneity was studied through logistic regression.

**Results:** DI was positively correlated with patient poor autonomy, to the housewife/househusband status of primary caregiver and to the presence of a formal caregiving. DI was also barely correlated with patient gender and with the hours of informal supervision ( $p < 0.10$ ). The housewife status of the primary caregiver was also positively associated with DI, while the female gender of the patient was negatively associated to it.

**Discussion:** The institutionalization of an AD-affected relative is a painful decision which is discouraged by the scarcity of adapted facilities and the need of an economical contribution in case of institutionalization in private facilities not receiving public support.

## 1. Introduction

Alzheimer's disease (AD) is the most frequent cause of institutionalization of adult subjects (Aguero-Torres, von Strauss, Viitanen, Winblad, & Fratiglioni, 2001). Recent investigations have documented that "Institutionalization rates among individuals suffering dementia considerably exceeded those rates of community-based samples" (Luppa, Luck, Brahler, Konig, & Riedel-Heller, 2008, p. 5). Institutionalization costs may have a tremendous impact on health care systems and/or on family's budgets depending on the public/private financing system of residences for AD patients. At the same time, home care of a patient usually determines significant costs (Colucci et al., 2014) which, lacking public home assistance should be covered by the own family. Caregiving burden is perceived by family members also because of their involvement in assistance and supervision of patients or of the need to cover the costs of specialized employees for the care of their relatives.

In the recent years the reasons of the choice of AD patients institutionalization was investigated with particular attention to the

emergence of the desire of institutionalization among family and/or caregivers (McCaskill, Burgio, Decoster, & Roff, 2011; Morycz, 1985; Spruytte, Van Audenhove, & Lammertyn, 2001). The caregiver decision to institutionalize a relative affected by AD is the final step of a complex process characterized by conflicting feelings, doubts and afterthoughts, that may persist even after the decision has been taken (Paulson & Lichtenberg, 2011; Vario & Sansoni, 2000). The main findings provided by the existing literature support the idea that desire of institutionalization (DI) is influenced by the characteristics of the patient and by those of the family caregivers.

On the one hand, caregivers whose AD-affected relative shows behavioral disturbances (Spijker et al., 2011) and severely reduced autonomy (Vernooij-Dassen et al., 1997) face a hard burden and therefore develop DI more easily. On the other hand, caregivers' perception of this burden is linked to their socio-demographic characteristics (Spruytte et al., 2001) which play a significant role in the arising of DI. Cultural aspects as well play an influential role in the process of DI development (Calderón & Tennstedt, 1998; Sansoni et al., 2013; Gwyther, Reed, Friedman, & Schulman, 2004). It has been found that

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Afro Americans and Latinos living in the USA turn to institutionalization of old relatives much later than the Caucasian population (Gaugler, Duval, Anderson, & Kane, 2007), probably because of the higher ethnic value assigned to caregiving in this community (Mausbach et al., 2004).

This work has investigated factors affecting DI in a sample of Italian AD patients ( $n = 171$ ) by using cross-sectional data collected through a survey of primary informal caregivers assisting relatives affected by AD in two cities, Naples and Rome, located respectively in the Centre and in the South of the country. Italy is an interesting context for assessing the determinants of the emergence of DI among primary caregivers. In spite of a diffuse concern about the actual strength of family ties in contemporary societies, several studies have shown that close family relations and intergenerational solidarity still characterize the Mediterranean areas (Glaser & Tomassini, 2000; Tomassini et al., 2004). In Center and Southern of Italy, in particular, taking care of an ill relative has a strong ethical value, also because these are areas where religion is very important in everyday life (WIN-Gallup International, 2012) and caregiving of the husband/spouse is a promise exchanged during weddings celebrated according to the catholic ritual, which is largely diffused in Italy.

The purpose of the present study was to evaluate how often caregivers report DI in this particular context and to identify patient-related and caregiver-related variables showing a statistically significant correlation with the emergence of DI.

## 2. Data collection and methodology of analysis

This paper relies on data collected through an original survey of primary informal caregivers assisting AD patients at home. Caregivers were interviewed during their patients' visits to two Alzheimer care units located in Rome (at "La Sapienza" University) and Naples (at the "A. Cardarelli" Hospital). In terms of local populations, Rome (approximately 3 million of inhabitants) is the most densely populated city in Italy while Naples (approximately 1 million of inhabitants) is the third one. In the Alzheimer care units participating to the survey, interviews were carried out over a three-month period, from January until April 2009 in Naples and from September until December 2009 in Rome. All the primary informal caregivers of patients who had a medical examination at the unit over this period were surveyed. All the patients who have a medical examination at the units are normally accompanied by their primary caregivers. The two samples can be therefore considered as representative of the population of patients assisted in the units where the survey was carried out. Even if data were collected in 2009, there is no reason to believe that they provide a different picture from the one that is observed nowadays. Indeed, over recent years no significant changes have been applied to the AD care units patients' recruitment system and to the management of AD patients at home.

Data were gathered before patient's medical examination and through an *ad hoc* questionnaire which was submitted by a psychologist with previous experience in data collection. The information collected through the questionnaire were totally anonymized before the study was run. All the caregivers involved in the survey were informed about the aim of the study to be carried out. The final sample included 171 caregivers, the 46.78% from the Naples unit and the 53.22% from the Rome unit.

One question in the survey was specifically designed to assess the caregivers' DI of the patient assisted. The informal caregivers' desire to institutionalize the patient may be measured through different methods, including a recently developed "Desire to Institutionalize Scale" (DIS). This is a 6-item questionnaire aimed to quantify the willingness of the caregiver to put the relative in a long-term care which consists of six yes/no questions. The literature suggests that the DIS offers a good predictive accuracy of subsequent institutionalization (Gallagher et al., 2011). The first item of this scale investigated whether the caregiver has ever considered the possibility to place the patient in a

boarding home or in an assisted living and therefore explores the prerequisite for institutionalization. Since this study specifically wants to investigate caregivers' desire to rely on these caregiving facilities, the survey used by this study measures DI by using a single question similar to this first DIS item. The question asks: *Have you recently thought about the possibility to institutionalize the patient?* Caregivers were asked to answer *yes* or *no* and answers were coded into one binary variable taking the value of 1 in case of *yes* and 0 otherwise. This variable was labeled DESIRE.

The analysis of data was carried out through two steps. First, data were inspected through descriptive statistics. Second, in order to identify the correlates of informal caregivers' desire to institutionalize their AD-affected relative, the variable that was labeled DESIRE was used as dependent in a regression analysis where both the caregivers-related and the patient-related variables were included among covariates.

Two features of this regression analysis are worth noting. First, since the dependent variable used in this study has a binary nature, the logistic regression analysis (Walker & Duncan, 1967) was identified as the appropriate method to model the probability or likelihood that caregivers desire to institutionalize their AD affected relative. Second, the following empirical analysis has to be intended as the search for correlations since the cross-sectional nature of the data employed and the omission of potentially relevant variables which were not available in the original survey do not allow the identification of any causal link among the variables under investigation.

The covariates used in the regression specification may be grouped as follows:

- demographic characteristics of the patient: age and gender.
- measures of demographic characteristics of the patient and the progression and severity of his/her disease: these variables included age, Mini Mental State Evaluation (MMSE) score whose original values were recoded into three categories (1 = 28-23, normal cognition or very mild dementia; 2 = 23-14, mild to moderate dementia; 3 = < 14, severe dementia), Activities of the Daily Living (ADL) index (whose values range from 0 = completely unable to perform daily life activities to 6 = able to perform all daily life activities) and one dummy variable assuming the value of 1 if the patient experienced aggressive behavior and needed to be treated with antipsychotics (such as chlorpromazine, risperidon, quetiapine, haloperidol) and/or antidepressants (such as citalopram, duloxetine, sertraline). We expect the primary informal caregivers' desire of institutionalization to be higher in case of patients more severely affected by the disease and who showed aggressive behavior.
- socio-demographic characteristics of the primary informal caregiver: gender, age, one dummy taking the value of 1 for those who are retired, one dummy taking the value of 1 for those who are housewife/househusband, one dummy taking the value of 1 for son/daughters of the patient; with respect to these variables, we expect that non-working informal caregivers do have more time to take care of their beloved patient affected by AD and, therefore, may be less prone to institutionalize them. The same may apply to the retired status. The effect of caregivers' age is *a priori* ambiguous since older caregivers may have a lower capacity to supply support to patients and therefore may exhibit a lower desire to institutionalize them; nevertheless, at the same time they may perceive the caregiving duty as an essential mission in their lives and therefore may be strongly adverse to institutionalize their beloved. Finally, also the effect of the dummy that identify those caregivers who are sons of the patients is *a priori* ambiguous.
- informal caregiving burden: the total amount of weekly hours of informal supervision supplied (which were measured through the diary method), the share of total informal supervision supplied by the primary informal caregiver, one dummy assuming the value of 1 in case of patients who benefit from formal supervision. With

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