

Dementia in the elderly. Health consequences on household members

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Abstract The growing number of the oldest-old will cause an increase in the number of mentally ill elderly persons in the population, given that no positive evolution of senile dementia is expected in the near future. Living in the household is the best strategy to contain the pace of mental deterioration, to better manage the disease and to maintain as long as possible the vigilance of the dement person. But dementia is one of the most devastating impairment, both for the persons who are affected by it and for their entire family network and friends, and its impact is high on life and well-being of all persons living with the dement elderly and maximum for his/her caregiver. The aim of this work is to evaluate the impact of the presence of an elderly person with dementia on the perceived health of co-living household members, using data from the Italian Health Interview Survey carried out by Istat in 2005.

Key words: Aging, mortality and health, Dementia, Household, Elderly

1 Introduction

The growing number of very old people, termed oldest-old, may cause an increase in the number of mentally ill persons in the population. It is estimated that, after the age of 65, an increase of five years of age implies the doubling of the prevalence of mental impairment (Moise et al, 2004). Among the centenarian population, prevalence of diagnosed dementia is estimated to range between 62% (Ravaglia et al., 1999) and 100% (Thomassen et al., 1998).

Dementia, and Alzheimer's disease which is its most common form, is a complex disorder, mainly affecting the elderly (Moise et al., 2004). It is a chronic disease that leads to a progressive disability ultimately resulting in death. At present, in fact, there is no effective treatment against this disease.

Among degenerative disorders, dementia is one of the most devastating, not only for the persons who are affected by it, but also for its effects on their entire family network and friends. It involves, in fact, the cognitive abilities of the individual,

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his/hers autonomy in the functions of daily life and behaviors. In the initial stages, the sick person is able to remain independent and to live alone, while at the end of the process, when it is often dumb, unable to move and interact, confined to bed and incontinent, he/she is very likely to live in institution. The duration of the disease is rather long. It is estimated that from the first symptoms (loss of memory) to the death 10 years on average could elapse, with a wide variation going from 3 to 20 years (Moise, et al., 2004).

It was estimated that the number of people with dementia in the UK will double from 2001 to 2040 (Ferri et al., 2005) and that, in the 20 years from 2006 to 2026, the population over 65 years of age will increase by 39% and the population with mental disabilities will increase by 82%, only as a result of the demographic ageing of the population. At the same time the number of people with a moderate mental disability will increase by 41% and those with moderate and severe disability by 63%. Also in the favorable hypothesis of a delayed onset of dementia and a reduction of its disabling consequences, the impact on the expected increase would be very small (about 1%) (Jagger et al., 2009).

The literature does not highlight any positive trend for the future evolution of the incidence of dementia, if not those that may be caused by a modification of cerebrovascular risk factors and stroke treatment (Feldman et al., 2005).

All studies carried out so far agree that living in the household is the best strategy to contain the pace of mental deterioration, to better manage the disease and to maintain as long as possible the vigilance of the dement person. But this does not happen without consequences, often serious, on physical and mental health of the household members and of the caregiver (Ory et al., 2000).

The aim of this work is precisely the evaluation of the impact of the presence of an elderly person with dementia in the household on the perceived health of co-living household members, using data from the Italian Health Interview Survey carried out by Istat in 2004/2005.

2 Data sources and definitions

The Italian survey on the health status of the population and on the use of health services provides some information on mental health of individuals. The overall sample size is about 50.500 households, 128.000 persons. The sampling design is a two stage one, with stratification in the first stage based on population size of municipalities for each region. In the second stage a minimum number of households is selected from each municipality and every member of the household is interviewed.

In the self-compiled part of the questionnaire, all interviewed persons (or their satisfying proxy respondents) are asked if they are affected by a set of chronic diseases and if they have been diagnosed by a doctor. One of the items of the list is Alzheimer's disease or other forms of senile dementia. In the questionnaire administered by interview, respondent are also asked if he/she is suffering from a disability (also not legally recognized) due to mental insufficiency. In this study the elderly person affected by dementia is, therefore, identified as a person who answered (directly or through a proxy) to be suffering from Alzheimer's disease or senile dementia, or who declared to be suffering from a permanent disability due to a severe mental impairment.

Using this definition it is possible to estimate a prevalence of dementia of 3.7%, among older people aged 65 years and more. A level that is significantly lower than that estimated for the age 65-84 years by the survey ILSA (Italian Longitudinal Study on Aging) with reference to the years 1992-93 (equal to 6.6%) (ILSA, 1997). Nevertheless, this study, that is one of the few examples of health examination longitudinal survey carried out in Italy, adopted a survey methodology markedly different from that used for the Italian health interview survey. Among the most important differences: the survey technique (medical examination vs. personal interview); the difference in the reference population (total persons living in Italy vs. persons living in private households), that is a very important difference for the estimation of the mental impairment prevalence because of the exclusion, in the health interview survey, of people living in institution. On the other hand, the ILSA survey refers to a sample which does not represent the population of the entire national territory, being carried out only in eight municipalities, and it adopts a different strategy for units selection.

The estimate of demented people provided by the Istat survey, however, is also lower than other estimates based on epidemiological surveys, carried out at international level providing prevalence rates of around 5-6% with a high variability (Rorsman et al, 1985: 3.4%; Copeland et al., 1992: 4.2%; Zhang et al, 1990: 4.6%; Lobo et al., 1995: 5.5%; Beard et al., 1991: 5.7%; O'Connor et al, 1989: 6.0%; Evans et al., 1989: 10.3%).

It could be stressed, however, that being the aim of this study to estimate, not the prevalence of dementia in the elderly population, but the impact of the presence of an elderly person with dementia on the household members' health, the underestimation of the dementia diffusion seems not to produce distorting effects on the results.

The outcome indicator selected was the poor perceived health as declared by the household member answering "poor" or "very poor" to the question "How is your health in general?" (with the following possible answers: very poor, poor, fair, good and very good). The evaluation of the impact is made controlling by the most important variables affecting the perception of health, such as age and gender, among demographic variables; living arrangement, education, housing condition and geographic area, among social variables; disability and multichronicity (defined as the presence of three or more chronic disease), among health variables.

3 Results

The Italian Health Interview Survey 2005 allows identifying approximately 409 thousand people aged 65 years and over who declared to suffer from dementia or mental impairment, according to the definition described in the previous paragraph. Of these, approximately 141 thousand are men and 268 thousand are women (slightly less than 2 women for each man are found in this condition). The disadvantage is surely due to the greater female aging comparing to men, however, a greater prevalence of mental impairment among women is also found comparing the same age groups. The prevalence of dementia is 3.7% (3.0% for men and 4.1% for the women) for the total of the elderly population, with a steep age gradient: the percentage goes from less than 1% for people aged 65-69 years to more than 18% (12% among men and 21% among women) for those aged over 90 years.

Overall, we can identify 881.000 individuals who daily face mental health problems of elderly people, including both the elderly affected by dementia living alone or living

with other family members (409 thousand), and the cohabiting relatives (472 thousand). Even considering that the available survey under-estimates dementia diffusion among the elderly, the problem is noteworthy and it will be more and more important with the increase of longevity.

Excluding from the analysis the 111 thousand old people with mental problems living without relatives, 472 thousand relatives cohabiting with the remaining 298 thousand elderly with dementia were surveyed. It can be estimated that around 1,6 cohabiting relatives, on average, share daily with each unhinged elderly his/her dreadful experience. This situation affects about the 8‰ of the population, and it peaks to 19‰ (tab. 1) for household members of persons with mental problems aged 75 years or over. The rate is higher among women in comparison to men; but among people aged 75 and over this difference does not persist any more, because of the longer women life expectancy, which makes them survive to men, but does not protect them from sickness.

Table 1: Proportion of persons cohabiting with an elderly affected by dementia on total population, by age and gender (*1000)

Age	Men			Women			Total		
	%	IC 95%		%	IC 95%		%	IC 95%	
0-24	4.1	2.9	5.2	4.4	3.2	5.6	4.2	3.4	5.0
25-44	5.7	4.5	6.9	4.3	3.2	5.3	5.0	4.2	5.8
45-64	8.3	6.7	9.9	10.5	8.7	12.2	9.4	8.2	10.6
65-74	11.2	8.1	14.3	16.7	13.3	20.1	14.2	11.9	16.5
75+	21.5	16.4	26.6	17.9	14.4	21.5	19.3	16.4	22.2
Total	7.5	6.8	8.3	8.7	7.9	9.5	8.1	7.6	8.7

Source: Survey "Health Condition and Use of Health Services 2005"

As expected, the mean age of household members living with the elderly with dementia is higher comparing to the population mean age (55 years versus 42 years); 39% of them are aged 65 years or more, and 21% are over 75; they are mainly women (121:100 on average) in all age groups, with the only exception of those aged 25-44 years (tab. 2).

Table 2: Age structure of the household members of the elderly with dementia living in households. Italy 2005 (*100)

Age	Men			Women			Total			F/M* 100
	%	IC 95%		%	IC 95%		%	IC 95%		
0-24	14.1	10.4	17.7	11.8	8.7	14.9	12.8	10.5	15.2	102.0
25-44	24.1	19.6	28.6	14.7	11.3	18.1	18.9	16.2	21.7	74.1
45-64	28.1	23.4	32.8	30.3	25.9	34.6	29.3	26.2	32.5	130.9
65-74	14.6	10.9	18.4	21.1	17.3	25.0	18.2	15.5	20.9	175.8
75+	19.1	15.0	23.3	22.1	18.2	26.0	20.8	17.9	23.6	140.5
Total	100.0			100.0			100.0			121.5

Source: Survey "Health Condition and Use of Health Services 2005"

The consequences of dementia of the elderly people on the perceived health of their household's members were evaluated controlling for those variables identified in literature as the most relevant determinants of own health state. In particular, the controlled personal characteristics include: gender, age, health condition (measured by means of presence of disability or multi-chronicity), the living arrangement, and the

level of education. Also contextual variables, such as the condition of the house in which the household lives and the area of residence, were included. Logistic regression models were used to compare perceived health of people having and not having an elderly person with dementia as cohabitant, controlling for confounding variables. Since several studies indicate depression as a frequent condition involving poor perceived health (Betts Adams et. al., 2004), the analysis was performed both not controlling (Model 1) and controlling (Model 2) also for this variable.

The outcome variable of the models, shown in table 3, is bad and very bad perceived health (labeled as “poor health”) assessed by respondents.

Table 3: “Poor” perceived health declared by respondents controlling for their socio-demographic and health characteristics and the presence of a dement elderly into the household. Logistic regression models performed on the total population not controlling (Model 1) and controlling (Model 2) for depression. Italy, Year 2005.

	<i>Model 1</i>		<i>Model 2</i>	
Variable (reference value)	Exp(B)		Exp(B)	
Sex (Male)				
Female	1.38	***	1.21	***
Age(<44)				
45-64	4.99	***	4.43	***
65-74	8.62	***	7.78	***
75+	8.73	***	8.18	***
Disability (No)				
Yes	12.49	***	11.94	***
Multichronic (No)				
Yes	3.89	***	3.10	***
Education (High)				
Medium	1.46	***	1.44	***
Low	1.89	***	1.88	***
Housing condition (Good)				
Bad condition	1.71	***	1.64	***
Living arrangement (Couple with children)				
Couple	1.21	***	1.18	***
One parent family	1.20	**	1.15	*
Elderly living with his/her son’s family	1.09	ns	1.08	ns
Other	1.18	*	1.17	*
Geographic region (North)				
Centre	1.57	***	1.56	***
South	1.48	***	1.54	***
Depression (No)				
Yes	---		4.85	***
Dement elderly (No)				
Yes	1.46	***	1.31	*
(-2)*Loglikelihood	29461.83		28411.87	
Degrees of freedom	16		17	

*** p<0.0001 ** p<0.001 * p<0.05

Results are in line with what is found in literature (Betts Adams, Sanders,2004): all confounding variables being equal, the presence in the household of an elderly person

affected by dementia has a significant impact on the perceived health of all household members (OR equal to 1.5 without controlling for depression). When depression is also controlled, the model improves its goodness-of-fit, but the impact of the presence of a dement elderly, although significant, decreases (OR: 1.3).

Some interesting results were obtained by the introduction, into the two models, of the interaction effects between the presence of the dement elderly and each one of the other variables. In table 4 only the interaction effects were reported for both models. The large majority of those effects are non significant, but the interaction with the respondent's age shows very high impacts for younger members of the family, aged up to 64 years (OR higher than 2.5), highly significant for people aged 45-64 when different familiar and social role may conflict with the need for care demanded by a cohabiting dement person. The interaction with the type of household allows to clarify that if the only structure having a significant main (positive) impact on perceived health of the household members is the extended family with different generations living together, when one of the member is affected by dementia, living in a couple, with or without children, plays a negative role on the relatives' health. In the first case, it could be the result of the burn-out requested to the healthy adult who is asked to provide care for the person with mental problems and support (both practical and emotional) for children. In the second case, the healthy partner has to face, frequently alone and without support, the difficult and heavy task of being the caregiver of a dement person, who growing older is almost always disabled.

Table 4: "Poor" perceived health declared by respondents controlling for their socio-demographic and health characteristics and the presence of a dement elderly into the household. Logistic regression models with interaction effects performed on the total population not controlling (Model 3) and controlling (Model 4) for depression. Italy. Year 2005 (1)

Variable (<i>reference value</i>)	<i>Model 3</i>		<i>Model 4</i>	
	Exp(B)		Exp(B)	
Age*Dement elderly		*		*
0-44*Dement Elderly (<i>Yes vs. No</i>)	2.64	*	2.44	*
45-64*Dement Elderly (<i>Yes vs. No</i>)	2.61	***	2.58	***
65-74*Dement Elderly (<i>Yes vs. No</i>)	1.26	ns	1.16	ns
75+*Dement Elderly (<i>Yes vs. No</i>)	1.11	ns	0.91	ns
Living arrangement*Dement elderly		**		**
Couple*Dement Elderly (<i>Yes vs. No</i>)	2.53	***	2.28	***
Couple with children* Dement Elderly (<i>Yes vs. No</i>)	2.25	**	2.08	*
One-parent family*Dement Elderly (<i>Yes vs. No</i>)	2.34	ns	2.02	ns
Elderly living with his/her son's family * Dement Elderly (<i>Yes vs. No</i>)	0.65	ns	0.60	ns
Other*Dement Elderly (<i>Yes vs. No</i>)	1.34	ns	1.15	ns
(-2)*Loglikelihood	29439.91		28390.48	
Degrees of freedom	24		25	

*** p<0.0001 ** p<0.001 * p<0.05

(1) Model 3 is adjusted for all the variables of Model 1; Model 4 is adjusted for all the variables of Model 2.

4 Discussion and conclusions

Estimating the prevalence of diseases through interview surveys has several well known limits. It happens that respondents (or persons answering in their place through “proxy” interviews) not necessarily know the right disease denomination, or they could not be keen to declare it, even having the correct knowledge of it. Alzheimer’s disease and dementia in general makes no exception to this rule, in spite of scientific evidence that highlights dementia as having the lowest proportion of false negative (clinically detected diseases, not declared by the respondent) and of false positive (diseases declared by the respondent, clinically not detected) (ILSA, 1997).

Some other relevant limitation of the data used has to be highlighted. One of the first and most relevant data problem, is that we are not able to identify who in the household takes concretely care of the dement person. There is no doubt that the negative impact on the relative’s health status will be stronger, as his/her involvement in care duties gets higher. Moreover the data source used does not allow controlling for the stage of dementia, which would be an important element in the analysis of the entity of the impact on the health of the cohabiting relatives.

Naturally, it cannot be neglected that we are considering cross-sectional data and, therefore, it is generally impossible to establish causal relations between variables. The direction and the intensity of the evidenced relations, however, unlikely can underlie other explanations (for households in which the elderly with mental impairment lives with his/her descendants, the hypothetical familiarity of the condition, in its initial stages, could alter the perception of the health state of the relative).

The severity of the disease would be useful information, because of its impact on the familiar strategies and its consequences on the health of the household members, and, above all, of the caregiver. Unfortunately, the available data source does not contain any information on the severity of the mental impairment.

The most important result of the work is represented by the verification of the strong impact of dementia among the elderly on the perceived health of the household members, who very often have to face by themselves and without adequate support, neither material nor psychological, the progressive and inexorable mental deterioration of one beloved person. In several countries, just in consideration of the social, but also therapeutic role, carried out by the household member of the elderly with dementia, structures and supports are put on hand in order to put household members in the position of cohabiting with the disease without paying a high price for their health. In Italy the support of the territorial services to the families with mentally impaired persons is still completely insufficient and widely differentiated over the territory. It is extremely important for the future the development of formal nets of care to support effectively the informal nets and the households in this difficult task as well as the availability of structures of care in order to face the most severe stages of the disease.

The growing number of dementia patients expected in the next decades, the more and more frequent marital dissolution and the decreasing fertility rates mean that there will be fewer spouses and fewer children of dementia patients, available to take on the role of caregiver (Riggs, 2001).

References

1. Beard, C. M., Kokmen, E., Offord, K., Kurland L.T.: Is the prevalence of dementia changing? *Neurology*, 41, 12, 1911-1914 (1991)
2. Betts Adams, K., Sanders, S.: Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease. *Dementia*; 3; 195-201(2004)
3. Copeland, J.R., Davidson I.A., Dewey M.E., Gilmore C., Larkin B.A., McWilliam C., Saunders P.A., Scott A., Sharma V., Sullivan C.: Alzheimer's disease, other dementias, depression and pseudodementia: prevalence, incidence and three-year outcome in Liverpool. *The British Journal of Psychiatry*. 161, 230-239 (1992)
4. Evans, D.A., Funkenstein, H. H, Albert, M.S., Scherr, P.A., Cook N.R., Chown, M.J., Hebert L.E., Hennekens C.H., Taylor, J.O.: Prevalence of Alzheimer's Disease in a Community Population of Older Persons. *JAMA*. 262, 18,2551-2556 (1989)
5. ILSA: Prevalence of chronic diseases in older Italians: comparing self-reported and clinical diagnosis, *International Journal of Epidemiology*, 26, 5, 995-1002 (1997)
6. Jagger, C., Matthews, R., Lindsay, J., Robinson, T., Croft, P., Brayne, C.: The effect of dementia trends and treatments on longevity and disability: a simulation model based on the MRC cognitive function and ageing study (MRC CFAS). *Age and ageing*. 38:319-325(2009)
7. Lobo, A., Saz, P., Marcos, G., DÍa, J.L.: *Archives of General Psychiatry*. 52(6), 497-506 (1995)
8. Moise, P., Schwarzingler, M., Um, M.Y, and the Dementia Experts' Group, *Dementia Care in 9 OECD Countries a Comparative Analysis*, DELSA/ELSA/WD/HEA 4, OECD Health Working Papers 13, p. 109 (2004)
9. Ory, M.G., Yee, J.L., Tennstedt S.L., Schulz R., *The Extent and Impact of Dementia Care: Unique Challenges Experienced by Family Caregivers*, in *Handbook on Dementia Caregiving: Evidence-Based Interventions for Family Caregivers*. Richard Schulz editor. New York, NY. (2000)
10. Ravaglia, G., Forti, P., De Ronchi, D., Maioli, F., Nesi, B., Cucinotta, D., Bernardi, M.: Prevalence and severity of dementia among northern Italian centenarians, *Neurology*. 53(2), 416-418 (1999)
11. Riggs, J.A.:The health and long-term care policy challenges of Alzheimer's disease, *Aging and Mental Health*, 5, Supplement 1, 138-145(8) (2001)
12. Rorsman, B., Hagnell, O., Lanke J.: Prevalence of Age Psychosis and Mortality among Age Psychotics in the Lundby Study Changes over Time during a 25-Year Observation Period, *Neuropsychobiology*; 13:167-172 (1985)
13. Thomassen, R., van Shaick, H.W., Blansjaar, B.A.: Prevalence of dementia over age 100. *Neurology*. 50:283-286 (1998)
14. Zhang, M.Y. The prevalence study on dementia and Alzheimer's disease. *National Medical Journal of China*, 70,424-428 (1990).