

**A comprehensive approach of the determinants of use of care in dementia.**

**The Recaredem (Recourse to care in dementia) cross-sectional study**

Rullier Laetitia<sup>1</sup>, Meillon Céline<sup>1</sup>, Bergua Valérie<sup>1</sup>, Pimouguet Clément<sup>1</sup>, Gonzalez-Colaço Harmand Magali<sup>1</sup>, Helmer Catherine<sup>1</sup>, Pérès Karine<sup>1</sup>, Dartigues Jean-François<sup>1</sup>, Amieva Hélène<sup>1</sup>

**Authors' affiliations:**

<sup>1</sup>Univ. Bordeaux, Inserm, Bordeaux Population Health Research Center, UMR 1219, F-33000 Bordeaux, France

**Corresponding author:**

Laetitia Rullier

University of Bordeaux, Inserm, Bordeaux Population Health Research Center, UMR 1219,  
146 rue Léo Saignat, CS61292, F-33076 Bordeaux Cedex, France

Phone: 0033 5 57 57 45 38 / Fax: 0033 5 57 57 14 86

E-mail address: [laetitia.rullier@u-bordeaux.fr](mailto:laetitia.rullier@u-bordeaux.fr)

## **Abstract**

**Background.** Given the rate of the undiagnosed cases of dementia and the consequences of inappropriate care, understanding the factors that explain the use of medical and health care in dementia is a critical concern. Our objective was to identify the psychosocial and medical determinants of use of care in dementia.

**Methods.** The study sample consisted of 308 participants: the persons with dementia (n=99) selected within three French population-based cohorts (i.e. PAQUID, 3C, AMI), their family caregivers (primary, n=96 and secondary, n=51), and their general practitioners (n=62). Use of care in dementia was considered according to two indicators: (1) recourse to secondary care, (2) number of community and health services used.

**Results.** Multiple logistic models including sociodemographics and psychosocial variables revealed that the determinants of non-use of care are similar both for the recourse to secondary care and for the number of community and health services used: no education and the contribution of the people with dementia to the decisions regarding their own care and dementia care services in the community area. In addition, satisfaction of the primary caregiver with the services used by his/her relative is associated with non-recourse to secondary care.

**Conclusions.** Taken together, these results highlight the predominant role of psychosocial factors in the use of care in dementia and the importance of addressing this issue through an integrative approach including psychological, social, medical and family dimensions.

**Running title:** determinants of use of care in dementia

**Key-words:** secondary care; community and health services; dementia; population-based studies; patient-, family caregiver-, and healthcare-related factors.

## INTRODUCTION

Dementia is a common condition in elderly people in constant increase with projections for 2050 estimating the number of cases to 14 million in Europe (Mura *et al.*, 2010) and 131.5 million in the world (Prince *et al.*, 2015). However, more than half of dementia cases remain undiagnosed, as reported by numerous studies conducted in a wide range of countries with various cultural, socioeconomics or health policy contexts such as Canada (Bush *et al.*, 1997), France (Helmer *et al.*, 2008), Germany (Pentzek *et al.*, 2009), Sweden (Olafsdottir *et al.*, 2000), or United States (Callahan *et al.*, 1995).

Reasons for poor case recognition rates are unclear and probably multi-factorial (Bradford *et al.*, 2009; Helmer *et al.*, 2008; Koch and Iliffe, 2010). They may depend on cultural, social, familial, demographic, and clinical determinants.

A systematic review of contributing factors for lack of care referral in dementia, classified these factors as GP-related, patient and caregiver-related and healthcare system-related factors (Bradford *et al.*, 2009). Among the healthcare-system factors, the lack of resources, in particular to accessible services for people with dementia, was the principal limiting factor. Regarding factors related to GPs, the main reasons for under-identification of dementia were the lack of education about dementia and lack of communication skills.

While attitudes of people with dementia toward dementia were also identified as barriers to see a physician due to dementia or to use community and health services (Bradford *et al.*, 2009; Brodaty *et al.*, 2005), some studies have identified other factors. People with dementia were more likely to have undetected dementia when they were older, had mild functional impairment (Helmer *et al.*, 2008), lower education (Helmer *et al.*, 2008; Savva and Arthur, 2015) and had mild cognitive impairment (Savva and Arthur, 2015).

The identification of dementia mostly relies on physician's suspicion based on people with dementia's symptoms but also on family caregivers' concerns (Bradford *et al.*, 2009; Brayne

*et al.*, 2007). Indeed, the influence of family caregivers - including not only the primary caregivers but also other family members - in decision making about the people with dementia's health care has been consistently reported (Hirschman *et al.*, 2004; Toseland *et al.*, 2002). Some factors related to family caregivers have been identified as potential barriers to care referral such as denying or preferring not to know the people with dementia's condition, and also lack of knowledge about dementia or services (Bradford *et al.*, 2009; Brodaty *et al.*, 2005; Koch and Iliffe, 2010).

Even though the benefit of early care referral in dementia has never been formally demonstrated (Brayne *et al.*, 2007), the absence of identification of dementia could be a barrier for appropriate care strategies and contribute to increase medical costs related to other comorbidities (Fillit *et al.*, 2002). Given the economic and social consequences of inappropriate care, understanding the factors that explain the use of medical and health care in dementia is a critical concern for policy makers and providers. In this context, population-based studies involving a systematic screening of dementia diagnosis provide a unique opportunity to study the characteristics of the undiagnosed population.

To our knowledge, no study has considered within the same analysis the different potential contributing factors for dementia care use including GP-, people with dementia-, caregiver-, and healthcare-related factors. Therefore, the present study was designed to address the following question: what are the psychological, social, family and medical determinants of use of care in dementia?

## **METHODS**

### ***Main context of the study***

The Recaredem (Recourse to care in dementia) study is a cross-sectional and ancillary study of three ongoing prospective population-based studies with similar design and methodology. Each cohort has been described in detail elsewhere:

The PAQUID Cohort (Dartigues *et al.*, 1992) started in 1989 with a sample of 3777 participants aged 65 and over, living at home in south-western France and followed-up for 25 years (N=231).

The Three-City (3C) study (3C Study Group, 2003) started in 1999 with a sample of 9294 participants aged 65 and over, followed up for 14 years, and living at home in three French cities (Bordeaux, Dijon and Montpellier). For the present study, only participants from Bordeaux sample were included (N=783).

The AMI study (Aging Multidisciplinary Investigation) (Pérès *et al.*, 2012) started in 2007 with a sample of 1002 retired farmers aged 65 years and older, living at home in south-western rural communities and followed-up for 7 years (N=659).

Each cohort has been approved by an Ethic Committee and all participants provided written informed consent.

### ***Dementia diagnosis and inclusion criteria***

Dementia was diagnosed at baseline and at each follow-up visit of each of the three cohort studies following similar procedures. Each visit was conducted at home and included a clinical, neuropsychological evaluation and a criteria check-list for dementia diagnosis on the basis of DSM IV criteria (American Psychiatric Association, 1994) completed by a psychologist and confirmed by a specialist (neurologist or geriatrician). Then, the diagnosis was reviewed and validated by an independent panel of specialized neurologists. Such diagnosis is called hereinafter the “study diagnosis” in the present study. For each of the three cohorts, we selected all prevalent cases of dementia, i.e. the participants who had received a “study diagnosis” at one of previous follow-up visits, who lived at home. The primary caregiver was the person reported by the participant as “mainly assisting him/her in his/her daily life”. Regarding secondary caregiver, the primary caregiver was asked to “give the name of another person, if any, who was implicated in caregiving”.

### ***Study population and data collection***

The specific data collection for the Recaredem study was conducted from January 2013 to January 2015 and included data collected from the participants with dementia of the three cohorts, their family caregivers (primary and secondary) and GPs. The primary family caregiver identified at previous follow-up visits by the participant was contacted by telephone and invited to participate. If he/she accepted, two one-hour interviews were conducted simultaneously at the participants' home by two psychologists, one with the participant and one with the primary caregiver. When the presence of another family caregiver was reported, the psychologist contacted by phone the secondary family caregiver to complete a 20-minute interview.

The data related to the GP were collected in two steps: 1) a telephone interview conducted by a geriatrician to collect data about GPs characteristics and practices in the field of geriatrics; and 2) self-rated questionnaires about GP's dementia representations and knowledge.

### ***Outcomes related to use of care in dementia***

Recourse to secondary care and community and health services use were used as indicators of use of care.

The participants were considered as having sought for secondary care if they had consulted a specialist (neurologist, geriatrician or psychiatrist) for cognitive problem symptoms. Specialists are in charge of assessing cognitive and behavioural disturbance, and providing diagnosis. In France as in many other countries (Helmer *et al.*, 2008; Petrazzuoli *et al.*, 2017), specialists prescribe anti-dementia medication (anti-cholinesterasic drug) whereas GPs are not allowed to do the first prescription. Moreover, they assess risky behaviour (wandering, falls...), give information to people with dementia and families, and monitor health situations by at least biennial consultations. This information was collected with the GP.

Community and health services use was collected with the primary caregiver using a comprehensive list of nine community and health services: (1) General home help, (2) Personal care assistance, (3) Nursing assistant care, (4) Private nurse care including help for taking medication or bathing or home-based hospital care, (5) Physiotherapy, (6) Speech therapy, (7) Adult day care, (8) Short-term respite care, (9) Other community services including meals on wheels. Therefore, the number of community and health services used ranges from 0 to 9. In France, most of these services are funded by an old-age financial allowance (i.e. general home help, personal care assistance, adult day care, short-term respite care, and other as meals on wheels). The other services depend on the medical prescription by the GPs (i.e. nursing assistant care, private nurse care, physiotherapy, speech therapy) and are funded by the social welfare system.

### *Explanatory variables*

The explanatory variables were categorized according to the Behavioral Model of Health Service Use (Andersen, 1995) which is the well-known model to explain the use of community and health services. This model classifies the explanatory variables in three categories: 1) Predisposing characteristics; 2) Enabling resources to access to services; 3) Needs referring to the individual's health status and associated needs for health care. The classification of the explanatory variables in the three categories of factors was also made according to Toseland and colleagues (2002) who used these factors in the context of dementia in considering people with dementia-, family caregiver-, and healthcare-related variables.

#### *Predisposing characteristics*

Sociodemographics of the dyad (participant with dementia and primary caregiver) were recorded: age, sex and education (see Appendix A1 published as supplementary material online attached to the electronic version of this paper at <http://journals.cambridge.org/ipg>.);

living condition (living alone vs living with other people); relationship of the dyad; sharing the same household.

#### *Enabling resources*

Social and family support were assessed as follows: daily assistance from a secondary family caregiver; frequency of visits at the participant's home per week from family/friends and also of social interactions (see Appendix A1); participants' contribution to decisions regarding their social and medical care; number of persons participating in decisions regarding participant's care.

Community and health resources of the participant with dementia were collected including the geographic location (rural, urban), old-age financial allowance. As in many countries, French elderly people may have access to a public financial support, the amount of which depends on both people's income and level of dependency. This old-age financial allowance can be used to pay non-medical care, in particular community health and human services.

We defined also a score of dementia care resources for each community area, ranging from 0 to 4 including gerontological integrated care setting, respite care, in-home dementia care professionals, community gerontological center (described earlier in Pimouguet *et al.*, 2013). We also considered if a consultation in secondary care setting is available in the community area.

GP's characteristics and practices in the field of geriatrics were collected: age, sex, type of professional practice, use of scales in the detection of cognitive impairment, and main reasons to explain the under-diagnosis of dementia in the primary care setting (see Appendix A1).

#### *Need variables*

Participant's health was considered as follows: number of comorbidities (see Appendix A1) ; number of years since the "study diagnosis" and the etiology of dementia; cognitive deterioration with the Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975) (score



ranging from 0 to 30); severity of Behavioral and Psychological Symptoms of Dementia (BPSD) with the brief form of the Neuro-Psychiatric Inventory (NPI-Q) (Kaufert *et al.*, 2000) (total score ranging from 0 to 36); functional disability with Katz's scale for Activities of Daily Living (ADL) (Katz *et al.*, 1963). Disability was considered when participants were impaired in at least one activity listed in this scale.

Primary caregiver's health was considered as follows: depressive symptoms with the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) (score ranging from 0 to 60); perceived burden with the Zarit Burden Interview (Zarit *et al.*, 1983) (score ranging from 0 to 88); emotional impact of BPSD with the NPI-Q (score ranging from 0 to 60). Caregivers were asked about the length of caregiving (number of months since the beginning of help) and whether they provided care to another person.

Finally, the Quality of Life - Alzheimer's Disease scale (QoL-AD) (Logsdon *et al.*, 1999) has been administered to the dyad. Like most quality of life measurements for dementia, the QoL-AD is insufficiently validated (Dichter *et al.*, 2016). However, this scale has been selected because it assesses health-related quality of life. Besides, it is one of the most largely used scales in the field of dementia and has shown good internal consistency, responsiveness and content validity (Perales *et al.*, 2013). The score ranges from 0 to 52.

### ***Statistical analyses***

First, a description of the acceptance rate of participants with dementia, caregivers, GPs, and missing data was performed. To explore the factors associated with use of care in dementia, we conducted the following analyses using logistic regressions for recourse to secondary care and linear regressions for community and health services use respectively:

- 1) A backward stepwise procedure was performed with all the variables of each of the three blocks (predisposing characteristics, enabling resources and needs variables). This analysis

was conducted separately for each of the three blocks in order to select the significant variables to be introduced in the final model.

2) A final backward stepwise procedure was performed with the variables previously retained from the previous multiple regression models for each of the three blocks.

For all analyses, P-values<0.05 were considered statistically significant. All models were adjusted on cohort study.

Before using linear regression models, the normality of residuals, the linearity of the relationship between the independent and dependent variables, the homoscedasticity, the lack of multicollinearity and auto-correlation have been verified.

Basic assumptions that have to be met for the use of logistic regression such as independence of errors, linearity in the logit for continuous variables, absence of multicollinearity, and lack of strongly influential outliers have also been checked.

To be included in the regression analyses, the data related to participants, family caregivers and GPs must have less than 10% of missing data to guarantee reliability of the results (Cheema, 2014). Analyses were performed using Statistical Analysis System (SAS) software ®version 9.3.

## **RESULTS**

### ***Main characteristics of the sample***

Our sample was composed of all prevalent cases of dementia identified in the three cohort studies at one of the previous follow-up visits and living at home at the previous follow-up: 76 participants, 57 and 58 for 3C, PAQUID and AMI study respectively (see Figure 1). Among these 191 eligible subjects, main reasons for attrition were: death (n=50), being unreachable (n=14) and institutionalized (n=24). Among the 107 participants contacted, only 8 refused. The acceptance rate was very good for the persons with dementia (92.5%), the primary and secondary caregivers (97% and 85%, respectively) and good for the GPs

(63.6%). Finally, the study sample consisted of 308 participants including 99 persons with dementia, 96 primary family caregivers, 51 secondary caregivers and 62 GPs.

*Insert Figure 1*

Two thirds of people with dementia (68%) had consulted at least once a specialist for cognitive problems. They have used an average of 2.9 (SD 1.5) community and health services. The most common services used were general home help (61.8%), private nurse care in particular for taking medication (47%) and bathing (51%), and physiotherapy (29.9%). Characteristics of people with dementia, primary caregivers, GPs and community and care resources are presented in Tables 1 to 3 according to the predisposing, enabling and need factors.

*Insert tables 1 to 3*

*The determinants of the recourse to secondary care*

The data related to GPs comprised more than 10% of missing data, thus, we decided not to consider these variables in the regression analyses for which the results are presented below. The multiple logistic model conducted for each of the three blocks separately showed with respect to predisposing variables that the non-recourse to secondary care was significantly associated with higher age (OR=0.88, CI 95%= 0.78-0.99), no formal education (OR=0.23, CI 95%= 0.07-0.74) of the participant, and higher satisfaction of the primary caregiver with respect to services used by the relative (OR=0.21, CI 95%= 0.07-0.69). With regard to enabling variables, the non-recourse to secondary care was significantly associated with the fact that the participant contributed to decision making regarding his/her own care (OR=0.11, CI 95%= 0.04-0.34), and with higher number of dementia care services in the community area (OR=0.55, CI 95%= 0.33-0.92). In the block of needs variables, only the Zarit score was significantly associated with the recourse to specialist consultation (OR=1.04, CI 95%= 1.03-1.07).

In the final model including only the selected variables from the previous multivariate analyses by block, the non-recourse to secondary care was associated with predisposing variables: no formal education (OR=0.29, CI 95%= 0.08-0.99) of the participant, and higher level of satisfaction of the primary caregiver with respect to services used by the relative (OR=0.19, CI 95%= 0.05-0.69); and with enabling variables: the fact that the participant contributed to decision making regarding his/her own care (OR=0.10, CI 95%= 0.03-0.35) and higher number of dementia care services in the community area (OR=0.53, CI 95%= 0.30-0.93) (table 4). The Hosmer and Lemeshow's test showed a goodness-of-fit of the final model.

***Insert table 4***

***The determinants of the number of community and health services used***

The data related to GPs comprised more than 10% of missing data, thus, we decided not to consider these variables in the regression analyses for which the results are presented below. In multiple regressions for each of the three blocks, with respect to predisposing variables, lower community and health services used was significantly associated with no formal education of the participant (B=-0.71, SE=0.33). With regard to enabling variables, lower use of community and health care services was significantly associated with the fact that the participant contributed to decision making regarding his/her own medical and social care (B=-0.68, SE=0.32), the old-age financial allowance (B=0.87, SE=0.33) and higher number of dementia care services in the community area (B=-0.39, SE=0.15). Two needs variables were significantly associated with lower community and health services used: lower ADL disability (B=0.75, SE=0.34) and higher health-related quality of life of the participant (B=-0.07, SE=0.03).

In the final model, the lower use of community and health services was significantly associated with no formal education of the participant (B=-0.66, SE=0.32) for predisposing

variables, with the fact that the participant contributed to decision making regarding his/her own medical and social care ( $B=-0.73$ ,  $SE=0.30$ ) and number of dementia care services in the community area ( $B=-0.38$ ,  $SE=0.14$ ) for the enabling variables (table 5). The test for lack of fit indicated that the final linear model was adequate.

*Insert table 5*

## **DISCUSSION**

Taking advantage of three ongoing prospective population-based studies, this study raised important results regarding the determinants of use of care in dementia by considering within the same study, various potential contributing factors including people with dementia-, caregiver-, and healthcare-related factors.

The most remarkable finding of the present study was that most of determinants of the use of care in dementia are similar for the recourse to secondary care and for the number of community and health services used. Indeed, the results showed that a predisposing variable, i.e. the level of education of persons with dementia, and two enabling variables, i.e. the fact that persons with dementia contributed in decision regarding their own care and the availability of dementia care services, are the strongest determinants of these two outcomes of use of care. Indeed, the associations were highly significant with the two indicators of use of care considered: recourse to secondary care and the number of community and health services used. The strength of the association remained almost unchanged after adjustment for confounding factors.

More specifically, the results show that low education is associated with the non-recourse to care, as reported by previous studies (Helmer *et al.*, 2008; Savva and Arthur, 2015; Scalmana *et al.*, 2013), seeming to contribute to the cumulative disadvantage of health disparities. Another striking finding of our study was that the use of care is strongly dependent on the decision of the person with dementia. Thus, when persons with dementia are not consulted,

the recourse would be facilitated, whereas making them participate in the decision would tend to prevent the use of care, probably because of their reluctance to accept help from social and medical services (Brodaty *et al.*, 2005). The decision of the person with dementia seems to be more contributive than needs related to the disease. These findings underline the tricky balance between the respect of the autonomy of people with dementia and their ability to be involved in care decision (Hirschman *et al.*, 2005). The availability of dementia care services is also a main correlate of use to care. Such specialized services for the management of dementia in community-dwelling setting aim at improving access to community and health resources. Paradoxically, our results suggest that the higher their density is in the area, the less people with dementia have recourse to secondary care and community and health services. At first sight, this result may be surprising, however, a greater panel of services available in a given area may be less well-known by potential users (and thus less likely used) than a limited number services. Moreover, caregivers' satisfaction with the services used by their relative is the only variable associated with recourse to secondary care. The more the caregivers are satisfied with the services used by their relative, the less people with dementia have recourse to secondary care. In other words, caregivers who deal relatively well with dementia-related symptoms thanks to community and health services probably do not see the necessity of consulting a specialist. These results not only highlight the importance of customer satisfaction, they also underline the key role of the family caregiver in the recourse to secondary care.

Taken together, consistently with recent studies (Pimouguet *et al.*, 2015), these findings suggest that the use of care in dementia is actually a marker of concern for people with dementia and/or their family caregivers, when the person with dementia is no longer consulted to make decisions, which may be delayed when appropriate care strategies are proposed by dementia care services, particularly for the less educated persons.

This study has some limitations which have to be underlined. The major limit is the rate of missing data in the GP survey (62 GPs of the 99 participants with dementia participated in this study) which prevented us to include the variables related to GPs in the explanatory analyses. However, to ensure that excluding such variables had no dramatic impact on the results, we performed the analyses with and without the GPs' variables: the results were very similar and did not evidence any statistical trend between use of care and variables related to GPs (results not shown here). Therefore, we chose not to include them in the analyses. The other important limit may be due to the procedure of study diagnosis of dementia which may have increased GPs' awareness of dementia diagnosis. Indeed, within the procedure of study diagnosis of dementia, the specialist who examined the people with dementia sent a mail to their GPs to inform them about the results of cognitive and clinical assessment. Thus, the GPs may have been more inclined to refer to a consultation in secondary care setting. This could explain that in our sample, 68% had recourse to secondary care, a rate which is slightly higher than in other studies (e.g. Bush *et al.*, 1997; Callahan *et al.*, 1995; Olafsdottir *et al.*, 2000). On the other hand, the rate of community and health services used in our study (62% of participants with at least one community help and 50% health care) is equivalent to that reported by Lim *et al.* (2012). Secondly, due to study design and participants recruitment procedure, the large majority of participants had a reliable informant who was most of the time their primary family caregiver. Therefore, we probably missed people with dementia who had no family caregiver and who were probably already institutionalized. Finally, the limited sample size in particular for the GPs sub-study associated with low statistical power could have underestimated some associations between recourse to care and GPs' characteristics.

## **CONCLUSION**

These results highlight the predominant role of psychosocial factors in the use of care in dementia and the importance of addressing this issue through an integrative approach including not only medical aspects but also psychological, social, and family dimensions.

Our results showed that no need variables are associated with the use of care, as previously shown by Toseland and colleagues (2002), which yet remain the main targets in health policy.

Our findings strongly reinforce the role of enabling factors that should deserve more attention from public health policies. Moreover, our results also highlight the importance of the needs perceived by the family caregiver with respect to his/her relative in the use of care. In this perspective, it is imperative that we enlarge our focus considering persons with dementia and family caregivers' needs as a whole in order to improve future interventions. As health and social services systems have to be prepared for the increasing number of persons with dementia and their family caregivers in future years, our findings may help to better plan support and care strategies taking into account the genuine determinants of the use of care in the context of dementia.



## **CONFLICT OF INTEREST**

None.

## **DESCRIPTION OF THE AUTHORS' ROLES**

Study concept and design: Amieva H., Bergua V., Dartigues J.F., Helmer C., Pérès K., Pimouguet C., Rullier L.; acquisition of data: Gonzalez-Colaço Harmand M., Meillon C., Rullier L.; statistical analysis and interpretation: Amieva H., Meillon C., Rullier L.; drafting of manuscript: Amieva H., Rullier L.; critical revision of manuscript: Bergua V., Dartigues J.F., Helmer C., Pérès K., Pimouguet C.

## **ACKNOWLEDGEMENTS**

This research was supported by a grant from the Fondation Plan Alzheimer.

The PAQUID study was supported by ARMA (Bordeaux), Caisse Nationale d'Assurance Maladie des Travailleurs Salariés, Conseil Général de la Dordogne, Conseil Général de la Gironde, Conseil Régional d'Aquitaine, Fondation de France, France Alzheimer (Paris), GIS Longévité, Institut National de la Santé et de la Recherche Médicale, Mutuelle Générale de l'Education Nationale, Mutualité Sociale Agricole, Novartis Pharma (France), and SCORInsurance (France).

The Three-City study is conducted under a partnership agreement between the National Institute of Health and Medical Research (INSERM), the University Bordeaux 2 Victor Segalen, and Sanofi-Aventis. The Fondation pour la Recherche Médicale funded the preparation and initiation of the study. The Three-City study is also supported by the Caisse Nationale Maladie des Travailleurs Salariés, Direction Générale de la Santé, MGEN, Institut de la Longévité, Conseils Régionaux d'Aquitaine et Bourgogne, Fondation de France, Ministry of Research-INSERM Programme "Cohortes et collections de données biologiques", Agence Nationale de la Recherche ANR PNRA 2006 and LongVie 2007, and the "Fondation Plan Alzheimer" (FCS 2009-2012).

The AMI study was supported by AGRICA (CAMARCA, CRCCA, CCPMA PREVOYANCE, CPCEA, AGRI PREVOYANCE), la Mutualité Sociale Agricole (MSA) de Gironde, la Caisse Centrale de la Mutualité Sociale Agricole (CCMSA), and the CNSA (Caisse Nationale de Solidarité et d'Autonomie).

## REFERENCES

- 3C Study Group.** (2003). Vascular factors and risk of dementia: design of the Three-City Study and baseline characteristics of the study population. *Neuroepidemiology*, 22, 316-325.
- American Psychiatric Association.** (1994). *Diagnostic and Statistical Manual of Mental Disorders (DSM IV). Fourth Edition.* American Psychiatric Association: Washington, DC.
- Andersen, R.M.** (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behavior*, 36, 1-10.
- Bradford, A., Kunik, M.E., Schulz, P., Williams, S.P. and Singh, H.** (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Disease and Associated Disorders*, 23, 306-314.
- Brayne, C., Fox, C. and Boustani, M.** (2007). Dementia screening in primary care: is it time? *Journal of American Medical Association*, 298, 2409-2411.
- Brody, H., Thomson, C. and Fine, M.** (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20, 537-546.
- Bush, C., Kozak, J. and Elmslie, T.** (1997). Screening for cognitive impairment in the elderly. *Canadian Family Physician*, 43, 1763-1768.
- Callahan, C.M., Hendrie, H.C. and Tierney, W.M.** (1995). Documentation and evaluation of cognitive impairment in elderly primary care patients. *Annals of Internal Medicine*, 122, 422-429.
- Cheema, J.R.** (2014). Some General Guidelines for Choosing Missing Data Handling Methods in Educational Research. *Journal of Modern Applied Statistical Methods*. 13, 53-75.
- Dartigues, J.F. et al.** (1992). The Paquid epidemiological program on brain ageing. *Neuroepidemiology*, 11, 14-18.

- Dichter, M.N., Schwab, C.G., Meyer, G., Bartholomeyczik, S. and Halek M.** (2016). Linguistic validation and reliability properties are weak investigated of most dementia-specific quality of life measurements-a systematic review. *Journal of Clinical Epidemiology*, 70, 233-45.
- Fillit, H., Hill, J.W. and Futterman, R.** (2002). Health care utilization and costs of Alzheimer's disease: the role of co-morbid conditions, disease stage, and pharmacotherapy. *Family Medicine*, 34, 528-535.
- Folstein, M.F., Folstein, S.E. and McHugh, P.R.** (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- Helmer, C. et al.** (2008). Primary and secondary care consultations in elderly demented individuals in France. Results from the Three-City Study. *Dementia and Geriatric Cognitive Disorders*, 26, 407-415.
- Hirschman, K.B., Xie, S.X., Feudtner, C. and Karlawish, J.H.T.** (2004). How does an Alzheimer's disease patient's role in medical decision making change over time? *Journal of Geriatric Psychiatry and Neurology*, 17, 55-60.
- Hirschman, K.B., Joyce, C.M., James, B.D., Xie, S.X. and Karlawish, J.H.T.** (2005). Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *The Gerontologist*, 45, 381-388.
- Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A. and Jaffe, M.W.** (1963). Studies of Illness in the Aged. The Index of Adl: A Standardized Measure of Biological and Psychosocial Function. *Journal of American Medical Association*, 185, 914-919.
- Kaufner, D.I. et al.** (2000). Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 12, 233-239.

- Koch, T. and Iliffe S.** (2010). EVIDEM-ED project. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC Family Practice*, 11, 52.
- Lim, J., Goh, J., Chionh, H.L. and Yap, P.** (2012). Why do patients and their families not use services for dementia? Perspectives from a developed Asian country. *International Psychogeriatrics*, 24, 1571–1580.
- Logsdon, R.G., Gibbons, L.E., McCurry, S.M. and Teri, L.** (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health & Aging*, 5, 21-32.
- Mura, T., Dartigues, J.F. and Berr, C.** (2010). How many dementia cases in France and Europe? Alternative projections and scenarios 2010-2050. *European Journal of Neurology*, 17, 252–259.
- Olafsdottir, M., Skoog, I. and Marcusson, J.** (2000). Detection of dementia in primary care: the Linköping study. *Dementia and Geriatric Cognitive Disorders*, 11, 223-229.
- Pentzek, M. et al.** (2009). General practitioners' judgment of their elderly patients' cognitive status. *Journal of General Internal Medicine*, 24, 1314-1317.
- Perales, J., Cosco, T. D., Stephan, B.C.M., Haro, J.M. and Brayne, C.** (2013). Health-related quality-of-life instruments for Alzheimer's disease and mixed dementia. *International Psychogeriatrics*, 25, 691-706.
- Pérès, K. et al.** (2012). Health and aging in elderly farmers: the AMI cohort. *BMC Public Health*, 12, 558.
- Petrazzuoli, F. et al.** (2017). Exploring dementia management attitudes in primary care: a key informant survey to primary care physicians in 25 European countries. *International Psychogeriatrics*, 29, 1413-1423.
- Pimouguet, C., Bassi, V., Somme, D., Lavallart, B., Helmer, C. and Dartigues, J.F.**

(2013). The 2008-2012 French Alzheimer plan: a unique opportunity for improving integrated care for dementia. *Journal of Alzheimer's Disease*, 34, 307–314.

**Pimouguet, C. et al.** (2015). Survival and early recourse to care for dementia: A population based study. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 11, 385–393.

**Prince, M., Wimo, A., Guerchet, M., Ali, G.C., Wu, Y. and Prina, A.M.** (2015). *World Alzheimer Report 2015: The global impact of dementia. An analysis of prevalence, incidence, costs and trends*, London: Alzheimer's Disease International.

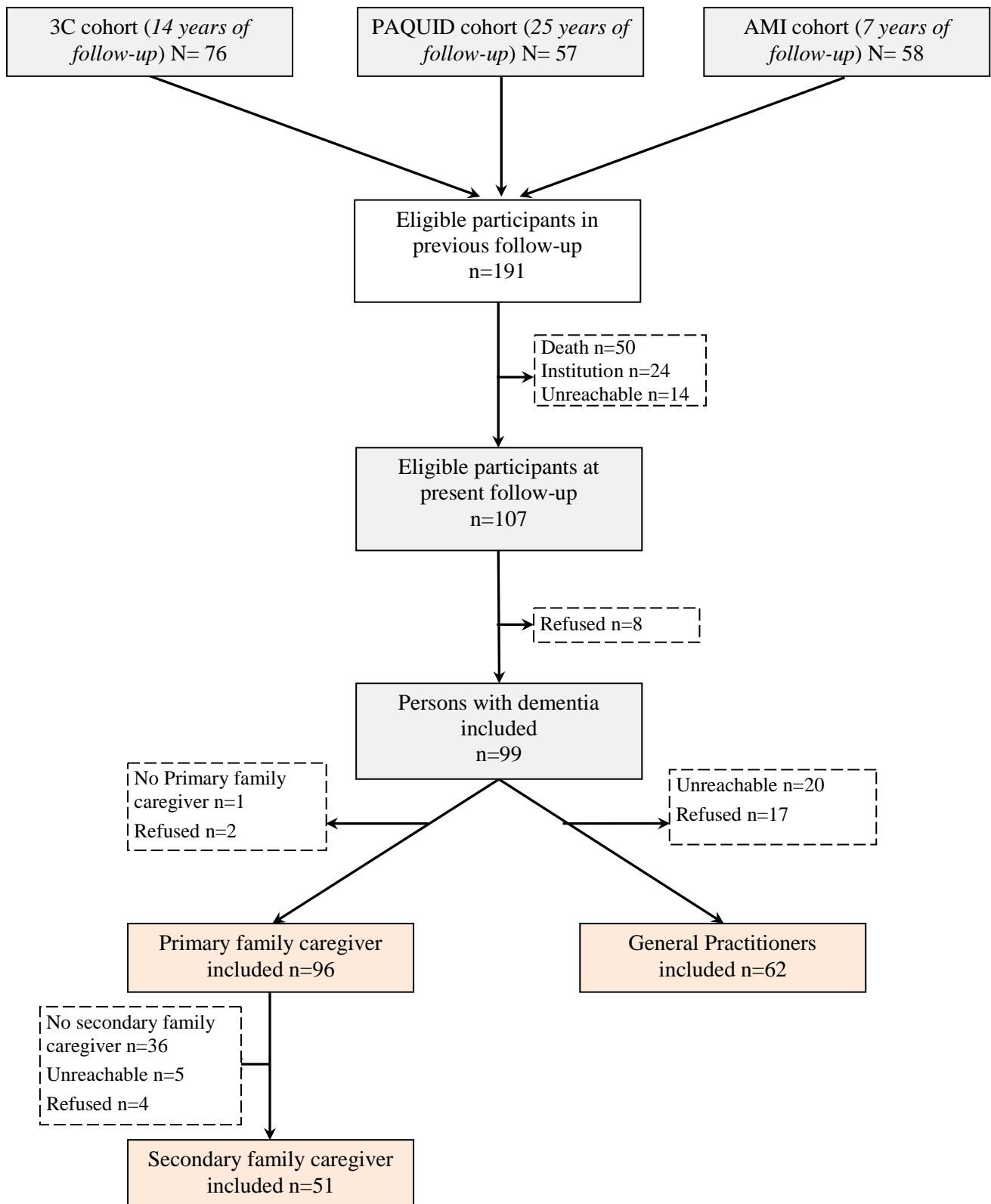
**Radloff, L.S.** (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.

**Scalmana, S. et al.** (2013). Use of health and social care services in a cohort of Italian dementia patients. *Functional Neurology*, 28, 265-273.

**Toseland, R.W., McCallion, P., Gerber, T. and Banks, S.** (2002). Predictors of health and human services use by persons with dementia and their family caregivers. *Social Science & Medicine*, 55, 1255–1266.

**Zarit, S.H., Orr, N.K. and Zarit JM.** (1983). *Working with families of dementia victims: A treatment manual*. Washington, D.C: Department of Health and Human Services, Administration of aging.

**Figure 1. Flow chart of the Recaredem study.**



**Table 1. Description of predisposing characteristics, n=99.**

<b>Predisposing variables</b>	<b>Mean (SD) or n(%)</b>
<i>Sociodemographics characteristics of the dyad</i>	
<b>Participant</b>	
Age (n=99)	87.4 (5.6)
Min-Max	73.9 - 101.8
Sex (n=99), Male	44 (44.4%)
Education (n=99), Intermediate or higher level	50 (51.0%)
Living condition (n=99), Living alone	39 (39.4%)
<b>Primary family caregiver (PCg)</b>	
Age (n=87)	67.3 (14.3)
Min-Max	24.9 - 90.7
Sex (n=93), Male	27 (29.0%)
Education (n=86)	
Intermediate level	31 (36.1%)
Higher level	29 (33.7%)
Living condition (n=91), Living alone	12 (13.2%)
Relationship with the participant (n=92)	
Children	42 (45.7%)
Other members of family	8 (8.7%)
Other	13 (14.1%)
Live in same household (n=90)	49 (54.4%)
<i>Satisfaction of PCg with services used</i>	
Services used by participant (n=87), Very satisfied	45 (51.7%)

PCg : primary family caregiver



**Table 2. Description of enabling resources, n=99.**

<b>Enabling variables</b>	<b>Mean (SD) or n(%)</b>
<b><i>Social and Family support</i></b>	
Assistance from a secondary caregiver (n=96), Yes	61 (63.5%)
Visits from family or friends at the participant's home (n=91)	
Two to three times per week	16 (17.6%)
Once per week	18 (19.8%)
Less than once per week	22 (24.2%)
Social interactions (n=91)	
Two to three times per week	15 (16.5%)
Once per week	12 (13.2%)
Less than once per week	27 (29.7%)
<b><i>Contribution to decision making related to participant's care</i></b>	
Participant's contribution to decision making (n=88), Yes	37 (42.1%)
Number of persons contributing to decision making (n=76), At least two persons	44 (57.9%)
<b><i>Community and health resources</i></b>	
Location (n=99), Rural	34 (34.3%)
Financial allowance (n=85), Yes	56 (65.9%)
Availability of dementia care services in the community area (n=99)	2.4 (1.1)
Availability of specialist consultation (n=99), Yes	68 (68.7%)
<b><i>GP's characteristics and practices in the field of geriatrics</i></b>	
Age of GP (n=51)	54.2 (9.6)
Min-Max	29 - 67
Sex (n=62), Male	51 (81.0%)
Type of professional practice (n=47)	
Private practice	23 (46.0%)
Private practice with colleagues or Mixed practice	27 (54.0%)
Use of scales to detecting cognitive impairment (n=50), Yes	13 (26.0%)
Reasons to explain the under-diagnosis of dementia	
Lack of time (n=46)	20 (40.8%)
Lack of interest (n=46)	9 (18.4%)
Not a priority in daily practice (n=46)	5 (10.2%)
Limited effectiveness of drug therapy (n=46)	26 (46.9%)
Other reasons (n=46)	15 (30.6%)

GP: general practitioner

**Table 3. Description of need variables, n=99.**

Variables	Mean (SD) or n(%)
<b><i>Participant's health</i></b>	
MMSE score (n=87)	18.4 (5.0)
Min-Max	3 - 29
Severity NPI Score (n=79)	7.1 (6.3)
Min-Max	0 - 28
ADL - disability (n=98), Yes	53 (54.1%)
Number of comorbidities (n=97), Median	1
Min-Max	0 - 3
Number of years since the “study diagnosis” (n=87)	5.02 (2.98)
Min-Max	0.84 - 18.53
Dementia etiology (n=99)	
Alzheimer's disease	69 (69.7%)
QoI-AD (n=82)	27.9 (5.7)
Min-Max	13 - 42
<b><i>Primary family caregiver's health</i></b>	
CESD score (n=85)	12.6 (13.0)
Min-Max	0 - 59
ZARIT score (n=89)	23.2 (19.5)
Min-Max	0 - 88
Length of caregiving (months) (n=87)	81.1 (71.3)
Min-Max	4 - 360
Provide care to another person (n=89), Yes	21 (23.6%)
QoI-AD (n=84)	35.5 (7.3)
Min-Max	13 - 52

**Table 4. Final multiple logistic model. Study of recourse to secondary care, n=84.**

<b>Variables</b>	<b>OR</b>	<b>CI 95%<sup>c</sup></b>	<b>p</b>	<b>R-square</b>
<b>Predisposing Characteristics</b>				0.3379
Education of the participant				
No formal education <sup>a</sup>	0.29	0.08 - 0.99	0.0472	
Satisfaction with all community services used by the participant				
Very satisfied <sup>b</sup>	0.19	0.05 - 0.69	0.0115	
<b>Enabling Resources</b>				
Participant's contribution to decision making	0.10	0.03 - 0.35	0.0003	
Availability of dementia care services in the community area	0.53	0.30 - 0.93	0.0267	

Note: <sup>a</sup> Reference : School certificate or higher ; <sup>b</sup> Reference : No satisfaction; <sup>c</sup>95% CI = 95% Confidence Interval.

This final model, adjusted on the cohort effect, tests the relationship between the recourse to secondary care (Dependent variable) and the variables selected from the previous multiple linear regressions conducted by blocks.

**Table 5. Final multivariate linear model. Study of community and health services use, n=85.**

<b>Variables</b>	<b>Beta</b>	<b>SE<sup>b</sup></b>	<b>p</b>	<b>R-square</b>
<b>Predisposing Characteristics</b>				0.1772
Education of the participant				
No formal education <sup>a</sup>	-0.66	0.32	0.0413	
<b>Enabling Resources</b>				
Participant's contribution to decision making				
	-0.73	0.30	0.0184	
Availability of dementia care services in the community area				
	-0.38	0.14	0.0083	

Note: <sup>a</sup> Reference : School certificate or higher ; <sup>b</sup>SE=Standard error  
This final model, adjusted on cohort effect, tests the relationship between the number of services used (dependent variable) and the variables selected from the previous multiple linear regressions conducted by blocks.