Impact of Untimely Access to Formal Care on Costs and Quality of Life in Community Dwelling People with Dementia

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ABSTRACT

BACKGROUND: Access to formal care is not always timely and a better understanding on the impact of untimely access is needed.

OBJECTIVE: To examine, from a societal perspective, the impact of untimely access to formal care in terms of total costs and quality of life over one year in community dwelling people with dementia.

METHODS: Within the Actifcare study, needs, resource use and quality of life were observed for one year in a cohort of 451 community dwelling people with dementia in 8 European countries. Untimely access to care was operationalized as having at least one unmet need for care identified by the Camberwell Assessment of Need for the Elderly (CANE) instrument. Two regression models were built for both total costs and quality of life measured by the EQ-5D-5L, one using sum of unmet needs and one using a predefined selection of need items.

RESULTS: Unmet needs were not associated with higher total costs but they were associated with a lower quality of life of people with dementia. Of all CANE items, only an unmet need for "company" was significantly related to lower total costs.

CONCLUSION: Total costs did not seem to differ between participants with unmet and met needs. Only few associations between specific unmet needs and costs and quality of life were found. Furthermore, quality of life of people with dementia decreases when multiple unmet needs are experienced, indicating that assessing and meeting needs is important to improve quality of life.

KEY WORDS access to care, untimely, unmet needs, dementia, costs, quality of life

INTRODUCTION

Dementia has a large impact on societies and the total worldwide costs were estimated $818 billion [1]. With increasing dependency alongside the progressive disorder, the need for unpaid informal care by family members increases [2], starting from some help in day-to-day activities to around-the-clock care and supervision. Formal care services are often needed to complement the informal caregiver in order to reduce caregiver stress and burden [2, 3] and maintain or improve the wellbeing of the person with dementia and support the informal caregiver. Several barriers for access to and utilization of formal care exist [2, 4-7] and potentially could result in a situation in which a need for formal care is unmet.

Several studies have shown negative associations between higher levels of needs and quality of life in people with dementia [8-10]. Experiencing unmet needs in day-to-day activities may also increase the risk of institutionalization as the decreasing functioning of the person with dementia poses challenges with meeting and managing increasing needs such as eating and toileting [11].

Not all care is unavoidable. Rudolph, et al. [12] found that experiencing falls is an important risk factor for avoidable hospitalization, which could have been prevented by e.g. home safety improvements. Together with literature on the association between unmet needs and quality of life, this suggests that untimely access to formal care could be associated with both lower quality of life and higher consequential costs. This care, which could be formal or informal, could have been prevented or reduced if the care to meet such needs was introduced in a timely manner.

From a health-economics perspective, it is of interest to examine the impact of unmet needs in terms of care costs and generic health-related quality of life (HRQoL). This could indicate

the potential for interventions targeting the prevention or reduction of unmet needs and help policy makers to distribute available resources most effectively.

A better understanding of the relationship between HRQoL, care costs and untimely access could indicate the importance of timeliness of care. This could guide the development of interventions for improving HRQoL of community dwelling people with dementia and managing care costs. This study therefore aims to explore the impact of untimely access.

METHODS

The ACcess to TImely Formal care study (Actifcare) includes a one year longitudinal cohort study following persons with dementia, and their informal caregivers, from eight European countries, with measures taken at baseline, six and twelve months. A detailed description can be found elsewhere [13].

PARTICIPANTS

In total, 451 community dwelling people with a diagnosis of mild to moderate dementia and their informal caregivers participated at baseline. Participants were eligible if they were not using regular assistance concerning personal (formal) care related to their dementia (e.g. help with washing), but were expected to start using formal care within one year and did have a Clinical Dementia Rating (CDR) of 1 or 2 (indicating mild or moderate dementia) or MMSE ≤24. All other eligibility criteria are described in detail elsewhere [13]. In each country ethical approval was obtained separately, and written informed consent was obtained for both the person with dementia and the caregiver.

For the current study, participants were eligible for analyses if at least one follow-up measurement was available. In the instance that one of the two follow up measurements was completely missing, this measurement was excluded from analyses. A follow-up measurement was considered completely missing if the assessment of care use and HRQoL could not be performed.

MEASURES

The needs of the persons with dementia were derived from the Camberwell Assessment of Need for the Elderly (CANE) instrument [14]. This measure consists of 24 items relating to the person with dementia, and two relating to the informal caregiver. Each item was scored as either having no need, a met need or an unmet need. Rater (interviewer) scorings were used, which take into account both the informal caregiver and the person with dementia perspective, together with any other available information. The concept of untimely access to care was operationalized using the CANE instrument. Having an unmet need was considered untimely access to care and having a met need as timely access to care. Needs might be met by input from an informal caregiver, or from a formal care service or from both. Informal caregiver-need related items were not used in the current analyses since the focus was on the needs relating to the person with dementia.

Generic HRQoL of the person with dementia was measured using the proxy-rated EQ-5D-5L [15], which measures HRQoL in five domains including mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Every domain is scored on a five-level scale ranging from no problems to being unable or having extreme problems. These scores were transformed into utilities using UK index values [16, 17].

Costs were measured from a societal perspective. The Resource Utilization in Dementia (RUD) instrument [18] was used to collect data on type and frequency of resource use from both the person with dementia and the informal caregiver. Participants were asked to fill out resource use for the past 30 days at baseline and for the past six months (since the last visit) at six and twelve months, except for informal care, which asked about the last 30 days at each measurement point.

To calculate the resource use related costs, quantities of resource use were multiplied with unit prices. By necessity in this study, the recall period differed between the items. All resource use quantities were rescaled to the same period and subsequently transformed to a 1-year period to enable analyses on total costs across all observations.

Country specific unit prices (Supplementary Table 1) were obtained from various international and national sources and all prices were transformed to Euros and to 2015 values using annual exchange rates and Harmonized Indices of Consumer Prices from http://ec.europa.eu/eurostat. Unit prices were averaged and applied to all countries (Supplementary Table 1). Informal care was valued according to the opportunity cost, of which the hourly cost was reflected by the average wage derived from http://ec.europa.eu/eurostat. To reflect the mix of retired and non-retired informal caregivers, 35% of the country specific average wage was used [19].

For the current study a total cost variable was constructed, comprising both the person with dementia- related care costs and the informal caregiver- related care costs as identified by the RUD instrument.

Analyses were performed in the statistical software package Stata version 13 (StataCorp, TX). Baseline demographic characteristics, baseline HRQoL and needs over time were described using descriptive statistics.

The impact of untimely access to care on care costs and HRQoL were examined in two steps. First, total rescaled annual costs and HRQoL were predicted using the sum score counting the number of unmet needs among all 24 needs in a regression analysis. Second, the associations between costs and the 24 CANE items, and HRQoL and the 24 CANE items were assessed in two separate multivariate regression analyses using an automated backward procedure. CANE items were dummy coded ('no need' or 'unmet need', the reference category was 'met need') and selected if: 1) the prevalence of unmet needs was ≥5% at baseline and 2) dummy pair showed to be significant in univariate regression analyses based on F-tests for multiple imputed datasets to test the joint effect of each dummy pair using a cut-off $p<0.05$. Each univariate significant CANE item dummy pair was incorporated and removed if not significant ($p \geq 0.05$; based on same test as in univariate analyses) in a backward procedure, starting with the least significant. In all regression analyses (univariate and multivariate), country and participant were used as random intercepts.

The distribution of total annual costs on imputed data was skewed (skewness factor was 5.01). They were log transformed to obtain a distribution with a skewness factor of zero by using ln (costs + 2186). Outliers on total annual costs were defined as 4 times the median absolute deviation and were omitted from analyses and descriptive statistics.

For the calculation of costs, frequencies of resource use volumes were imputed across the entire dataset by multiple imputation using the Stata 13 chained equations and predictive mean matching command to construct an imputation model with age and gender of both the

person with dementia and informal caregiver, MMSE, IADLS, PSMS and NPI, CANE, quality of life as well as RUD items as predictor variables. Ten imputed datasets were generated [20].

SENSITIVITY ANALYSIS

Different scenarios were tested examining robustness of results. First, the analyses on both total costs and HRQoL were rerun including any omitted outliers and performed by means of the same backwards procedure as the main analyses. Second, instead of EQ-5D-5L utilities, ICECAP-O [21] utilities were used, which focus on wellbeing instead of health, and consists of five attributes: attachment, security, role, enjoyment and control. Scores were transformed into utilities ranging from 0 (no capability) to 1 (full capability) using the UK tariff [21]. Franklin, et al. [22] showed that the ICECAP-O provides complementary information next to the EQ-5D (3L), as not all domains of health (mobility and pain/discomfort) did show a significant relationship with capabilities of ICECAP-O. To assess the overlap between ICECAP-O and EQ-5D-5L the correlation between their utility scores was estimated. Third, instead of including country as the random intercept, the region (Northern, Western and Southern Europe) was used as fixed effect in regression analyses. Finally, a multivariate regression model was fitted to the change in costs and to the change in HRQoL between baseline and 12 months' follow-up, leaving 6 months' follow-up out. Independent variables comprised dummy coded clustered transitions based on having no need, unmet or met need at 12 months follow-up. For this fixed model the baseline level of need was not taken into account as the emphasis was on the level of need at 12 months.

RESULTS

Of all 451 participants, 52 (12%) participants were excluded because they were defined as a complete loss to follow-up, leaving the data from 399 participants for the current analysis. Of these 399 participants, 10 participants had complete missing data at 6 months and 42 participants had complete missing data at 12 months, partly due to death (n=17). These measurements were excluded from analyses. Data for participants with parts of questionnaires missing were imputed through multiple imputation. Nine additional participants were excluded because they had an outlier in total costs, leaving 390 participants for the primary analyses.

Table 1 shows the baseline characteristics of the people with dementia and the informal caregivers. The mean age of the people with dementia was 77 years, of whom 53% were female. Mean age of the informal caregivers was 67 years, of whom 67% were female. Of these 390 participants, 41 were not living in their own home at 6 months and at 12 months follow up, 49 participants were not living at their own home (i.e. intermediate forms of accommodation, dementia-specific residential accommodation, long-term institutional care or other).

Descriptive statistics of the person with dementia EQ-5D-5L, as rated by the informal caregiver, at baseline are shown in Figure 1. Between 3.6% and 10.5% showed severe problems and between 0.3% and 4.6% showed extreme problems.

[Please insert table 1 about here]

[Please insert Figure 1 about here]

Percentages of needs and transitions over time are displayed in Figures 2a and 2b.

The largest proportion of rater reported needs that remained unmet were found for "daytime activities" and "company".

UNMET NEED PREDICTORS OF COSTS

Total annual costs were not significantly related to the sum of unmet needs (step 1). The following CANE items were significant in the univariate analysis using costs as outcome and were selected for the costs model (Supplementary Table 2) in the second step of the analysis: looking after the home, daytime activities, mobility/falls, information, accidental self-harm, company and benefits. The final model (step 2) showed that costs were significantly different for "company" only (Table 2; Supplementary Table 3), where having an unmet need was associated with lower costs (€-2,709, p=0.012) compared to having a met need. Results (not displayed) showed that having no need for all items, except "information", led to lower costs compared to having a met need.

UNMET NEED PREDICTORS OF HRQoL

The sum of unmet needs (step 1) was significantly associated with HRQoL (p<0.001), reflecting a lower HRQoL (-0.017) for each additional unmet need (also see Supplementary Figure 1). The following CANE items were significant in the univariate analysis using HRQoL as outcome: looking after the home, daytime activities, mobility/falls, psychotic

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symptoms, psychological distress, accidental self-harm, company and benefits. The final model showed that having an unmet need on "mobility/falls" was significantly related to a lower HRQoL (-0.054, p=0.006) compared with having a met need (Table 3; Supplementary Table 4). Having no need was significantly related to a higher HRQoL compared to having a met need on all the items in final model.

<mark>[Please insert Table 3 about here]</mark>

SENSITIVITY ANALYSIS

Sensitivity analysis allows us to see how sensitive our results are to the assumptions of our models [23]. Inclusion of the nine participants with outliers (costs ranging between €121,238 and €269,845) on total costs showed the same results for HRQoL, meaning the same CANE items remained significant after the backward procedure. Using costs as outcome showed some deviation i.e. "Company" was no longer significant. There was a significant positive correlation between ICECAP-O and EQ-5D-5L utilities at baseline, r=0.47; n=377; p <0.001, indicating weak to medium correlation. When using ICECAP-O scores instead of EQ-5D-5L scores, "psychological distress" instead of "mobility/falls" was significant (Supplementary Table 5). Including region as a fixed factor did not change the results. Finally, the fixed effects model using costs and HRQoL change scores between baseline and 12 months follow-up showed no significant results for either of the two outcomes.

POST HOC ANALYSIS

A post hoc analysis (Supplementary Table 6.1 and 6.2) was carried out to examine whether consequential care could be identified when splitting total care costs into informal care- and formal costs (non-transformed), using the same backwards procedure on selection of CANE items. Results showed no significant cost differences when informal care costs and formal care costs were used as the outcome of interest.

DISCUSSION

We explored predictors of cost and health-related quality of life amongst people living with dementia. Only a weak association was found between unmet needs and 1-year total care costs resulting in lower costs. HRQoL was lower for those with an unmet need on the CANE item "mobility/falls" and also decreased with an increasing number of unmet needs.

It was expected that untimely access to care would lead to higher costs compared to timely access, especially in terms of costs related to informal care. Neither primary- nor sensitivity and post-hoc analyses confirmed this expectation. CANE item "Company" was significantly related with lower care costs when experiencing an unmet need. However, after sensitivity analysis, this association did not hold and therefore was considered not robust.

These results could suggest that having a met need indicates most likely that the need is being met by formal care, causing immediate higher costs that are not counterbalanced by the savings due to preventing consequential care. Another explanation might be that consequential care costs occur over a longer time period. For example, if the most common response to an unmet need for company is day care, then in the short-term, whilst the need is

unmet, there will be a cost-saving related to not providing day care. On the longer term however, it is possible that lack of company and social contact could turn into isolation and self-neglect. Although we adjusted for participant, country and region in our models it is possible that differences between countries and regional differences within countries regarding care use influences how unmet needs are addressed and could influence the association between unmet needs and care costs.

An unmet need does not necessarily indicate a situation in which no formal care at all is provided. A need could have been met by informal, rather than formal care. The fact that total costs did not significantly differ between unmet and met needs could indicate that formal care was provided, but that the level of care was considered insufficient or not appropriate to meet the need. In other words, access to care could be realized already [24]. van der Roest, et al. [25] also showed that, although formal care was delivered, needs were still reported as unmet. Patrick and Peach [26] made a further distinction between under-met needs (needs that are partially satisfied) and unmet needs (needs that are not satisfied at all). In the current study such a distinction was not made, although this kind of distinction could lead to possible cost differences. Additionally, in some CANE areas several unmet needs could exist (e.g. physical health). However, the instrument records only one, making a specific distinction not possible. As expected, our results showed a negative association between the amount of unmet needs and HRQoL, which is supported by previous studies [8-10]. In current study we mainly focused on health related outcomes, since these are considered to be important outcomes in health-economic studies and evaluations. However, it is possible that this resulted in an underestimation of other QoL domains. Therefore, the ICECAP-O was used as complementary instrument. As our correlation analysis showed, ICECAP-O and EQ-5D-5L were weak to moderately correlated, confirming the potential of complementing each other. This was also stated by Franklin, et al. [22], found in a validation study by Makai, et al. [27]

and recommended to use both alongside each other when performing evaluations of interventions in older people [28]. When looking at the specific CANE items, "mobility/falls" was significantly associated with a lower QoL measured by the EQ-5D and "psychological distress" was significantly associated with a lower QoL measured by the ICECAP-O. This is possibly related to the specific scale's sensitivity to the needs domain as mobility is an item in the EQ-5D, and psychological distress might be closer to the concept of capabilities measured by the ICECAP-O. Nevertheless, needs on the social domain would have been expected to be associated with HRQoL as this was found to be an important domain for older people [29]. Since HRQoL (EQ-5D-5L) is scored by the informal caregiver, we included caregiver characteristics to final model to examine whether this would influence the results. The results (Supplementary Table 7) showed that adjusting for age, gender, living together and care related QoL, did not alter the results regarding significance and direction of effects. Although not within our scope of the current study, the analysis showed that other (informal caregiver related) factors were also associated with HRQoL of the person with dementia as scored by the informal caregiver.

Livingston, et al. [30] stressed the need of individualizing dementia care by tailoring care to individual and cultural needs. Our results furthermore imply that HRQoL is increasingly affected when unmet needs accumulate, showing the importance of also taking into account the number of unmet needs when considering an individual's situation.

Our study was subject to some limitations. First, the one year follow-up can be considered too short to pick up the longer-term impact of unmet needs. Second, although the sample was meant to be typical, generalization of the results may be limited because the cohort consisted of a convenience sample. Third, reasons for not considering formal support might be similar

to reasons for not participating in a scientific study that evaluates access to formal care, introducing a possible selection bias towards persons who are in a stable situation regarding their needs and received care. Fourth, as supported by Figures 2a and 2b, the proportion of transitions in needs was lower than expected, possibly resulting in too small a variation to potentially show an association with HRQoL and costs.

A further important consideration when interpreting these results was that we did not correct for multiple testing as the secondary analyses with ICECAP-O as an outcome was purely for explorative purposes.

RECOMMENDATIONS FOR RESEARCH, PRACTICE AND POLICY

Identifying, managing and preventing unmet needs of people with dementia living at home is important as our research has indicated this as a potential pathway to improve HRQoL. The long-term impact of untimely access to care remain unknown, which will be part of an extension of the Actifcare cohort for 5 years. The results showed that the number of unmet needs has an impact on HRQoL. As individual and cultural differences in needs exist, it would be of interest to examine whether need profiles exist i.e. whether clusters of people could be identified on the basis of their combinations of needs and whether such clusters are associated with differing HRQoL.

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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Table 1: Characteristics of the person with dementia and informal caregiver at baseline (n=390)

Characteristic	Mean (SD), range or n(%)	% missing
Person with dementia		
Age	77.4 (7.8), 47 – 95	0%
Gender, male n (%)	182 (47)	0%
Years of education	10 (4.6), 0 – 25	<1%
PSMS (0 – 6)	3.7 (1.8), 0 - 6	<1%
IADL (0 – 8)	3.5 (2), 0 – 8	<1%
MMSE total (0 – 30)	19 (5), 3 – 30	7%
NPI-Q total (0 – 30)	7.5 (5.6), 0 – 30	<1%
EQ-5D-5L, person with dementia proxy scored utility*	0.72 (0.20), -0.074 – 1	<1%
ICECAP-O, proxy scored utility*	0.70 (0.16), 0.15 – 0.98	3%
Number of unmet needs (rater)	1.7 (2) 0 - 11	2%
Informal caregiver		
Age	66.5 (13.3), 28 – 92	0%
Gender, male n (%)	130 (33)	0%
Years of education	12 (4.4), 0 - 24	<1%
Relationship, n (%)		0%
Spouse	241 (62)	
Partner	13 (3)	
Son/daughter	114 (29)	
Other (e.g. friend)	22 (6)	
CarerQoL, utility	0.76 (0.17), 0.106 – 1.002	4%
Lives together with person with dementia n (%)	284 (73)	<1%

PSMS, Physical Self Maintenance Scale; IADL, Instrumental activities of daily living; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory

* using UK tariff

Table 2. Multivariate results of final model using costs as outcome (n=390)[1]

CANE item	Unmet vs met need*			
	Coefficient[2]	Standard error	Back transformed coefficient[3] (€)	p
Looking after the home	-0.027	0.080	-564	0.737
Daytime activities	-0.026	0.052	-547	0.618
Mobility/falls	0.003	0.074	70	0.965
Information	-0.113	0.075	-2,288	0.128
Company	**-0.136**	**0.054**	**-2,709**	**0.012**
Benefits	-0.033	0.079	-694	0.675

In bold: significance <0.05; *No need vs met need not displayed in table; constant is 9.968

[1]Table only displaying dummy pairs shown to significantly improve the model.

[2] this is the estimated (rounded) coefficient of the model fitted to the log transformed costs outcome.

[3] the coefficient was back-transformed using the following formula:

$$\left(\exp\left(\text{constant} + 1 * \text{CANE}_{dummy2} + 0 * \text{CANE}_{dummy3}\right) - a\right)$$

$$- \left(\exp\left(constant + 0 * CANE_{dummy2} + 0 * CANE_{dummy3}\right) - a\right)$$

Constant = beta coefficient of the constant of the regression model

CANE_{dummy2} = beta coefficient for the dummy reflecting the presence of an unmet need

CANE_{dummy3} = beta coefficient for the dummy reflecting the presence of no need

a = 2186, which reflects the correction factor

Table 3. Multivariate results of final model using quality of life as outcome (n=390) [1]

CANE item	Unmet vs met need*		
	Coefficient	Standard error	p
Looking after the home	-0.005	0.022	0.831
Daytime activities	-0.003	0.012	0.812
Mobility/falls	**-0.054**	**0.020**	**0.006**
Psychotic symptoms	-0.019	0.024	0.428
Psychological distress	-0.015	0.018	0.405
Benefits	0.030	0.021	0.162

In bold: significance <0.05; *No need vs met need not displayed in table; [1]Table only displaying dummy pairs shown to significantly improve the model.
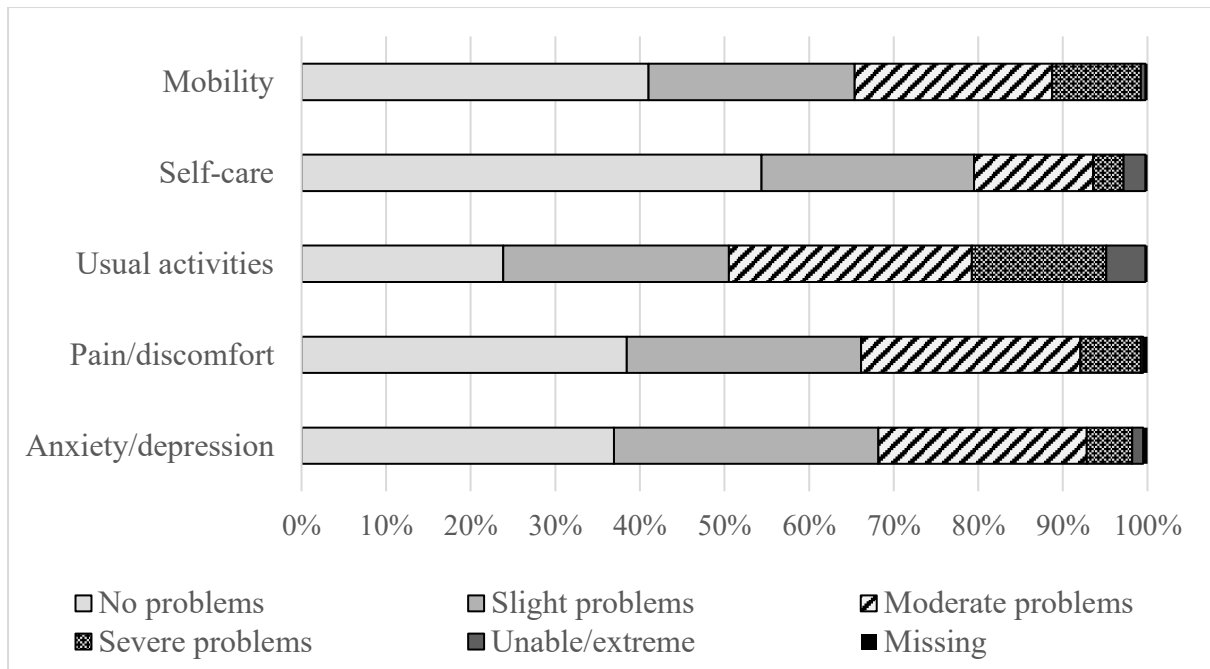
Figure 1. Baseline percentages of proxy reported patient quality of life for each dimension (EQ-5D-5L; n=390).
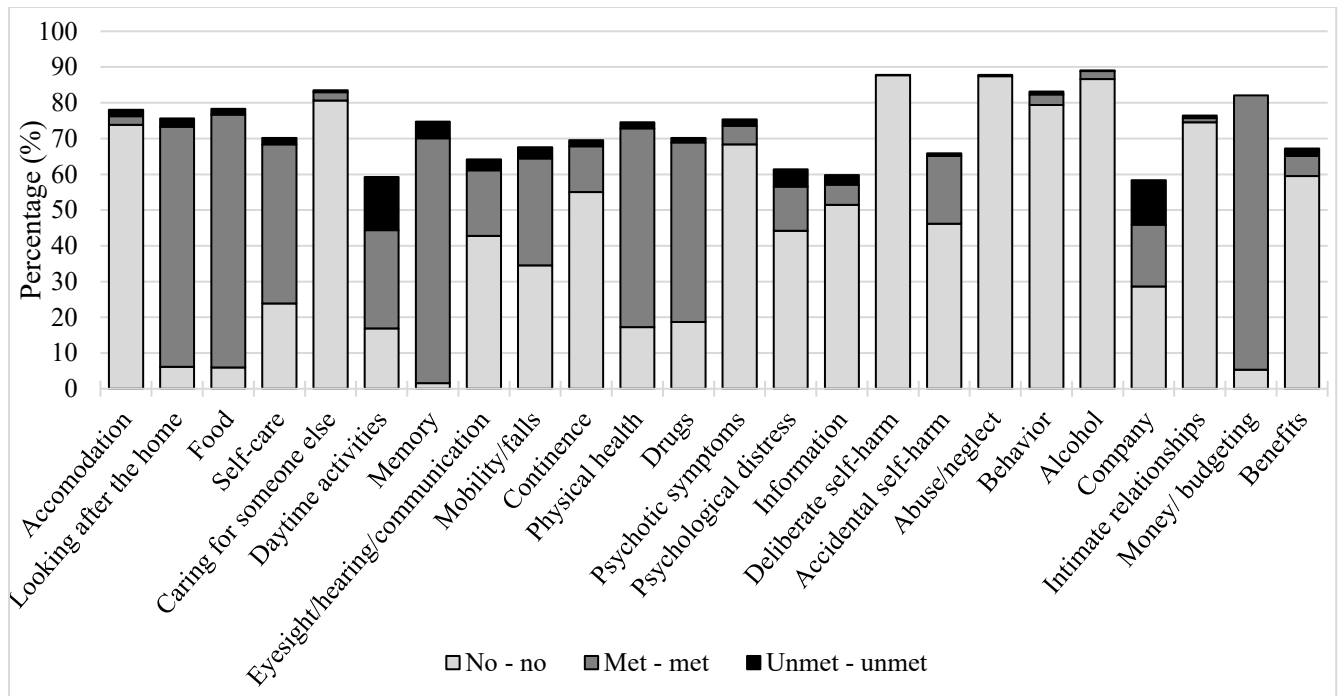
Figure 2a. Percentage of need status on all CANE items between baseline, 6 months and 12 months follow up for those participants in whom no change of needs was observed. Missing transitions are not displayed.

Figure 2b. Percentage of need status transitions on all CANE items between baseline, 6 months and 12 months follow up for those participants in whom a change of needs was observed. Missing transitions are not displayed.

Supplementary Table 1 Unit prices transformed to Euro 2015

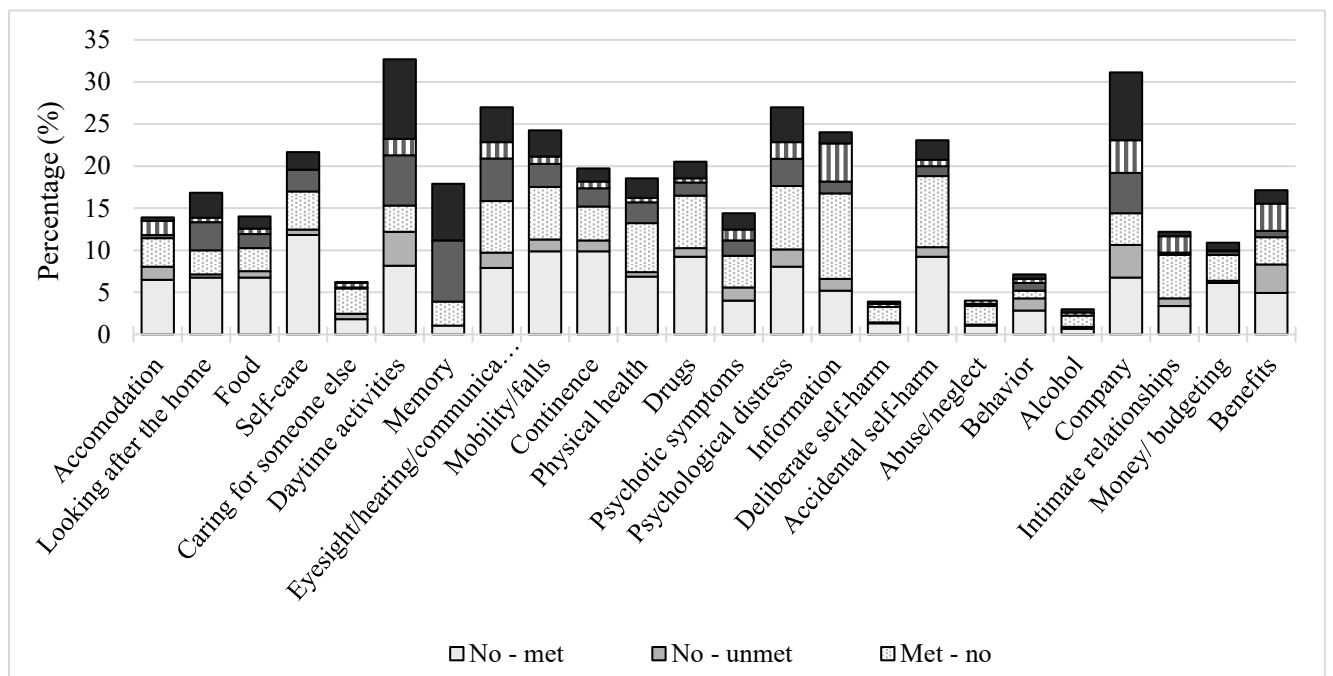|	Unit	Norway	Sweden	Germany	Ireland	Netherlands	United Kingdom	Italy	Portugal[a]	Mean
		North	*North*	*West*	*West*	*West*	*West*	*South*	*South*	
Living accommodation										
own home	day	0	0	0	0	0	0	0	0	0
Intermediate forms	day	22	140	58	79	134	111	27	40	76
Dementia specific residential	day	252	180	116	157	168	111	53	37	141
Long-term institutional care	day	249	180	116	157	168	111	53	90	141
Other	day	0	0	0	0	0	0	0	0	0
Admission to hospital										
Geriatric	night	1462	518	255	841	477	388	427	[b]	576
Psychiatric	night	1462	518	523	352	477	388	427	191	549
Internal medicine	night	1462	518	343	841	477	388	427	884	587
Surgery	night	1462	518	861	841	406	388	427	884	643
Neurology	night	1462	518	496	841	396	388	427	1361	596
General ward	night	1462	518	496	841	477	388	427	884	606
Other	night	1462	518	496	841	477	388	427	884	606
Emergency room	visit	235	324	54	275	260	83	79	84	174
Care professional										
General practitioner	visit	38	124	19	52	33	48	25	34	47
Geriatrician	visit	139	425	65	162	91	47	78	[b]	134
Neurologist	visit	139	425	65	162	99	47	78	65	135
Psychiatrist	visit	139	425	19	162	91	63	78	65	130
Physiotherapist	visit	75	101	28	29	33	25	21	16	41
Occupational therapist	visit	75	101	28	29	33	28	21	16	41
Social worker	visit	92	101	35	29	65	36	21	16	49
Psychologist	visit	156	101	60	29	64	54	21	16	63
Other	visit	139	425	65	162	91	47	78	65	134
Services										
District nurse or equivalent	hour	74	47	13	33	73	32	44	33	44
Home aid/orderly	hour	60	47	5	19	50	28	20	17	31
Food delivery	visit	9	24	11	7	5	7	5	4	9
Day Care	hour	17	14	21	17	11	15	16	13	15
Transportation	visit	32	31	4	18	4	29	1	1	15
Other	hour	60	47	5	19	50	28	20	7	31
Informal care										
Informal care instrumental ADL	hour	11	6	6	8	7	7	5	3	7
Informal care personal ADL	hour	11	6	6	8	7	7	5	3	7
Informal care supervision	hour	0	0	0	0	0	0	0	0	0
Productivity losses										
Mean wage	hour	30	18	18	23	19	19	16	8	19

Abbreviations: ADL, activities of daily living

Living accommodation 'other' mainly contained holiday at relatives' home or hotel; Services 'other' mainly contained housekeeper or low level home care help.

Unit prices were obtained from various international and national sources. All prices were converted to Euros and to 2015 values using annual exchange rates and Harmonised Indices of Consumer Prices from http://ec.europa.eu/eurostat.

^a Updated prices for Portugal were available in various Administrative rules, however, due to issues with transforming prices to the items of the RUD questionnaire in various cases prices reported by Luengo-Fernandez, Leal, Gray[31] have been used as well as assumptions based on authors' opinions.

^b Type of care not yet applicable/available in this country at time of fieldwork.

Supplementary Table 2 Selection of CANE items (n=390)

	≥5% unmet need at baseline	Univariate regression < 0.05		Inclusion multivariate regression	
		Costs	QoL	Costs	QoL
1 Accommodation	No	n/a	n/a		
2 Looking after the home	Yes	Yes	Yes	Yes	Yes
3 Food	No	n/a	n/a		
4 Self-care	No	n/a	n/a		
5 Caring for someone else	No	n/a	n/a		
6 Daytime activities	Yes	Yes	Yes	Yes	Yes
7 Memory	Yes	No	No		
8 Eyesight/hearing/communication	Yes	No	No		
9 Mobility/falls	Yes	Yes	Yes	Yes	Yes
10 Continence	No	n/a	n/a		
11 Physical health	No	n/a	n/a		
12 Drugs	No	n/a	n/a		
13 Psychotic symptoms	Yes	No	Yes		Yes
14 Psychological distress	Yes	No	Yes		Yes
15 Information	Yes	Yes	No	Yes	
16 Deliberate self-harm	No	n/a	n/a		
17 Accidental self-harm	Yes	Yes	Yes	Yes	Yes
18 Abuse/neglect	No	n/a	n/a		
19 Behavior	No	n/a	n/a		
20 Alcohol	No	n/a	n/a		
21 Company	Yes	Yes	Yes	Yes	Yes
22 Intimate relationships	No	n/a	n/a		
23 Money/budgeting	No	n/a	n/a		
24 Benefits	Yes	Yes	Yes	Yes	Yes

Supplementary Figure 1 Boxplots of EQ-5D-5L proxy scored utility of person with dementia by number of unmet needs (non-imputed data)
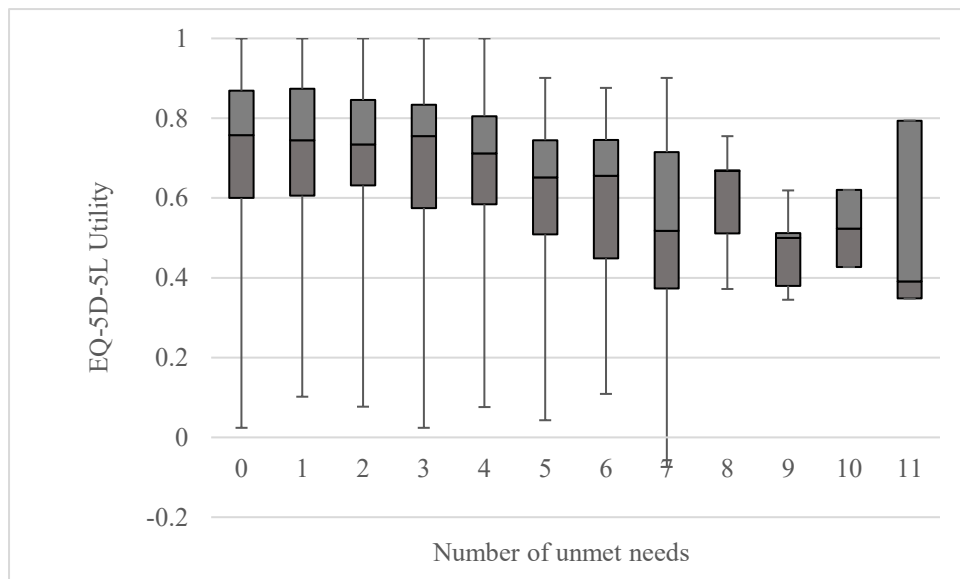
Supplementary Table 3 backwards procedure using costs as outcome

	CANE item	Dummy pair	Dummy 2: Unmet vs met need			Dummy 3: No need vs met need		
		p, F-test*	Coefficient	Standard error	p**	Coefficient	Standard error	p**
Starting model***	Looking after the home	**<0.001**	-0.035	0.079	0.658	**-0.311**	**0.064**	**<0.001**
	Daytime activities	**<0.001**	-0.027	0.052	0.599	**-0.213**	**0.052**	**<0.001**
	Mobility/falls	**<0.001**	-0.002	0.075	0.982	**-0.183**	**0.044**	**<0.001**
	Information	**<0.001**	-0.108	0.074	0.147	**0.188**	**0.049**	**<0.001**
	Accidental Self-harm	0.053	-0.079	0.089	0.375	**-0.109**	**0.046**	**<0.05**
	Company	**0.030**	**-0.126**	**0.054**	**<0.05**	**-0.108**	**0.050**	**<0.05**
	Benefits	**0.022**	-0.032	0.079	0.683	**-0.147**	**0.058**	**<0.05**
Final model	Looking after the home	**<0.001**	-0.027	0.080	0.737	**-0.321**	**0.064**	**<0.001**
	Daytime activities	**<0.001**	-0.026	0.052	0.618	**-0.214**	**0.052**	**<0.001**
	Mobility/falls	**<0.001**	0.003	0.075	0.965	**-0.194**	**0.044**	**<0.001**
	Information	**<0.001**	-0.113	0.075	0.128	**0.182**	**0.049**	**<0.001**
	Company	**0.018**	**-0.136**	**0.054**	**<0.05**	**-0.114**	**0.050**	**<0.05**
	Benefits	**0.022**	-0.033	0.079	0.675	**-0.146**	**0.058**	**<0.05**

* p-value of each dummy pair; **p-value of each dummy (2 and 3); ***See Supplementary Table 2

Supplementary Table 4 p-values of backwards procedure using EQ-5D-5L utilities as outcome

	Starting model*, p value F-test**	Backward step 1, p value F-test**	Final model, p value F-test**
Looking after the home	**<0.05**	**<0.05**	**<0.05**
Daytime activities	**<0.001**	**<0.001**	**<0.001**
Mobility/falls	**<0.001**	**<0.001**	**<0.001**
Psychotic symptoms	**<0.01**	**<0.01**	**<0.01**
Psychological distress	**<0.001**	**<0.001**	**<0.001**
Accidental Self-harm	0.837	n/a	n/a
Company	0.325	0.314	n/a
Benefits	**<0.05**	**<0.05**	**<0.05**

*Starting model includes selected items (see Supplementary Table 2); **p-value of each dummy pair

Supplementary Table 5 Sensitivity analyses (n=390) with ICECAP-O utilities as outcome using final model (step 2)

	Unmet need vs met need		
	Coefficient	Standard error	p
Looking after the home	-0.006	0.018	0.727
Daytime activities	-0.002	0.011	0.845
Mobility/falls	-0.007	0.017	0.688
Psychotic symptoms	-0.028	0.022	0.195
Psychological distress	**-0.039**	**0.016**	**0.018**
Benefits	-0.004	0.020	0.850

In bold: significance <0.05; reference dummy met need

Supplementary Table 6.1 Post hoc results of backward multilevel model using non-transformed informal care costs (support with personal and instrumental activities of daily living, and supervision) as outcome (n=390)[1]

	Unmet need vs met need		
	Coefficient (€)	Standard error	p
Looking after the home	-556	794	0.484
Mobility/falls	1,140	748	0.128
Information	-1,410	809	0.084
Benefits	-594	785	0.449

[1]Table only displaying dummy pairs shown to significantly improve the model.

Supplementary Table 6.2 Post hoc results of backward multilevel model using non-transformed formal care costs* as outcome (n=390)[1]

	Unmet need vs met need		
	Coefficient (€)	Standard error	p
Daytime activities	-2,449	1,284	0.057
Mobility/falls	-2,402	1.424	0.239
Information	-2,787	2,064	0.177

*including accommodation costs, hospital costs (both caregiver and person with dementia emergency visits costs (both caregiver and person with dementia), costs of professional visits (both caregiver and person with dementia), costs for home- and social services (including day care). [1]Table only displaying dummy pairs shown to significantly improve the model.

Supplementary Table 7 results of post-hoc analysis adjusting for informal caregivers characteristics using EQ-5D-5L as outcome

Informal caregiver characteristics / CANE item	Coefficient	Standard error	p
Gender, male	0.005	0.015	0.737
Age	**-0.002**	**0.001**	**0.007**
Living together, yes	**0.072**	**0.016**	**<0.001**
CarerQoL, utility	**0.145**	**0.037**	**<0.001**
Looking after the home, unmet vs met	0.005	0.021	0.815
Daytime activities, unmet vs met	-0.001	0.012	0.959
Mobility/falls, unmet vs met	**-0.042**	**0.020**	**0.035**
Psychotic symptoms, unmet vs met	-0.016	0.024	0.493
Psychological distress, unmet vs met	-0.007	0.018	0.674
Benefits, unmet vs met	0.033	0.021	0.115

In bold: significance <0.05; *No need vs met need not displayed in table

Supplementary Table 8 baseline and 12 months mean total costs per CANE item on original (non-imputed) data after outlier exclusion

CANE item	Baseline		12 months	
	Met need mean total costs (€)	Unmet need mean total costs (€)	Met need mean total costs (€)	Unmet need mean total costs (€)
Accommodation	23,851 (n=23)	19,165 (n=14)	31,780 (n=40)	27,547 (n=12)
Looking after the home	18,063 (n=278)	15,730 (n=19)	22,966 (n=263)	20,213 (n=21)
Food	17,913 (n=293)	13,837 (n=9)	22,596 (n=278)	27,042 (n=14)
Self-care	18,645 (n=189)	22,806 (n=11)	25,397 (n=206)	23,885 (n=16)
Caring for someone else	11,912 (n=18)	12,900 (n=4)	22,540 (n=11)	19,683 (n=6)
Daytime activities	17,170 (n=122)	19,597 (n=109)	25,539 (n=162)	19,506 (n=83)
Memory	16,787 (n=312)	14,279 (n=42)	22,616 (n=255)	16,810 (n=38)
Eyesight/hearing/communication	17,748 (n=115)	26,018 (n=34)	21,978 (n=101)	21,000 (n=35)
Mobility/falls	20,983 (n=141)	20,065 (n=24)	25,813 (n=147)	22,014 (n=21)
Continence	23,256 (n=73)	19,777 (n=13)	29,245 (n=86)	31,130 (n=19)
Physical health	16,596 (n=252)	18,700 (n=15)	22,819 (n=22)	22,687 (n=15)
Drugs	16,963 (n=220)	15,775 (n=18)	22,734 (n=214)	21,778 (n=18)
Psychotic symptoms	17, 805 (n=46)	15,663 (n=19)	23,511 (n=42)	25,606 (n=15)
Psychological distress	15,390 (n=91)	16,071 (n=44)	24,458 (n=85)	17,088 (n=30)
Information	17,670 (n=67)	12,019 (n=46)	19,131 (n=27)	14,313 (n=17)
Deliberate self-harm	16,998 (n=5)	12,416 (n=4)	14,581 (n=4)	n/a (n=0)
Accidental self-harm	18,304 (n=106)	14,957 (n=21)	23,617 (n=107)	17,904 (n=8)
Abuse/neglect	25,455 (n=15)	13,835 (n=1)	7,967 (n=3)	n/a (n=0)
Behavior	20,573 (n=18)	29,276 (n=7)	30,008 (n=28)	19,817 (n=11)
Alcohol	13,272 (n=15)	19,515 (n=6)	13,588 (n=11)	15,955 (n=1)
Company	19,207 (n=80)	18,274 (n=102)	25,605 (n=114)	19,384 (n=62)
Intimate relationships	17,789 (n=22)	16,722 (n=15)	29,962 (n=10)	17,836 (n=4)
Money/budgeting	16,935 (n=305)	23,881 (n=6)	22,196 (n=286)	33,216 (n=2)
Benefits	23,284 (n=2)	14,590 (n=35)	23,609 (n=41)	22,468 (n=26)