

# Understanding care of people with dementia in Spain: Cohabitation arrangements, rotation and rejection to long term care institution

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## SUMMARY

**Background** Most people with dementia in Spain live at home with their families. Current changes in the family structure are transforming the care of people with dementia through new cohabitation arrangements and rotation practices.

**Objective** To describe the cohabitation arrangements of families of people with dementia in Spain and to understand the caregivers' characteristics related to rotation and the rejection of long term care institutions.

**Methods** A cross sectional study -NEDICES study- was conducted using both quantitative and qualitative methodologies. 150 caregivers of people with dementia from two communities from Madrid, Spain, were surveyed using a questionnaire designed to describe cohabitation arrangements and care. Qualitative methods included: 13 caregivers participating in focus groups, and 3 caregivers in Semi Structured Interviews aimed to understand rotation practices and rejection to long term care institution.

**Results** Characteristics related with rotation were: sex of persons with dementia, widowhood, socio-economic status, caregiver relationship and burden of the caregiver. The qualitative study showed that the use of the rotation was related to normative behaviors and with obligation feelings, along with a change in the role of women in the current Spanish family. The use of long term care institutions was related to geographical distance of the family.

**Conclusions** The results of this study suggest that rotation has appeared in Spain as a new mechanism of care for people with dementia, and its related to the rejection of long term care institutions. Copyright © 2008 John Wiley & Sons, Ltd.

KEY WORDS —dementia; long term care institutions; cohabitation arrangements; caregivers

## INTRODUCTION

The care of people with dementia in Spain is mainly provided within the family. Nevertheless social changes in the last 30 years have altered the type of care and cohabitation arrangement of elderly people in

general and particularly of people with dementia (Yanguas *et al.*, 2000). Social changes such as larger numbers of elderly people living alone, changes in the women's role at home and new ways of understanding and putting up with family relations (Alberdi, 1999; Garrido, 2000; Pérez-Díaz *et al.*, 2001; INE, 2004) have translated in unprecedented cohabitation arrangements and have led to different types of dementia care such as, for example, to live alternatively in several homes—'rotation' (Rivera, 2001; de la Cuesta, 2005; Losada *et al.*, 2006).

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We combined qualitative and quantitative approaches to describe the cohabitation arrangements of people with dementia in Spain and to explain the causes of rejection of long term care institution of persons with dementia by caregivers and the rotation.

Very few studies have addressed how people with dementia live in Spain and, to our knowledge, no studies have explained the cohabitation arrangements according to latin and mediterranean countries, e.g. rotation (Marrugat, 2005), and the causes of rejection of the use of long term care institutions in Spain (Rivera *et al.*, 1999; Bermejo, 2004).

## METHODS

Quantitative data for these analyses were derived from the Neurological Disorders in Central Spain (NEDICES) cohort study, a longitudinal population-based survey of the prevalence, incidence and determinants of older age-associated conditions of the elderly (Bermejo *et al.*, 2001; Morales *et al.*, 2004). Cross-sectional results from the NEDICES study have been already published elsewhere (Benito-León *et al.*, 2004; De Toledo *et al.*, 2004; Morales *et al.*, 2004).

Qualitative data were based in a phenomenological approach (Becker, 1998; Mckeown *et al.*, 2004). The goal of phenomenological research is to analyse how experience is built and communicated in the world of everydaylife (Holstein and Gubrium, 1998).

Focus groups (FG) were used in order to facilitate interactions between participants about their experiences (Krueger and Casey, 2000). Using FG, the researchers are also allowed to consider issues and questions which they may not have previously considered (Madriz, 2000).

### Study design

This study was conducted as a combination of quantitative and qualitative methodologies. The quantitative section is based on the study of caregivers proceeding from cohort study NEDICES. A sample of prevalent cases of dementia were selected and the caregivers of persons with dementia analyzed. The caregivers completed a questionnaire including the following variables: socio-demographics items, structured questions which analysed the care network, informal and formal care and standardized scales—Zarit burden Scale (Zarit *et al.*, 1980), Katz Index (Katz *et al.*, 1963), Pearlin Scale (Pearlin *et al.*, 1990).

The section of the study using qualitative methodology consisted in two FG and three consecutive interviews. FG were composed of caregivers of people

Table 1. Composition (and selection criteria) of FG

FG 1 Date: 02/06/2000	FG 2 Date: 02/15/2000
Medium-low social class	Medium-high social class
Females only	Males and females
Daughters	Daughters, husbands and wives
Different kinds of cohabitation arrangement: institution, family or living apart from family	Different kinds of living accommodation: family and living apart from family
Different kinds of dementia intensity	Different kinds of dementia intensity
Seven participants	Participants: three male and three female

with dementia. Caregivers discussed what they thought about the care provided to their relatives (difficulties and needs as caregivers, consequences of care in daily life and their opinion about the use of long term care institution). According to the results obtained from the FG, three semi-structured interviews (SSI) were designed, complementing the discourses showed in the FG. The composition of the FG and SSI, as well as selection criteria of the participants are shown in Table 1 and Table 2.

The following inclusion criteria for caregivers of people with dementia were applied: Age—participants aged 18 and older; Dementia severity—caregivers with relatives diagnosed with any kind of dementia according to DSM-III (mild, moderate and intense) (WHO, 1988); Time of care—caregivers must have provided care to a person who had been diagnosed with dementia for at least 1 year; and at least 1 h of daily assistance in the last year.

### Setting

The quantitative part of this study took place in two communities from central Spain: (1) Las Margaritas, a

Table 2. Composition (and selection criteria) of SSI

SSI 1 Date:03/17/2000	SSI 2 Date:04/03/2000	SSI 3 Date:04/25/2000
Proceeding from informal contact	Proceeding from Alzheimer's family organizations	Proceeding from informal contact
Male	Male	Male
Son	Son-in-law	Son
Medium-low social class	Medium-low social class	Medium-High social class
Living in several families alternatively	Living in a single family	Living in several families alternatively
Intense dementia	Intense dementia	Moderate dementia

working-class neighborhood in Getafe (Greater Madrid); and (2) Lista, a professional-class neighborhood in Salamanca district (Central Madrid).

FG and SSI were set up in Madrid at the Spanish Association of Sociologists, because this place was considered a neutral space, necessary to conduct FG (Morgan, 1998). Each session was convened by an experienced FG moderator: first author in the FG and a research assistant, who collaborated in this survey, was present as a recorder.

### *Participants and data collection*

The cases in the quantitative section of this study come from the NEDICES study (Morales *et al.*, 2004), that was originally designed with two phases. Phase 1 involved door-to-door screening of eligible people. The screening included the use of standardized questionnaires administered by lay interviewers. Phase 2 involved a neurologist's examination of those individuals who screened positive in Phase 1. The estimated prevalence of dementia in the general study (Margaritas and Lista) were near 6% (Benito-León *et al.*, 2004; De Toledo *et al.*, 2004). We used a sample of successive cases, once the previous diagnosis of dementia was confirmed by the study neurologist, the caregivers were interviewed. The first 150 caregivers of these persons diagnosed with dementia (belonging to the prevalent cases) that accepted the interview were included in the sample and were studied (43 cases were unreachable and could not be interviewed).

For the qualitative section of this study the members of the FG and SSI were selected from outpatient clinics, members of Alzheimer's family organizations and informal contacts. People who had previously answered the applied questionnaire in the population study could not participate in FG or SSI, because their discourse would have been determined by the items from the quantitative questionnaire (Morgan, 1998). SSI were implemented only for male caregivers. Since men generally do not take on the role of caregiver, we did not consider it necessary to create a male caregivers FG; however, the individual trajectory of care in male caregivers was aim of interest and, therefore, was pertinent to perform SSI. The FG and interviews were performed in the winter and spring of 2000 and systematically recorded and analysed using the 'MAXqda' program. The quotation was literal, referring to the FG number and to the transcription page (e.g. 2FG, 5: 2; 2. p. 5); and in the case of interviews, the reference was also included in the transcription page (e.g. 3SI, 7; Semi-structured p. 3. 7).

The sample of caregivers from the qualitative section come from a different population than the ones in the quantitative section for two reasons: (a) persons who had answered questions in the quantitative section could not participate in FG and SSI because of the possibility of same source bias (Madriz, 2000); (b) demographic characteristics of caregivers in the qualitative section were very similar to those of the caregivers in the quantitative section; we considered that the discourse generated had been very similar if the caregivers proceeding from quantitative section would have participated in FG or SSI.

A list of themes for the FG were generated, which were regarding the main areas of concern for dementia sufferers caregivers, according to the scientific literature and previous research but without rejecting other domains not taken into account in these guidelines such as the perception of the family as caregiver of old people, strategies of care, and view of formal support (institutionalization of people with dementia). The SSI guideline was more strict than that of the FG, although the questions asked were similar.

### *Data analysis*

In the quantitative study, statistical analyses were performed using SPSS software (version 11.0; SPSS, Inc.; Chicago, IL). All analysis were descriptive. Categorical variables were compared using chi-square tests.

In the qualitative study, an interpretative approach to analysis was adopted to understand the meaning of the caregivers' experiences.

## RESULTS

### *Quantitative study*

Main socio-demographics data (age, sex and marital status) from persons with dementia are presented in Table 3. In relation to the intensity of dementia (DSM-III-R) and etiology most of the cases presented severe dementia (60.6%) and Alzheimer's disease as aetiology (74%).

The main features related to cohabitation arrangements are shown in Table 4. We highlighted the percentage of elderly people who lived in long term care institution (20%) and those who lived in several homes 'rotating' among several relatives (15.3%); if we compare the studied populations, only the persons with dementia in Margaritas lived in several homes.

Features of primary caregivers are shown in Table 3. Women mainly assumed the role of primary care-

Table 3. Socio-demographics data of people with dementia and their caregivers

	N	%
<i>Patient</i>		
Male	39	26.0
Female	111	74.0
<i>Caregiver</i>		
Male	33	22.0
Female	117	78.0
<i>Age</i>		
<i>Patient (Media = 86; SD = 6.5)</i>		
65–69	1	0.7
70–74	8	5.3
75–79	14	9.3
80–84	31	20.7
85–89	47	31.3
More than 90	49	32.7
<i>Caregiver (Media = 59.9; SD = 13.6)</i>		
18–39	6	4.0
40–59	88	58.7
60–79	37	24.6
More than 79	19	12.7
<i>Marital status</i>		
<i>Patient</i>		
Single	14	9.3
Married	41	27.3
Widower	95	63.3
<i>Caregiver</i>		
Single	19	12.6
Married	104	69.4
Separated/divorced	5	3.4
Widower	18	12.0
Not specified	4	2.6
<i>Relationship of caregiver with patient</i>		
Spouse	31	20.7
Daughter	70	46.7
Son	15	10.0
Son and daughter-in-law	12	7.9
Other	22	14.7

Table 4. Cohabitation arrangement of people with dementia according to neighbourhoods

	Margaritas		Lista		Total	
	N	%	N	%	N	%
Who did person with dementia live with?						
Alone	1	1.0	3	5.9	4	2.7
With steady family	61	61.6	32	62.7	93	62.0
Several homes*	23	23.2	0	0.0	23	15.3
In institution*	14	14.1	16	31.4	30	20.0
Lived with steady family						
Lived only with spouse					35	37.6
Lived with sons					58	62.4

\* $p < 0.05$ .

Table 5. Features of people with dementia and their caregivers according to living in one or several homes

	Living in one home		Living in several homes 'rotation'	
	N	%	N	%
<i>Geder*</i>				
Male	30	32.2	5	21.7
Female	63	67.8	18	78.3
<i>Persons with dementia's age</i>				
65–79 years old	20	21.5	0	0.0
More than 79 years old	73	78.5	23	100.0
<i>Marital status*</i>				
Single	7	7.5	0	0.0
Widower	40	43.0	23	100.0
Married	46	49.5	0	0.0
<i>Studied areas*</i>				
Margaritas	61	65.5	23	100.0
Lista	32	34.5	0	0.0
<i>There are formal caregivers*</i>				
Yes	24	25.8	1	4.3
No	69	74.2	22	95.6
<i>Caregiver relationship*</i>				
Spouse	31	33.3	0	0.0
Son/daughter	48	51.7	17	74.0
Son-in-law/daughter-in-law	2	2.2	4	17.3
Grandson/granddaughter	0	0.0	2	8.7
Others	12	12.8	0	0.0
<i>Zarit Scale** (includes addition of all items)</i>				
Never	0	0.0	22	4.4
Almost never	420	20.5	22	4.4
Sometimes	133	6.5	22	4.4
Many times	241	11.8	88	17.3
Almost always	1252	61.2	352	69.5

\* $p > 0.05$ ; \*\* $p = 0.064$ .

givers, with daughters of dementia patients being the caregiver in almost half of the cases.

Differential analyses between persons with dementia living alternatively in several homes and persons with dementia living in one home are shown in Table 5. Persons with dementia living in several homes were mainly women (almost 80%). All persons with dementia living in several homes were widows living in the Margaritas neighbourhood.

### Qualitative study

*Care and motivation for primary caregivers: causes of cohabitation arrangements.* Care justification was argued from two axes: obligation (norms) and mother love (feelings); on the one hand, obligation imposed by social rules and tradition and, on the other hand, love determined by a reciprocal feeling based on the belief that parents took care of their children or them.

Sometimes even affective ties lead to gratification feelings in some caregivers.

'My mother has helped me a lot when I am at work and she has helped me to raise my son, then, if I can, I am going to take care of her'. (FG 1, 10).

When sons were the primary caregivers they seemed to have less anguish since they normally had more support than daughters within their homes and even shared such care proportionally with the wife (persons with dementia's daughter-in-law) and/or children (people with dementia's grandchildren):

'... there are people that due to their work or incompatibility of character between daughters and mothers or a father-in-law with his daughter-in-law and many times ... they think: I rather see her in a nursing home where she is taken care of, than having her here all day long fighting'. (FG 2, 35).

Married persons who took care of their spouses assumed this role. Although they did not need to argue about it, they thought it was an obligation (detached from marriage) and a love act coherent with ties made by a couple married for life.

During the last decades, social evolution has brought equality for women; nonetheless, most female caregivers wanted to go on taking care of their relatives, although with cooperation from the male part of the family in order that she can combine her role in public life with her role at home.

'... because if there is a strong family network then you say, with a little help that every one puts, without involving too much, lightens a little, but on one person all the weight, it is very burdensome ...'. (FG2, 46).

*'Rotation' and institutionalization: controversial cohabitation arrangement.* 'Rotation' was used by caregivers participating in FG and SSI, and it was considered that the consequences for the persons with dementia could not be adequate, but it was the best option for caregivers before using a long term care institution. The use of the 'rotation' was related to normative behaviours and to obligation feelings, along with a change in 'role' of women in the Spanish family. Nevertheless the adoption of cohabitation developed into contradictions and guilty feelings, showing again the power of the tradition and social norms.

'... It seemed like those in the family who were opposed to send her to a nursing home loved her more than the

others, and then we decided care her two months every one ...'. (SSE1, 2).

'... no, I speak the truth, this situation of going from hand to hand and that nobody want to stay with her, as the song says, I do not agree, but I also understand, you begin to think, and it is not logical, that is years and years taking care of her mother ...'. (2FG, 25–26).

Nursing homes for relatives were strongly rejected in the discourses or considered the last resource. The wrong image of long term care institution was related to family failure, and the long term care institution was identified with abandonment. There were two confronted mentalities, one traditional which identified long term care institutions with asylums where people lived with nothing or no one, and a modern one which perceived long care term institutions as a resource without negative connotations. Women felt guiltier than men when they talked about the possibility of their relatives living in a long term care institution. Caregivers, detractors of entrance in long term care institutions, connected the institutionalization with family distance and with no love feelings of relatives towards persons with dementia. These rejections were exclusively towards long term care institution, not towards day centres or to institutional respite care.

'... Every elderly who has some relatives is being supported but if they have none, they must go to public long term care institutions, where nobody goes to visit them ... the situation is really sad ...'. (1FG, 7).

## DISCUSSION

The aim of this study was to analyse cohabitation arrangements such as rotation and to study the causes that explain the rejection of institutionalization and rotation in Spain. Two different methodologies were used in this study.

Data about cohabitation arrangements showed, in general, percentages similar to data shown by other surveys (Fischer and Lieberman, 1999; Canadian Study of Health and Aging Working Group, 2002), except from the issues of 'rotation' and institutionalization:

'Rotation' or cohabitation arrangement of dementia patients in several homes is a care strategy that has only been mentioned and analysed in surveys that studied elderly people in general or disabled elderly (not exclusively dementia) (Rodríguez, 1994; Colectivo IOE/INSERSO/CIS/Instituto de la mujer, 1995; Rivera, 2001; de la Cuesta, 2006). In this survey,

'rotation' was used only in a medium-low socio-economic level urban area (Margaritas), and its main aim was to share the burden of care between family members. Three features of rotation stand out: (1) rotation took place in low socio-economic level places—Margaritas neighbourhood; (2) all caregivers belonged to second and third generation; (3) caregivers had a higher score in the Zarit scale.

Institutionalization of persons with dementia in our study sample was low if we compare these data to other studies outside of Spain (Grafstrom *et al.*, 1992; Fisher and Lieberman, 1999; Canadian Study of Health and Aging Working Group, 2002). A possible explanation for this difference is that institutionalization of elderly people in Spain is very low (Fundación Encuentro, 2001). Nevertheless, in the higher income neighborhood of Lista, the elderly lived in nursing homes, indicating that, in Spain, more people with dementia from high socio-economic levels live in nursing homes than those from low socio-economic levels (García Navarro, 2000).

The data from caregivers who participated in the FG and SSI-, who rejected the idea of their relatives living in long term care institutions, had a profound sense of family participation (which included encouraging the patients to participate in self-care and occupational activities) (Vallone *et al.*, 2002; Ho *et al.*, 2003).

The use of nursing homes for people of medium class in Spain remains uncommon because of its high cost or because of being reserved for persons of extremely low resources, nevertheless we consider that the rejection of long care institutions is rooted primarily in cultural factors rather than economic factors as participants in the FG did not argue economic factors for not placing family members suffering from dementia in long term care institutions.

We need to acknowledge the main limitation in our study. It would have been desirable to have included two FGs: one composed of only women of medium-high social class and another one composed of women of medium-low class. This addition would have strengthened our results.

On the basis of our results we recommend two specific policies: diversification of aids to the families and people with dementia, and direct collaboration of voluntary organizations with the National Health System and the Ministry of Social Affairs.

In conclusion, the results of this study suggest that societal changes in Spain have translated into new strategies to cope with the care of people with dementia; we specifically describe 'rotation', as a new mechanism of care, which is directly related to the rejection of long term care institutions.

## CONFLICT OF INTEREST

None known.

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