

An analysis of caregiver profile and its impact on employment situation: primary caregivers of patients of Alzheimer´s and other dementias in the South Western of Spain.

Un análisis del perfil del cuidador y su impacto sobre la situación laboral: cuidadores principales de enfermos de Alzheimer y otras demencias en el Sur Oeste de España

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Abstract

The aim of this paper is to analyse the main demographic and socio-economic conditions of the primary caregivers of Alzheimer's and dementia sufferers, and their relationship to the employment situation of the caregiver. *Material and Methods:* Empirical analysis of the data obtained from surveys of 694 primary caregivers of Alzheimer's and dementia sufferers through the Andalusian Associations of Relatives of Alzheimer's Patients. The sampling procedure was selective non-probabilistic sampling. The SPSS 19 statistical software package was used to process the data. The verification of the hypothesis of independence of variables was performed using the chi square test under the usual parameters. *Results:* The employment rate of working-age caregivers is much lower than that of the general population, especially in older women with low levels of education who live with the patient. The data revealed that caregiving which takes place in the home represents the main restriction preventing access to the labour market, i.e. living with the patient is an additional handicap, and an even greater one for women. *Conclusions:* Those who care for dementia patients have greater limitations in accessing the labour market than the rest of the population, and this limitation is significantly greater when care is provided in the home. As such, health and social policy, with a view towards encouraging employment, needs to take into account the option of boosting available resources outside of family care.

Resumen

El objetivo es analizar las principales características demográficas y socio-económicas de los cuidadores principales de enfermos de Alzheimer y otras demencias, y buscar una la relación entre dichas características y su vinculación con el mercado laboral. *Material y Métodos:* Análisis empírico de los datos obtenidos de 694 encuestas realizadas a cuidadores principales de enfermos de Alzheimer y otras demencias, a través de Asociaciones de familiares de enfermos de Alzheimer andaluzas. El procedimiento de muestreo fue el muestreo no probabilístico selectivo. Para el tratamiento de los datos se ha utilizado el paquete estadístico SPSS 19. El contraste de las hipótesis de independencia de variables se ha realizado con el test de la chi cuadrado bajo los parámetros habituales. *Resultados:* La tasa de ocupación de los cuidadores en edad laboral es muy inferior a la de la población general, especialmente

en mujeres, de mayor edad, nivel de formación bajo y que conviven con el enfermo. De los datos analizados se revela como principal restricción para el acceso al mercado laboral el modelo de cuidado en casa, es decir, la convivencia con el enfermo es un hándicap adicional, mayor para el colectivo femenino. *Conclusiones:* Cuidar de un enfermo es una limitación superior respecto a población no cuidadora para el acceso al mercado laboral, y esta limitación es significativamente superior cuando el enfermo se atiende en el domicilio, por lo que de cara a políticas socio-sanitarias con incidencia en el fomento del empleo es necesario considerar la opción de incrementar recursos externos al cuidado familiar.

Palabras clave: Cuidado informal; Cuidadores; Demencia; Empleo; Salud Pública, Informal care; Caregivers; Dementia; Employment; Public Health

Jel Codes: I10, I13, J7

1. Introduction

Projections of population aging (United Nations, 2013) over the coming decades warn of the increase in dementia and other diseases associated with old age, which will in turn become a public health challenge (World Health Organization & Alzheimer's Disease International, 2012). Based on the number of people worldwide potentially affected by some form of dementia in 2010 (35.6 million), it is estimated that their number will almost double every 20 years, reaching 65.7 million in 2030, and 115.4 million in 2050 (Alzheimer's Disease International, 2010). From the age of 65 onwards, the prevalence of dementia, with Alzheimer's disease accounting for around 60%, doubles every five years, which implies a direct relationship between aging and dementia. Dementia is also one of the main causes of disability in the elderly. It represents almost 12% of years lived with disability from a non-communicable disease, and is the leading cause of dependency in old age (Alzheimer's Disease International, 2014; United Nations, 2013; World Health Organization, 2008). For Andalusia, the geographical scope of this paper, if we make calculations based on prevalence figures from Prince et al., 2013, the resulting prevalence would be 5.83%, implying 94,805.45 potential cases, given a national total of 650,774.29 (6.15% prevalence).

The healthcare needs of dependent sufferers are covered firstly by the family (informal care), and secondly by the health system and social services (formal care). In a broad sense, the term informal care is understood to mean the non-remunerated care provided for people in the community with a disability or chronic illness, either during childhood or old age (García-Calvente et al., 2004; Andersson et al., 2002; Rodríguez, 2006). Informal care, in some studies (Rapp et al. 2011), represented more than 80% of total care.

Traditionally, and especially in Mediterranean countries, the family has taken a leading role in the care of the elderly and the sick (Durán, 1999; Instituto de Mayores y Servicios Sociales, 2014; Rogero-García, 2009; Instituto Nacional de Estadística, 2009; Carretero et al., 2009; Garcés et al., 2010). The family provides support for carrying out activities of daily living (ADL), and instrumental activities of daily living (IADL) to people in situations of dependency. However, the distribution of care work is usually unequally shared within the family. Most of the burden is assumed by one of its members, usually a woman, who becomes the primary caregiver. The profile of the primary caregiver is a female (76.3%), middle-aged (between 45 and 64 years of age), with a family relationship with the patient (wife or daughter), who lives with the dependent person, with a low socio-economic status, and without paid work (Pope et al., 2012; Rivera et al., 2009; Instituto Nacional de Estadística, 2009; Carretero et al., 2009; García-

Calvente et al., 2010; García-Calvente et al., 2004; La Parra, 2001), a pattern that is repeated for the primary caregiver of patients with Alzheimer's and other dementias (World Health Organization & Alzheimer's Disease International, 2012; Garcés et al. 2010; Alonso et al., 2004; Moscoso et al., 2007; Zhu et al., 2008.).

The task of caring involves a time and energy commitment, as well as an economic and health burden. Women who provide care suffer the negative effects of this overload, which often take a toll on their physical and mental health and amount of free time available, due to neglect of self-care and social isolation. In illnesses requiring long-term care, such as Alzheimer's and other dementias, these negative effects are accentuated (Gibbons et al., 2014; Alonso et al., 2004; Oliva & Osuna, 2009), especially in the severe stages of the disease (Gallagher et al., 2011). Caregiving becomes a psychologically stressful and physically exhausting task (Schmitz & Stroka, 2013; Zhu et al., 2008; Schulz & Martire, 2004; Colvez et al., 2002). In addition, there is a cost in terms of lost opportunity due to the time spent in caregiving (Van Houtven et al., 2013; Hassink & Van den Berg, 2011; Van den Berg & Spauwen, 2006; Wimo et al., 2002; Carmichael & Charles, 2003). As Lilly et al. said (2010), to be a caregiver entails a reduction in revenue for both men and women, compared with those who are not caregivers, in their research both caregiving men and women had significantly higher personal and household incomes than non-caregivers. This may become an additional obstacle for women who wish to enter or stay in the labour market, due to the excessive burden and the difficulty of combining both responsibilities (Carmichael & Charles, 2003). Often they must leave their job in order to carry out caregiving duties (García-Calvente et al., 2004; Wimo et al., 2002; Hassink & Van den Berg, 2011).

The aim of this paper is to analyse the demographic and socio-economic profile of the primary caregivers of sufferers of Alzheimer's and other dementias, and to find the relationship, if any, between the employment status of the primary caregiver and their socio-demographic characteristics, and the profile of the patient in Spain.

2. Methods

A questionnaire for primary caregivers of sufferers of Alzheimer's and other dementias was designed and subsequently developed into an electronic format, to make it accessible through an online platform. At the same time, we contacted various Western Andalusian associations of relatives of Alzheimer's patients. Once the collaboration of the participating associations was obtained we proceeded to train those in charge of administering the questionnaire to primary caregivers (Social Workers and/or Psychologists linked to the

associations), first in paper format and then on the on-line platform. The objective of the training was to get homogeneous data, according to classification criteria, ensuring the correct interpretation of each item.

The sampling procedure was selective non-probabilistic sampling. The collection of data took place over six months, from January to June 2012, during which time one of the researchers maintained weekly contact with those responsible for data collection.

694 surveys from the four provinces which make up Western Andalusia (Cadiz, Cordoba, Huelva and Seville) were analyzed. The reason for focussing the analysis on this part of Andalusia is twofold: firstly, we are interested in carrying out an initial analysis in an area with a high level of cohesion and homogeneity; secondly, to make the planning and preparation of field work operationally effective and feasible, taking into account the particular complications of the available sampling frame. To verify the hypothesis of independence of variables we used the chi-square test under the usual parameters. Tables are presented with corresponding probability values (p-value) of each of the tests performed. All calculations were analysed using the SPSS 19 statistical software package.

3. Results

3.1 Main characteristics of Alzheimer's caregivers

The profile of the primary caregiver of patients with Alzheimer's and other dementias is, as expected, of a women (76.2%), older than 50 years (71.4 %), with a family relationship with the patient (89%), specifically a son/daughter (59.5%), who lives with the patient (70.5%), with a basic level of education (66 %), who lives in urban habitat (68.7%), in densely populated areas or intermediate zones (70.8%). Some significant differences between men and women should be noted: firstly, more than half of the male caregivers were over 65 years old (up to 32.7% of the total over 75 years), while about one-third of female caregivers (31.3%) are under 50 years old, and more than 45% between 50 and 64; secondly, female caregivers are usually daughters of the patients (65%), while male caregivers are usually the spouse or partner (52.7%); thirdly, 42.4% of male caregivers have secondary or higher level education, whereas for women this figure is 31.4% (Table 1) .

See Appendix table 1

3.2 Caregivers and the labour market

As previously specified, the aim of this paper is to study the relationship of the primary caregivers of sufferers of Alzheimer's and other dementias to the labour market. We have to bear in mind the particular circumstances of time constraints and availability for this profile. The first result is, as expected, the handicap imposed on caregivers (Kassink & Van den Berg, 2011; Lilly et al., 2010), with an employment rate of 43.5% for the age group 35-65 years, compared to the estimated rate of 70.2% for the whole of Western Andalusia (as can be calculated from the Active Population Study). In Table 2 we can see more specific results: only 31.7% of caregivers are employed, 27.8% are retired or in a similar circumstance, which means that over 40% are unemployed but not retired. This figure may be an indicator of the difficulty in accessing the labour market. However, only 22.3% of caregivers under 65 say their working situation is a result of, or is linked to, their duties as caregivers of Alzheimer's patients (there is no significant distinction between those who work, and those who don't work and aren't retired, as shown in Table 3).

See Appendix tables 2 and 3

When we analysed the employment situation of carers, according to sex and age for those under 65 years old (to avoid interference from retirement age carers), clear differences emerge for both variables, especially when taken together (see Tables 2 and 4). 72.7% of male caregivers work outside home, as opposed to only 39.3% of female caregivers. These differences remained in those younger than 50, with 87.1% of male caregivers having a job, compared with 50.6% of women. However, the question of whether respondents consider that being a caregiver affects their employment situation does not vary according to sex. Nevertheless, differences were observed according to age ranges, a greater proportion of younger people believe that being a caregiver does affect their employment situation.

See Appendix table 4

If we take as a benchmark the level of education, only 17.4% of caregivers with basic education are working, compared with 53.1% of those with an intermediate level of education, and 67.6% of those with higher qualifications. There is an increasing level of employment with level of training. Although many of the caregivers with lower levels of education are older, if we consider only those under 65 it can be seen that the relationship between employment status and being a caregiver does not depend on level of education.

On the other hand, the family relationship and cohabitation with the patient can be considered significant variables (Table 5), due to their influence on the employment status of the caregiver. Firstly, as shown in Table 2, almost half of caregivers who are sons or daughters of the patient say they are working outside home, and this percentage is slightly lower (39.0%) among family members who are in-laws; however, less than 3% of spouse caregivers have work. There is a clear negative impact on the employment situation for those who live with the patient, only 22.9% having a job, compared to 52.7% for caregivers who do not cohabit. That results are similar to those found by Nguyen & Connelly (2014), Heitmueller (2007) and Carmichael & Charles (2003). They found that cohabitation has a deterrent effect on caregivers' employment, and that effect is greater for those who cohabit.

Our results indicate differences between the two variables, family relationship and cohabitation, and the employment status of caregivers. In the case of family relationship, the difference by age group can be explained by the fact that most children or in-laws (sons- and daughters-in-law mostly) are, to a greater extent, of working age than are spouses of patients. They also have, in general, a better level of education (a variable also related to age). However, cohabitation has a direct bearing as a factor (though not a determining one) relating to being a caregiver. This is indicated by the significance of this variable in relation to their employment status (see Tables 2 and 5). For 26.2% of caregivers who live with the patient, their employment status is linked to this kind of work, compared with 15.9% observed among those who do not live with the patient.

See Appendix table 5

Regarding the influence on the employment situation of the last socio-demographic variables considered, the type of habitat (rural or urban) and population density of the residential area seem very significant; there are clearly higher percentages of caregivers who work in urban and/or densely populated areas (35.0% and 49.9%, respectively), although this incidence does not seem to be linked to being a caregiver, but to increased availability of employment in these areas.

Another aspect to consider regarding the employment status of caregivers of patients of Alzheimer's and other dementias, among those who have a job, is whether being a caregiver determines the kind of work they have. As can be seen in Table 2, almost two-thirds of working caregivers work full time. 22.9% of them have had to ask for some kind of reduction in working hours, due to their being a caregiver. However, being employed full or part time is influenced more by other factors, such as gender, age and level of education (see Tables 2 and 5).

We also examined whether being a caregiver had led them to reject opportunities for promotion or further training (see Tables 3 and 5). Firstly, 22.5% of those who work, and over 23% of those who do not work and have not reached retirement age, said that they have turned down a promotion at some point. Secondly, 27.5% of those who neither work nor are retired, and 29.1% of those who were working at the time of being interviewed, said they have rejected training opportunities.

Finally, it is noted that, contrary to what one might think, the severity of illness (mild, moderate or severe) is not shown to be a significant factor in the employment rate calculated among caregivers (with a p-value of 0.58).

4. Discussion

Although women over 50 years of age predominate among primary caregivers, in most cases being daughters of the patient, it is significant that, for male caregivers, the average age is higher and their relationship with the patient is that of partner or spouse. In both cases, it is more common for the caregiver and patient to live in the same home. Fewer than 30% live in nursing homes or similar residential care facilities, and the educational level of caregivers is limited to basic studies (or no studies).

What is evident from the study is that the particular circumstances of time constraints and availability involved with being such a caregiver limit their access to and/or ability to remain in the labour market. Firstly, there is an obvious difference in the employment rate among caregivers aged between 35 and 65 and the overall population for the same age group, with this being almost 27% lower in Western Andalusia. However, this difference is not perceived as such in many cases, since only 22% of working-age caregivers believe that their employment status is linked to their role of caregiving. Here, it is necessary to point out that, contrary to expectations, the severity of the illness does not significantly influence the calculated employment rate.

Secondly, if we analyse the casuistry between caregivers themselves, different factors are revealed that must be kept in mind, such as sex (in those under 65, the percentage of employed male caregivers is twice that of women), age (there is a higher employment rate among younger caregivers), and educational level (employment increases according to higher educational levels).

Thirdly, personal circumstances between caregiver and patient also have a bearing on the employment status of the caregiver, though more probably correlated with age and education level. Thus, caregivers who are sons/daughters or in-laws (sons- and daughters-in-law mostly, and on average younger and with higher levels of education) have a similar employment rate to the average, while this can be considered insignificant for spouse caregivers in working age (with a higher average age).

Fourthly, caregiver and patient cohabitation adversely affects the employment status of the former, the rate of employment reducing to less than half that among caregivers who do not live with the patient. This is due to the fact that for such cases, in general, they live in nursing homes or similar residential care facilities. Related to this last factor is the influence of the type of residence (rural or urban) and population density on the employment status of the caregiver, given that employment among caregivers of urban and/or densely populated areas is higher. Finally, when we study the characteristics of employment type, being a caregiver does not seem to significantly affect the distinction between full or part time work (contrary to expectations). This seems to be determined by other factors (gender, age, level of studies, etc.). There does seem to be a limitation on employment, as borne out by the rejection of promotion or further job training opportunities, with around 30% of caregivers reporting that they have rejected such opportunities.

To end, we note that there are various possibilities for further studies to complement this work. We consider it of interest to know how the caregiver's profile affects the selection of support services, or to carry out a specific analysis for the cases of early onset of the disease due to particular socio-occupational circumstances, as well as to evaluate the restrictive modifications occurring at the moment in the implementation of the dependency law, or the changes in the near future resulting from improvements in training of female caregivers, given that as is well known, those who undertake university studies are predominately women.

Appendix

Table 1.

Main characteristics of Alzheimer's caregivers in Western Andalusia.

		Total	Men	Women
Sex	Men	23.8%		
	Women	76.2%		
Age	Under 40's	6.5%	5.5%	6.8%
	Between 40's – 49's	21.8%	13.3%	24.5%
	Between 50's – 59's	32.7%	22.4%	35.9%
	Between 60's y 74's	23.7%	26.1%	23.0%
	75 or more	15.3%	32.7%	9.9%
Age 40	Under 40's	93.5%	94.5%	93.2%
	40 or more	6.5%	5.5%	6.8%
Age 50	Under 50's	71.7%	81.2%	68.7%
	50's or more	28.3%	18.8%	31.3%
Age 3	Under 50's	28.3%	18.8%	31.3%
	Between 50's – 64's	41.0%	27.9%	45.2%
	65 or more	30.6%	53.3%	23.5%
Educational level	Basic	66.0%	57.6%	68.6%
	Medium	18.8%	24.2%	17.1%
	High	15.2%	18.2%	14.3%
Relationship with the patient	Spouse	29.5%	52.7%	22.3%
	Son/Daughter	59.5%	41.8%	65.0%
	In-Laws	5.9%	3.6%	6.6%
	Others	5.0%	1.8%	6.0%
Cohabit	Yes	70.5%	72.7%	69.8%
	No	29.5%	27.3%	30.2%
Habitat: Rural / Urban	Urban	68.7%	79.4%	65.4%
	Rural	31.3%	20.6%	34.6%
Density of population	Densely populated	35.9%	51.5%	31.0%
	Intermediate	34.9%	29.1%	36.7%
	Low density	29.3%	19.4%	32.3%

Source: Own elaboration

Table 2.
Employment status of caregivers of Alzheimer's patients in Western Andalusia
 (%.s./total).

		Work	Retired	No work No retired	Labour situation linked to be a caregiver (Under 65´s)	Caregivers who work (% s. Caregivers who work)		
						Full time	Part time	Reduction of working hours
Total western Andalusia		31.7%	27.8%	40.5%	22.3%	66.2%	33.8%	22.9%
Sex	Men	34.5%	55.2%	10.3%	26.0%	87.7%	12.3%	23.2%
	Women	30.9%	19.1%	49.9%	21.6%	58.6%	41.4%	22.8%
Age	Under 40´s	57.8%	2.2%	40.0%	28.9%	50.0%	50.0%	23.1%
	Between 40´s - 49s	56.0%	0.0%	44.0%	31.1%	57.1%	42.9%	21.4%
	Between 50´s – 59´s	40.4%	3.5%	56.1%	17.3%	76.7%	23.3%	24.7%
	Between 60´s -74s	9.1%	57.9%	32.9%	13.8%	86.7%	13.3%	26.7%
	75´s or more	3.8%	82.1%	14.2%	0.0%	50.0%	50.0%	0.0%
Age 40	Under 40´s	57.8%	2.2%	40.4%	21.6%	50.0%	50.0%	23.1%
	More than 40´s	30.1%	29.4%	40.0%	28.9%	68.4%	31.6%	22.9%
Age 50	Under 50´s	56.4%	0.5%	39.4%	16.5%	55.5%	44.5%	21.8%
	More than 50s	22.2%	38.3%	43.1%	30.6%	77.1%	22.9%	24.1%
Age 3	Under 50´s	56.4%	0.5%	43.1%	30.6%	55.5%	44.5%	21.8%
	Between 50´s – 64´s	36.7%	7.8%	55.5%	16.5%	77.7%	22.3%	25.5%
	More than 65´s	2.8%	79.2%	17.9%	0.0%	66.7%	33.3%	0.0%
Educational level	Basic	17.4%	32.9%	49.6%	24.8%	46.8%	53.2%	24.1%
	Medium	53.1%	17.7%	28.9%	19.4%	77.9%	22.1%	19.1%
	High	67.6%	17.1%	15.2%	17.0%	77.5%	22.5%	25.7%
Relationship with the patient	Spouse	2.9%	73.7%	23.4%	15.2%	83.3%	16.7%	16.7%
	Son/Daughter	46.5%	6.3%	47.2%	23.1%	68.4%	31.6%	22.8%
	In-laws	39.0%	12.2%	48.8%	20.0%	37.5%	62.5%	31.3%
	Other	20.0%	28.6%	51.4%	22.7%	57.1%	42.9%	14.3%
Cohabit	Yes	22.9%	36.6%	41.0%	26.2%	61.3%	38.7%	23.4%
	No	52.7%	6.3%	40.2%	15.9%	71.3%	28.7%	22.4%
Habitat: Rural / Urban	Urban	35.0%	25.6%	39.2%	23.7%	68.1%	31.9%	26.7%
	Rural	24.7%	32.3%	43.1%	19.0%	60.4%	39.6%	11.3%
Density of population	Densely populated	40.9%	26.5%	32.4%	24.4%	77.2%	22.8%	33.0%
	Intermediated	28.2%	23.6%	48.1%	21.7%	55.9%	44.1%	16.2%
	Low density	24.9%	34.0%	41.1%	20.3%	58.0%	42.0%	12.0%

Source: Own elaboration

Table 3.

The Rejection of offers of a job or training of Alzheimer's caregivers in western Andalusia

(Under 65's)

	% s./Caregivers who work	% s./ Caregivers who do not work neither are retired	p-valor
Working situation linked with being a caregiver	20.2%	25.8%	0.155
They have rejected propositions for job promotion	22.5%	23.3%	0.840
They have rejected propositions of training	29.1%	27.5%	0.04

Source: Own elaboration

Table 4.

Percentage of caregivers who work, by sex and age
p-value of the chi-square test of independence
(H0: To work or is not independent of the sex of the caregiver)

	Men	Women	p-value (Sex-Work)
Under 40's	88.9%	50.0%	0.035
More than 40's	31.4%	29.6%	0.673
Between 40's – 49's	86.4%	50.8%	0.002
Under 50's	87.1%	50.6%	0.000
More than 50's	22.4%	22.1%	0.939
Between 50's – 59's	67.6%	34.9%	0.000
Between 50's – 64's	63.0%	31.8%	0.000
Between 60's – 74's	9.3%	9.1%	0.967
Under 65's	72.7%	39.3%	0.000
More than 65's	1.1%	4.1%	0.204
More than 75's	1.9%	5.9%	0.281

In bold type values with probability under 0,05

Source: Own elaboration

Table 5.
Relationship between employment status and their main caregiver´s circumstances.
p-value of the chi-square test of independence (H0: independent variables)

	Caregiver´s circumstances								Area of residence	
	Sex	Age	Age 40	Age 50	Age 3	Level of Education	Relationship with caregiver	Living with the patient	Habitat Rural / Urban	Density of population
Working situation (Under 65´s)	0.000	0.000	0.161	0.000	0.000	0.000	0.000	0.000	0.034	0.000
If work.... full or part time	0.000	0.008	0.063	0.001	0.003	0.000	0.061	0.116	0.302	0.006
If work.... reduction of working hours	0.954	0.813	0.985	0.692	0.326	0.748	0.787	0.862	0.021	0.004
Working situation linked with being a caregiver (Under 65´s)	0.397	0.003	0.264	0.000	0.000	0.280	0.749	0.009	0.263	0.675
Rejection of job promotion for being a caregiver (Under 65´s)										
Work	0.329	0.274	0.152	0.468	0.468	0.694	0.391	0.126	0.156	0.480
No work. neither retired	0.075	0.021	0.105	0.003	0.003	0.313	0.158	0.991	0.654	0.402
Rejection of training propositions for being a caregiver (Under 65´s)										
Work	0.141	0.702	0.794	0.362	0.362	0.769	0.762	0.282	0.071	0.164
No work. neither retired	0.185	0.094	0.563	0.138	0.138	0.405	0.604	0.736	0.565	0.545

In bold type values with probability under 0,05
 Source: Own elaboration

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