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Title: **Unmet care needs are common among community-dwelling older people with memory problems in Finland**

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Unmet care needs are common among community-dwelling older people with memory problems in Finland

Abstract

Aims: Ageing in place has become a policy priority. Consequently, residential care has been reduced, and more older people with multiple care needs reside at home with the help of informal care or home care services. An increasing share of these people have memory disorders. We examine the extent to which memory problems, in addition to other individual characteristics, are associated with unmet care needs among community-dwelling older people.

Methods: The study employs cross-sectional survey data from community-dwelling people aged 75+ collected in 2010 and 2015, analysed using binary logistic regression analysis. The study population consists of people who have long-term illnesses or disabilities that limit their everyday activities (N1928). Nine per cent reported substantial memory problems. Of these, 35.7% had a proxy respondent.

Results: People with memory problems have more care needs than those with other types of disability or illness. They receive more care but still have more unmet needs than others. About a quarter of people with memory problems report that they do not receive enough help. This result does not change significantly when the proxy responses are excluded. Even a combination of informal and formal home care is insufficient to meet their needs.

Conclusions: Insufficient care for people with memory problems implies a serious demand to further develop home care services. The care needs of this population are often complex. Unmet needs are a serious risk to the well-being of people with memory disorders, and may also create an extensive burden on their informal caregivers.

Keywords: Formal home care, informal care, unmet needs, insufficient care, memory problems

Unmet care needs are common among community-dwelling older people with memory problems in Finland

Introduction

For two decades in Finland, the emphasis of care policies for older people has been on ageing in place and residing at home for as long as possible. Cost savings have been introduced in all types of public services for older people, but especially in residential care [1, 2]. Regardless of the national policy aim to improve and broaden home care services to compensate for these reductions in residential care [3], the coverage of home care has decreased [2, 4].

In principle, the care people receive at home consists of home care services and informal care offered by family members or other people close to the recipient. Public home care in Finland is needs-tested, available to all citizens, and organized by local municipalities [5]. These services are in principle directed to and used by all social groups according to need, and not for example according to purchasing power [6]. Although these services are mainly publicly funded, public funding covers only a proportion of the services; most services are partly covered by either fixed or income-related client fees that vary between different service types and municipalities. Additionally, people can buy private services, including home care services, and cover the costs out of their own pocket. For some of these costs, people can apply for a tax credit for household expenses up to 60% of the cost of the service [7]. In addition, despite the public responsibility for providing 'indispensable subsistence and care' (The Constitution of Finland), a significant amount of care is provided by families and other persons close to the recipient [8].

An earlier Finnish study showed that the more care needs an older person has, the more care s/he receives from both formal services and informal caregivers [9]. Due to their range of challenging symptoms, a higher need for care is typical among people with different types of memory disorders [10-12]. It is estimated that there are around 190,000 persons with memory disorders in Finland, and around 14,000 persons fall ill yearly [13]. People with memory disorders today constitute an increasing

proportion of clients in home care [14] and receive a considerable amount of informal care. The significance of these conditions for individuals' lives – both care receivers and caregivers – has therefore also increased.

However, not all older people receive sufficient care or help regarding their needs. Unmet needs occur when a person has disabilities for which help is needed but is either unavailable or considered insufficient [15, 16]. In Finland in 2014, unmet needs were quite common among public home care clients aged 75+: one in four considered that the quantity of home care services was insufficient for their needs [17]. To our knowledge, no research has been done on unmet care needs of persons with memory problems in Finland.

Aims

Using data from community-dwelling older people with long-term illnesses or disabilities, we examine whether home care is sufficient for those with memory problems. Information about unmet needs is urgently needed, as an increasing number of older people with disabilities reside in private homes and the number of those with memory disorders is significantly increasing.

Methods

We use a cross-sectional survey conducted in 2010 and 2015, focusing on people aged 75+ living at home or in serviced housing (excluding institutional care) in the two Finnish cities of Jyväskylä and Tampere [18]. This survey collected information on the everyday life situations of older people: their everyday activities, needs for care, use of care, socio-economic and demographic backgrounds, and self-reported physical and mental health.

A covering letter about informed consent, the 12-page self-administered questionnaire and a prepaid envelope were sent to 1000 participants in each city, followed by two follow-up letters to non-respondents. Participants' addresses were drawn from population registries. In the first wave, 1436 questionnaires were obtained (response rate 71.5%), and in the second 1474 (response rate 73.7%).

Since this study neither involves the physical integrity of subjects nor deviates from the principle of informed consent, ethical committee approval was not required. However, standard survey method guidelines for good scientific practice were followed. For example, participants were informed in the covering letter about the purpose of the survey, and the confidentiality and anonymity of the collected data.

For this study, the study population consists of those who had one or more long-term illnesses or disabilities that limited their everyday activities, and who had answered the question 'Do you have memory problems?' (1 = not at all, 2 = somewhat, 3 = a lot) (N 1928). Nine per cent (N 185) chose option 3 and were classified as people with memory problems. Among people with memory problems the share of proxy responses was 35.7%, while among people without memory problems it was 3.0%.

In the Finnish survey, the questions were formulated using two terms, 'help' and 'care', depending on the content of the question. In this study, we use the concepts of informal care, formal home care and (in)sufficient care to cover both help and care.

Insufficient care and unmet needs

Unmet needs were measured with two different questions. First, unmet needs related to functional problems were investigated using an eight-point question regarding instrumental activities of daily living (IADL) and a five-point question regarding activities of daily living (ADL) (Table 1). The response options were: 1) I can cope without difficulty, 2) I do not cope by myself but I get enough help, or 3) I do not cope by myself and I need more help. Those who chose option 3 were considered to be receiving insufficient care, i.e. to have unmet needs. Second, the respondents were asked in general 'Do you receive enough help?' and the response options were 1) I do not need help, 2) Yes, I receive enough help, and 3) I do not receive enough help. Again, those who chose option 3 were considered to have unmet needs.

Explanatory variables

To capture the impact of memory problems, in addition to other individual factors contributing to the need of care, we apply the conceptual framework of the individual determinants of care use [19]. In this framework, the use of care depends on predisposing, enabling and need factors. In previous research, this framework has been expanded to represent the determinants of insufficient care use, i.e. unmet care needs [20]. Predisposing factors include demographic and social characteristics that existed prior to the onset of illness, such as age and gender. Enabling factors represent conditions that make health care resources available to the individual: in this study, marital status, number of children, household type, education and monthly disposable household income. Need factors are the illness-related factors that are the immediate cause of the use of care: in this study, memory problems, self-rated health and functional limitations. The latter variable was constructed from those who reported problems with different IADL and ADL.

Statistical analysis

Those who indicated that they needed help and care in response to the question 'Do you receive enough help?' – i.e. who chose the response options 2) Yes, I receive enough help (N 1112) or 3) I do not receive enough help (N 272) – were included in the binary logistic regression. This method was used to estimate the association of receiving enough help, i.e. sufficient care, with memory problems and other enabling, predisposing and illness-related need factors. The outcome variable was sufficient care (0 = receives enough care and help, 1 = does not receive enough care and help). The analyses were conducted for the whole study group and in addition for those who solely used informal care, and for those who used both informal and formal home care.

Results

The average age was 82.7 years. Those with memory problems were slightly older than the rest (Table 1). More than half the study population were single, divorced or widowed, and almost as many lived alone. Those with memory problems more often had a partner and lived with someone. The majority

of respondents had children. Regarding socio-economic characteristics, those with memory problems on average had a lower education compared with respondents without memory problems.

Although everyone included in this study had a long-term illness or disability, not everyone subjectively rated the state of their health as poor. Almost 87% of respondents with memory problems, and 75% of those without memory problems, estimated their health as poor (Table 1). Regarding IADL and ADL, people with memory problems had a higher number of functional limitations than those without memory problems (Table 1).

Care and help received from family members, other informal caregivers and formal home care

Almost all of the respondents received informal care, and one third received public home care on a weekly or daily basis (Figure 1). The most common types of care were solely informal care or a combination of weekly or daily informal care and weekly or daily public home care, possibly topped up with privately purchased services.

Informal care was slightly more common for people with memory problems (98.8% versus 94.9%) (Figure 1). Informal caregivers were most often spouses, children and daughters-in-law. These were even more frequent caregivers for people with memory problems than for those with other kinds of disability, who received informal care more frequently from grandchildren and friends. However, the only statistically significant difference was that people without memory problems more often received help from a friend than those with memory problems.

People with memory problems received public home care services considerably more often (55.1%) than those without memory problems (29.5%). However, relying solely on public services was highly uncommon. Solely receiving informal care was more common among those without memory problems.

Association of memory problems with sufficient care and help

In all, five per cent of those with memory problems stated that they did not need help or care, whereas almost a quarter of the others could manage without care (Table 2). Of those with care needs, 26% of people with memory problems and 19% of those without memory problems reported unmet needs. Regardless of whether care was received solely from informal caregivers, or from both formal services and informal caregivers, unmet needs were more common among people with memory problems than among others. However, the difference was statistically significant only for those who received care from both informal and formal caregivers. In all, insufficient care was more frequent among those who solely received informal care.

To estimate the impact of the proxy respondents among people with memory problems, we analysed unmet needs separately among those who did not use a proxy respondent (Table 2). Removing proxy responses did not change the results significantly, and the differences between people with and without memory problems remained. However, when the proxy responses were removed, the number of respondents declined, especially among people with memory disorders, and the differences were no longer statistically significant.

In relation to ADL and IADL needs, people with memory problems reported more often than others that they did not receive sufficient care and help (Table 2). Among people with memory problems, one in four or one in three had unmet needs, depending on the IADL in question, excluding managing financial affairs and taking medication, which were less often subject to unmet needs. Among people without memory problems, the corresponding proportions varied from 13% to 23%. Between one in five and one in four people with memory problems, and more than one in 10 of those without memory problems, had unmet ADL needs. The difference in unmet needs between people with and without memory problems was statistically significant in relation to showering and getting in and out of bed.

The univariate model (Table 3) shows that male gender, living alone, low income, memory problems, poor self-rated health and a higher number of functional difficulties increased the likelihood of unmet care needs. Memory problems remained significant in models 2–4, but after ADL and IADL variables

were included in the final model, the effect of memory problems fell to insignificance. The only significant indicator for unmet needs was poor self-rated health in the final model.

When only those who used solely informal help were included in the analyses, a lower income and a higher number of ADL problems were associated with insufficient care (final model 5). Among those who received help from both informal caregivers and public home care, memory problems and a higher number of ADL problems were associated with insufficient care (final model 5).

Discussion

People with memory problems need and receive more care, but they also have unmet care needs more often than people with other types of disability or illness. Among those who receive both public home care and informal care, those with memory problems and high numbers of ADL limitations have unmet needs most often. Among those who rely solely on informal care, those with low incomes and high numbers of ADL limitations have unmet needs most often. The difference in unmet needs between people with and without memory problems is more noticeable with regard to IADL than ADL needs.

In all, the severity and types of memory problem vary, from subjective memory complaints with no clear cognitive impairment to progressive memory disorders and dementia. As the causes of memory problems vary, so the symptoms differ, ranging from anxiety, depression and stress to confusion, language difficulties, neurological disorders, and ADL and IADL problems [21]. Regardless of this variety, a higher dependency on and need for services is common among people with different types of memory disorders [10-12]. Previous research shows that higher needs entail unmet needs; hence, people with dementia have more unmet needs than people without dementia [22]. In a study of community-dwelling older people with cognitive impairment and their informal caregivers in the US, almost all of the older people had at least one unmet need [23]. In that study, the unmet needs were estimated in domains such as safety, general health/medical care, meaningful activities and legal issues. A recent European study found that people with middle-stage dementia had most unmet needs in the domains of company (15%), information (13%) and daytime activities (9%) [24]. Overall, making

comparisons is problematic, because unmet needs are estimated differently, and study populations vary across different studies [15]. For example, a nationally representative Swedish study found that under 2% of people aged 75 years or older with an ADL need had unmet needs [25]. In that study, unmet need was defined as not receiving any help, whereas in our study it was defined as receiving insufficient help. In a literature review [15] of research from different countries, it was estimated that the share of older people with unmet ADL needs varied between 3% and 35%, depending on the study in question.

In addition to the complexity of definitions of unmet needs, measuring needs objectively is challenging. Both informal caregivers [24, 26] and professional care workers [27] often estimate needs and unmet needs to be higher than do those who need the care. There is a question as to whether people with memory disorders or their informal caregivers underestimate or overestimate their care needs. However, researchers have pointed out that due to the nature of the illness, people with memory disorders may lack the insight and ability to judge their own needs and received care [26], and informal caregivers may therefore have a clearer overview in that respect.

Public formal home care is targeted at those who have the highest physical and mental health needs [1, 4]. Older adults who have higher care needs are more likely to receive care from more than one source [9, 28]. It is probable that in our study, those who received care from both informal and formal caregivers had the highest needs. In this group, memory problems and a higher number of ADL limitations were indicators of insufficient care. This implies that memory problems create demanding care needs that are not met, even with a combination of public home care services and informal care. The consequences of unmet care needs are drastic: a lower quality of life [29], predictive of residential care and even death [30]. In terms of appropriate help and decent living conditions, attention should be given to the group of people who live at home with memory problems and complicated care needs. Our study shows that community-dwelling people with disabilities, including those with memory problems, receive a significant amount of informal care, which notably saves costs in public care [31].

However, this places persons in need of care in unequal positions, as available informal care resources vastly differ between individuals. Most of the survey respondents in this study received informal care, but of course this is not the case with all older people. Presumably, those who do not have informal caregivers are the likeliest to receive insufficient care.

Strengths and limitations

This study is subject to some limitations. The number of those with memory problems was rather low, which decreases the statistical power of the analyses. It is common for people with cognitive problems to be under-represented in survey studies, since filling in a questionnaire requires cognitive skills. Around 36 percent of the responses of people with memory problems were given by proxy respondents. Nevertheless, we have no reason to think that proxy respondents would not have the ability to evaluate whether the care recipient received enough care and help. We did not have information on the severity or type of the memory problems, i.e. whether the condition was mild or severe, and whether it was temporary or progressive. We must therefore exercise caution when comparing our results with previous studies on people with different types of memory disorder such as dementia, although it is likely that our study group included people with dementia. With regard to the analyses of the different types of care people received, missing responses decreased the statistical power. A detailed examination of missing responses revealed that half of those who skipped the formal care questions used informal care, and a fifth of those who skipped the informal care question used formal care. It is possible that some respondents answered only those questions that were most relevant to them. However, we do not know this for sure. In addition, use of each care type was asked with individual questions, thus long and detailed questionnaires might have reduced the motivation to respond, especially among this group, where everyone had an illness or disability. The question concerning the sufficiency of care did not include information about which type of care people felt they lacked: informal care, formal care or both. This information would be important for care policy. The data were collected in 2010 and 2015. From 2005 to 2015, the work strain in home care increased

[32]. Since then, the coverage of formal home care has continued to decrease [2]. There is no reason to expect that the situation with formal home care has improved since 2015.

This study provides highly important information on the unmet needs of community-dwelling older people with long-term illnesses or disabilities. Rather than studying individuals' memory problems, this study describes possible weaknesses in the Finnish care system for older people, especially for those with memory problems. To our knowledge, no research has been published to date on community-dwelling persons with memory problems and unmet needs in Finland. Regardless of some shortcomings related to response rates and missing responses, the data is a major strength of this study. Data include extensive information on different predisposing, enabling and needs-based determinants of care use. Due to the ageing population and increasing longevity, the number of people with memory disorders is predicted to increase significantly in the coming decades. Adequate information on care needs is urgently needed for the sufficient allocation of services.

Conclusions

The policy objectives of ageing in place and living independently at home for as long as possible need to be carefully considered in the cases of persons with memory problems and other demanding care needs. The number of old persons with memory disorders is increasing significantly, but public services are not sufficiently extensive to respond to the most demanding and complicated needs of community-dwelling older persons. The fact that people with memory problems receive insufficient care more often than others indicates that they need services of better quality and quantity.

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Will be delivered before publication in order to preserve anonymity.

Conflict of interest

The authors declare that there is no conflict of interest.

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Table 1. Study population characteristics. *N* = the number of respondents.

	N	Total %	No MP %	MP %	P-value
Gender (%)	1921				
Women		62.5	63.0	57.8	
Men		37.5	37.0	42.2	0.199
Age (average)	1843	82.7	82.5	85.1	<0.001
Filling in the questionnaire (%)	1899				
Alone/with someone		92.4	95.5	62.2	
Proxy		6.1	3.0	35.7	<0.001
Marital status (%)	1925				
Single, divorced, widowed		58.2	58.9	51.4	
Married, cohabiting, registered partner		41.6	40.9	48.6	0.050
Has children (%)	1872	85.9	85.7	88.1	0.900
Number of children (average)		2.3	2.3	2.4	0.461
Household type (%)	1905				
Living alone		56.1	57.3	44.9	
Living with someone		42.7	41.8	51.4	0.004
Education (%)	1886				
Primary education or less		70.2	69.4	78.4	

Secondary education		27.6	28.6	18.4	0.004
Income (%)	1812				
< €1000		21.5	21.6	20.5	
≥ €1000 & < €2500		60.9	60.5	64.3	
≥ €2500		11.6	12.0	7.6	0.186
Self-rated health (%)	1892				
Very good/good/fair		22.0	23.2	10.8	
Poor/very poor		76.1	75.0	86.5	<0.001
Needs help with (%)					
Grocery shopping	1801	39.0	35.4	73.5	<0.001
Going to hobbies, activities or meetings, or visiting other people	1752	39.3	35.3	77.3	<0.001
Obtaining home assistance or other services	1400	38.0	33.9	75.1	<0.001
Managing financial affairs	1832	37.8	33.1	82.7	<0.001
Minor repairs or refurbishments at home or gardening	1564	59.2	57.1	79.5	<0.001
Cleaning, laundering	1820	58.0	55.2	83.8	<0.001
Cooking	1804	32.1	27.3	77.3	<0.001
Taking medication	1857	20.2	14.6	73.5	<0.001

Number of IADL problems (average)		4.0	3.5	7.2	<0.001
Needs help with (%)					
Showering	1870	17.5	13.9	52.4	<0.001
Eating	1874	6.1	3.4	31.4	<0.001
Getting out of bed/round the bed	1872	6.4	4.5	24.9	<0.001
Toileting	1873	5.7	3.7	24.3	<0.001
Dressing or undressing	1876	9.8	7.3	33.5	<0.001
Number of ADL problems (average)		0.5	0.3	1.7	<0.001

Notes: Table includes everyone who reported at least one disability or long-term illness that limited everyday life. Missing answers included in total percentages. No MP = those without memory problems. MP = those with memory problems. Needs help with = those who responded with options 2) I do not cope by myself but I get enough help or 3) I do not cope by myself and I need more help. P-value refers to the difference between people with and without memory problems. Range of missing variables in single questions varies between 0 and 17.4%. Statistically significant p-values ($p < 0.05$) in bold.

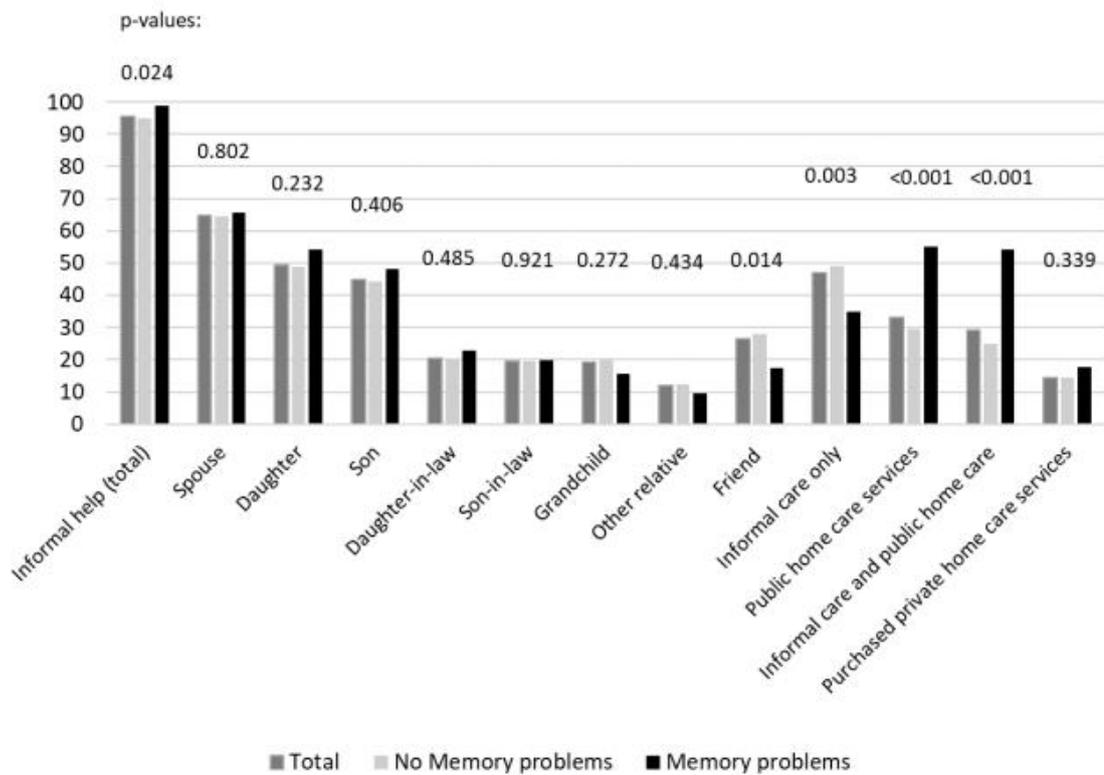


Figure 1. Regular use of informal and formal home care.

Notes: Those who responded that they received help/care weekly or daily are included. Missing answers are excluded. Proportions of missing answers: informal care 27.9%, public formal home care 49.7%, self-purchased private care 51.3%. P-value refers to the difference between people with and without memory problems. Significance level: $p < 0.05$

Table 2. Receipt of sufficient help and care: comparison between people with and without memory problems in those who needed help. Total N 1810 (missing responses 118), without memory problems N 1634, with memory problems N 176. N in the first column refers to the number of people in the subsamples of those who reported needing help and care and who provided a response to the care type question.

	n	Total	No MP	MP	P-value
<i>Receiving enough help and care</i>					
Do not need help/care %		23.5	25.5	5.1	<0.001
Those who need help/care	1384				
Enough, %		80.3	81.3	73.7	
Not enough, %		19.7	18.7	26.3	0.023
Used informal care only ¹	343				
Enough help and care, %		70.8	81.6	75.0	
Not enough help and care, %		19.2	18.4	25.0	0.308
Used informal and public home care ¹ ,	257				
Enough help and care, %		84.0	88.6	72.6	
Not enough help and care, %		16.0	11.4	27.4	0.002
<i>Receiving enough help and care²</i>					

Do not need help/care, %		25.0	26.3	6.4	<0.001
Those who need help/care	1256				
Enough, %		80.6	80.9	76.7	
Not enough, %		19.4	19.1	23.3	0.300
Used informal care only ¹	318				
Enough help and care, %		79.6	80.2	75.0	
Not enough help and care, %		20.4	19.8	25.0	0.804
Used informal and public home care ¹	203				
Enough help and care, %		86.2	88.4	76.9	
Not enough help and care, %		13.8	11.6	23.1	0.072
<i>IADL: not enough help/care³</i>					
Grocery shopping	753	16.2	13.8	27.2	<0.001
Going to hobbies, activities or meetings, or visiting other people	758	25.5	22.6	37.8	<0.001
Obtaining home assistance or other services	730	19.9	18.3	26.6	0.033
Managing financial affairs	730	9.4	8.1	16.3	0.005
Minor repairs or refurbishments at home or gardening	1142	22.5	20.3	37.4	<0.001
Cleaning, laundering	1118	20.7	19.2	29.7	0.004

Cooking	619	16.2	13.2	25.9	0.001
Taking medication	390	8.5	4.7	15.4	<0.001

ADL: not enough help/care, %³

Showering	339	15.6	12.4	23.7	0.013
Eating	117	14.5	10.2	19.0	0.200
Getting out of bed/round the bed	124	16.9	11.5	26.1	0.048
Toileting	109	17.4	12.5	24.2	0.128
Dressing or undressing	189	12.7	11.0	16.1	0.356

Notes: MP= those with memory problems. No MP = those without memory problems. ¹ Of those who reported needing help/care. ² Without proxy answers. ³Of those who needed help/care with the IADL or ADL in question. P-value refers to the difference between people with and without memory problems. Statistically significant p-values (p<0.05) in bold.

Table 3. Predisposing, enabling and need determinants associated with receiving insufficient care: odds ratios for binomial logistic regression analysis. Those who reported needing care (n 1384) are included in the analysis.

	Insufficient care					Insufficient care, informal care only		Insufficient care, informal care and public home care	
	Model 1	Model 2	Model 3	Model 4	Model 5	Model 1	Model 5	Model 1	Model 5
	OR	OR	OR	OR	OR	OR	OR	OR	OR
<i>Predisposing</i>									
Age	1.002	0.991	0.990	0.992	0.971	1.012	0.962	0.987	1.021
Gender (ref. woman)	0.674	0.667	0.782	0.759	0.714	0.916	1.269	1.295	1.193
<i>Enabling</i>									
Marital status (ref. single, divorced, widowed)									
Married, cohabiting, in a registered	1.309		1.408	1.497	1.574	0.921	1.812	1.200	1.816

partnership									
Number of children	0.734		0.690	0.705	0.734	3.460	3.598	2.579	2.053
Household type (ref. lives alone)									
Lives with someone	0.711		0.619	0.590	0.484	0.792	0.438	1.093	0.403
Education (ref. primary school or less)									
Secondary education or more	0.792		0.929	0.999	0.925	0.436	0.554	0.549	0.606
Income (ref. < €1000)									
≥ €1000 & < €2500	0.627		0.713	0.740	0.838	0.659	0.552	1.267	1.777
≥ €2500	0.328		0.471	0.459	0.486	0.164	0.099	0.414	1.049
<i>Need</i>									
Memory problems (ref. no/sometimes)	1.552	1.654	1.720	1.662	1.164	1.479	0.977	2.929	2.838
Self-rated health (ref. very good/good/fair)									
Poor/very poor	3.275			3.013	2.333	13.102	6.583	5.481	3.102

Number of ADL problems	1.117	1.128	1.399	1.349	1.384	1.316
Number of IADL problems	1.151	1.084	1.259	1.143	1.200	0.840

Notes: OR = odds ratio: 0 = receives sufficient care, 1 = does not receive sufficient care. Model 1 is a univariate model. Statistically significant odds ratios (p-value <0.05) in bold.