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Caregiver Preferences and Willingness-to-Pay for Home Care Services for Older People with Dementia: A Discrete Choice Experiment in the Milan Metropolitan Area

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HIGHLIGHTS

- Older people with dementia in Italy are often cared for at home.

- This survey elicited the preferences of informal caregivers about home care services.

- The most valued item was mixed health and social care.

- This study can inform the implementation of policies in the field of dementia.

Caregiver Preferences and Willingness-to-Pay for Home Care Services for Older People with Dementia: A Discrete Choice Experiment in the Milan Metropolitan Area

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ABSTRACT

Objectives. Dementia is a major health and social care challenge in high-income countries where most people are cared for in their own homes. This study aimed to elicit caregivers' preferences for alternative bundles of home care services in the Milan metropolitan area.

Methods. A binary discrete choice experiment was administered to a sample of informal caregivers of people with dementia recruited through a network of non-profit organizations. The experiment included four attributes: 1) number of home care hours per month; 2) type of

care; 3) caregiver peer support group organization; 4) monthly family's cost (in euros), each articulated into three levels. A mixed logit model was used to analyze the responses using Stata.

Results. A total of 93 self-administered questionnaires were collected in January-April 2023. Two thirds of both caregivers (67.7%) and care recipients (65.6%) were female, with a mean age of 59.0 (±12.1) years and 82.2 (±6.5) years, respectively. The experiment showed that increased home care hours, mixed health and social home care, caregiver meetings with professional support and lower monthly costs were mostly valued by caregivers. Some preference heterogeneity was detected in relation to care recipient's characteristics (e.g., age).

Conclusions. These results are expected to inform policymakers about caregivers' priorities in the field of dementia based on the values placed on hypothetical public home care services. *Keywords*: dementia; caregiver; home care; Milan; discrete choice experiment; preferences.

1. BACKGROUND

Dementia has become a major health and social care challenge worldwide, with nearly 10 million new cases per year and a prevalence of 55 million. Alzheimer's disease is the most common form accounting for 60-70% of all dementia cases.[1] More than half (around 60%) of people with dementia are cared for in their own homes for as long as possible and most of this care is provided informally by family members.[2,3] The 'aging in place' approach has been adopted internationally and oriented to helping older people in remaining in their own homes and keeping relationships within their local community. The drivers behind this policy have been the high costs of residential and nursing homes, but also preferences expressed by people for aging in their home.[4] The existence of a family caregiver is a key determinant in

implementing such an approach; for example, having a co-resident caregiver can reduce by twenty times the risk of transition into residential care.[5]

However, the home care approach inevitably results in a redistribution of care work from residential to community setting, and especially in higher workload, financial burden, and responsibilities in charge of families.[6] The quality-of-life of family caregivers of people with dementia is generally compromised, and half of dementia costs are attributable to informal care.[1] The literature showed that caregivers are likely to experience major health and financial issues due to their caring role, also considering that most caregivers are older, retired and physically frail themselves.[7] The mental health deterioration among family members of people with dementia was exacerbated by the Covid-19 pandemics when 90% of informal caregivers in Italy reported to have at least one symptom of distress such as concerns or anxiety.[8]

Health and social services traditionally tend to prioritize the needs of the sick person over the carer's ones but policies to support family caregivers have been implemented in recent years,[6] based on the awareness that without their work the formal care system would collapse.[7] Indeed, various forms of home care support ranging from healthcare and psychosocial interventions to disability allowance and other types of monetary benefits have been delivered in different countries.[2] In the UK, for example, carer's allowance can be provided to people who spend at least 35 unpaid hours per week looking after someone else.[9]

In Italy, there are about 14 million people aged above 65, of which one third is affected by chronic conditions or multimorbidity.[10,11] The number of people living with dementia is about 1.2 million but is expected to increase to up to 1.6 million cases by 2030 because of the aging population.[12] Several monetary and non-monetary measures are in place to support people aged above 65 and/or disabled and their families. A universal national allowance (*Indennità di*

Accompagnamento, EUR 527.16 in 2023) is granted to non-self-sufficient people (including those living with dementia), irrespective of their income level (by Law 18/1980). To help informal caregivers in reconciling their work with caring duties, Law 104/1992 grants three days of paid leave each month, and an extraordinary leave of up to 2 years, to employed people who assist family members with disabilities. In Lombardy, 'measure B2' is a monthly social voucher (ranging between €400 and €800) aimed at ensuring full permanence of frail people in their home and life context.[13] Regarding in-kind services, the National Health Service (NHS) guarantees home care to frail and disabled people through the provision of medical, rehabilitation and nursing services. The service cost is 50% each covered by NHS and municipalities, although a means-tested co-payment may be required to users. Home care is supplemented by social interventions provided by each Municipality, based on a multidimensional assessment of the person's needs.[14] Large variations exist, indeed, in the level of additional resources devoted by individual Regions and municipalities,[15] as well as in the type of public services delivered. The Municipality of Milan provides a wide range of initiatives targeting frail older people: social home care, daycare centers, Alzheimer Cafés, and meeting centers.[16] These services can be provided either free of charge or under symbolic payment that is progressive on families' income. However, municipal initiatives reach only a limited number (less than 3%) of the target beneficiaries,[17] questioning their ability to respond to the needs of a rising demand. Moreover, extant services for older people with dementia are limited and unspecific, being part of more generic interventions for frail people, while the support to caregivers is still limited to the benefits from Law 104/1992 on work-life balance. In 2014, the Parliament approved the first Italian National Dementia Plan, which promotes several actions in favor of people with dementia and their caregivers. These actions relate to four areas: supporting dementia prevention, developing clinical guidelines, mapping and monitoring public services, and improving family empowerment and quality-of-life. The Plan

was assigned with a 15 million euros endowment for the period 2021-2023 but requires formal adoption from every region, which should implement it accounting for context-specific issues.[12] Despite the intentions, in 2021 only 12 out of 21 regions had adopted the Plan,[18] showing how the system is still far from developing adequate responses to dementia.

Ultimately, several policies are being implemented to help older people with dementia (and their families) in remaining and being assisted at home, but there is limited evidence about user acceptability and preferences for different types of home care support,[2] especially in Italy. The discrete choice experiment (DCE) is a stated preference technique that has been widely applied in health economics to quantify patients' preferences for healthcare interventions, products, services, or policies. In a DCE, people are required to select their preferred option from a choice set including two (or more) alternatives.[19,20] This study used a DCE to elicit informal caregiver preferences and willingness-to-pay (WTP) for alternative hypothetical bundles of public home care services for older people with dementia and their caregivers living in the Milan metropolitan area (Italy).

2. METHODS

2.1 Sample recruitment and data collection

A DCE was included in a larger survey that involved a sample of informal caregivers recruited through a network of non-profit organizations. The target participants were unpaid caregivers (e.g., family members, friends) of people aged above 60 with various types of dementia (e.g., Alzheimer) and living in Milan or neighboring areas. The participants had to report a formal diagnosis of dementia or at least clear symptoms of cognitive decline of their care recipient. The self-administered questionnaire in Italian was delivered either by email or manually by the recruiting centers, filled in entirely anonymously and redelivered either digitally or on paper. The questionnaire also included two quality-of-life instruments:

CarerQoL-7D for caregivers and EQ-5D-5L (proxy version) for care recipients. The utility values were computed from the two questionnaires using UK tariffs and the Italian value set, respectively.[21,22] The participants were rewarded with a 30-euro supermarket voucher to be spent in Lombardy. The study received ethical approval on December 19th, 2022 (code: FA000508.01). The survey was conducted between January and April 2023.

2.2 Selection of attributes and levels

Four attributes articulated into three levels each were included in the experiment based on literature review, prior interviews with caregivers, and expert opinion. In detail, we first conducted searches by title/abstract in PubMed in March-April 2023 using as keywords 'discrete choice experiment', 'preferences', 'willingness-to-pay', 'Alzheimer', 'dementia', 'older people', 'home care'. In total, we reviewed eight DCEs that investigated preferences in the field of home care or long-term care for older people with (or without) dementia [2,3,6,23-27]. Second, we questioned a small sample (n=11) of family assistants living in Milan (and neighboring areas) on their priorities and unmet needs in relation to home care for their loved ones. Lastly, we organized an online focus group with a geriatrician and several social care professionals working for non-profit organizations involved in this study to gather their expert opinion and ensure that the attribute/levels identified were realistic enough and describing services that could be included in the regional provision. In synthesis, building on the elements emerged from the literature, we used interviews and experts' opinions to tailor them to the local context. The final selection of attribute and levels is reported in Table 1 and includes: 1) the number of professional home care hours per month; 2) the type of care provided (i.e., health, social, mixed); 3) the caregiver peer support group (i.e., none, among caregivers only, with also professional support); 4) the monthly family's co-payment (€).

The questionnaire provided the list of all attribute levels together with accompanying information. In detail, the number of home care hours are those formally provided at the older

person's place by qualified professionals. Home care is considered health care when predominantly oriented to health needs (e.g., administration of medicines, management of medical aids, motor and neuromotor rehabilitation, etc.), and social care when mainly targeting social and relational needs (e.g., socialization, entertainment, education, etc.); the balanced care is intended as a mix between the two types of assistance previously described and provided by an interdisciplinary team of health and social care professionals. Peer support groups are described as periodic meetings between caregivers to provide mutual help and share useful information relating to care for the older person. In the experiment, we distinguished between informal group (i.e., meetings between caregivers only) and group with professional support (i.e., caregiver meetings with various professionals – psychologists, social assistants, neurologists, lawyers, etc. - attending in turn). Lastly, the cost attribute refers to an ideal contribution the participant is requested to pay to benefit from the service package described by the non-monetary attributes. The inclusion of the cost attribute allowed us to estimate the monetary value of each remaining attribute, i.e., the marginal WTP for a discrete change in the level of a given attribute. In addition, we specified that such a hypothetical bundle of services should be considered additional to (and not a substitute of) those currently offered by the public health and social sector in Lombardy as well as other types of assistance families may benefit from (e.g., paid home assistant).

2.3 Experimental design

From a full factorial design involving 81 different scenarios (i.e., 3 levels ^ 4 attributes), a fractional factorial design was derived to reduce the number of possible combinations and generate an appropriate number of choice sets using Ngene software.[27,28] We opted for an optimal orthogonal in the differences (OOD) design (D-optimality: 100%) that shows the advantage that attributes never take the same level within the same choice set so that the differences across alternatives are maximized and participants are forced to trade on all

attributes.[29] Thus, we created nine choice sets each including two unlabeled alternatives (A and B) described by different combinations of attribute-levels and representing hypothetical service packages for people with dementia and their caregivers. We did not include a 'zero-cost' option due to the difficulties in defining a 'status quo' in a context of very heterogeneous and even lacking social care service provision. Moreover, the forced choice nature of the task revealed how participants made trade-offs between attributes-levels when making their choice. An example of choice task is shown in Figure A1. The final version of the questionnaire was pilot tested in a small sample of caregivers. A minimum number of 83 respondents was identified using the 'rule of thumb' according to the formula: $N > 500c/(t \times a)$, where c is the maximum number of levels per attribute, t is the number of choice tasks, and a is the number of alternatives.[19]

2.4 Statistical analysis

A mixed logit model for panel data (*cmxtmixlogit*) was used to analyze the total choices, explore differences in preferences across subgroups, and calculate WTP post-estimation. The are other econometric models such as the latent class model that, liked the mixed logit, demonstrated to allow the analyst to collect a rich variety of information about behaviors from panel data[30]; however, we opted for the mixed logit that is the most used model (in 39% of DCEs published in 2013-2017) for analyzing preference data in health economics[20]. This model is recommended for DCEs since it accounts for the panel data structure, provides more reliable standard errors and accounts for unobserved preference heterogeneity by allowing coefficients to vary randomly across individuals.[31] The random parameters for all attribute-levels were estimated assuming a normal distribution. The quantitative attributes (i.e., hours and cost) were treated as numerical variables, while qualitative attributes (i.e., type of home care and caregiver support group) were coded as dummy variables. The model coefficients (sign and value) indicate the direction and magnitude of influence of each attribute-level. A p-

level ≤0.05 was considered statistically significant. However, the full model with all attribute levels was included, irrespective of statistical significance. The WTP for non-monetary attributes was calculated as the ratio of cost coefficients and the other attributes coefficients. We also run an extended model including interaction terms between attribute-levels and socio-demographic characteristics to examine the determinants of preferences' heterogeneity. The relevant interactions were included based on univariate screening and backward selection (p ≤0.05). Log-likelihood, Akaike information criterion (AIC) and Bayesian information criterion (BIC) were computed to assess the fit of different models. All the analyses were performed using Stata 17 (StataCorp). Moreover, we calculated the number of dominant preferences (i.e., always choosing the alternative with the best level of a given attribute) to explore the extent to which respondents traded-off attribute-levels in the experiment.[32]

3. RESULTS

3.1 Sample's characteristics

A total of 108 questionnaires were collected but 15 were uncomplete and thus excluded from the analysis. The final sample's characteristics (n=93) are reported in Table 2, while the caregiving situation is shown in Table A1.

Two thirds (67.7%) of caregivers were female; the mean age was 59.0 (±12.1) years. Most were children (65.6%) or spouses (23.7%). They lived with the care recipient in 36.6% of cases. The great majority (85.0%) provided informal care on an ongoing basis throughout the year (on average, five days a week and eight hours a day), and almost half (45.2%) performed more than ten different caregiving tasks (e.g., meal preparation, personal hygiene, bureaucracy, companionship). Over half had a job (57.0%) and at least one chronic condition (58.1%).

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The mean age of people with dementia was 82.2 (±6.5) years; around two thirds (65.6%) were female. The great majority (91.4%) had at least one child. Half had also a paid caregiver (50.5%) and/or could rely on the support of another family member (61.3%). The mean time since dementia diagnosis was 3.0 (±2.8) years, and most (89.2%) were affected also by other chronic conditions (mainly cardiovascular diseases, 55.9% and depression, 39.8%). The mean CarerQoL-7D and EQ-5D-5L utility values were 62.6 (±20.1) and 0.28 (±0.3) for caregivers and care recipients, respectively.

3.2 Caregiver's preferences

The DCE results showed that increased home care hours, mixed health and social care, caregiver groups with professional support and lower co-payment per month were mostly valued by caregivers of older people with dementia (Model 1, Table 3). The most preferred attribute-level was mixed health and social care, for which the average WTP was estimated at €290, followed by caregiver groups with professional support, for which the average WTP was about €171 (Table 4). No dominant preferences were identified in relation to any attributes. Preference heterogeneity was detected in relation to care recipient's characteristics only. In detail, caregivers of very elderly people (aged above 80) expressed higher preferences for groups with professional support, participants caring for a woman expressed lower preferences for home health care, and participants caring for a person with a lower quality-of-life (EQ-5D-5L index value < 0.3) expressed higher preference for increased professional home care hours and home care of healthcare type (Model 2, Table 3). According to AIC, Model 2 offered a better fit than Model 1.

4. DISCUSSION

Following the widespread 'aging in place' paradigm, most older adults wish to stay at home during their late life years, relying on family caregivers or home care services to perform their daily activities.[4] Also in Italy, almost all people over 65 live at home with various forms of support. However, the available take up rates of public interventions supporting home staying are quite low, especially for in-kind services. For example, only 12.5% of over 65 receive the universal national allowance,[33] 6.2% benefit from home care with health support,[34] and less than 1% from home care with social support.[35] Indeed, older people experiencing difficulties in personal care mainly ask for support from family caregivers (84.4%), followed by paid caregivers (35.8%), and others (12.3%).[11] The precise number of informal caregivers at national level is unknown but recent estimates reported on around 2.8 million people aged 18-64 years who provide unpaid ongoing assistance to sick, elderly or disabled family members.[36] Eventually, in Italy more than elsewhere, there is a mixed welfare system in which the State, not-for-profit organizations, families, and the market play complementary roles over time.[37]

Despite the large predominance of people aging at home, the acceptability and implications of this care model, especially for family caregivers, are largely unknow. Previous research in Italy has tried to explore family caregivers' needs and the role of public solutions in answering to those needs. Recent studies illustrated how caregivers require support in balancing daily and caregiving activities, finding limited (if not absent) response in public initiatives.[38,39] The current study reports on the first survey that used a stated preference technique (i.e., DCE) to explore public preferences for alternative home care service packages for people with dementia in Italy. As the cognitive demands required by a DCE are unfulfillable by people with dementia,[27] we surveyed their family assistants. In our sample, around two thirds of caregivers and care recipients were female, in line with international data

showing that dementia disproportionally affects women both directly (as patients) and indirectly (as carers), as they provide 70% of care hours for people living with dementia worldwide.[1] Moreover, welfare systems are neither neutral nor impartial regarding models of family organization and power relations between genders.[40,41]

Overall, in our study, the participants expressed higher preference for additional professional home care hours, mixed health and social care, and caregiver groups with professional support. Cost had significant impact on caregiver's choices with less expensive service packages being preferred. These results are aligned with our expectations about the direction of preferences for each attribute. Similarly, in two previous experiments conducted in Ireland to elicit public preferences for home care services to people with dementia and support policies for family carers, increased home care hours per week and caregiver peer support groups were highly valued by citizens.[3,6]

The study results also indicated the existence of some heterogeneity in preferences. The strength of preferences for caregiver groups with professional support was greater for caregivers of very elderly people (above 80), who are likely to benefit more from professional health, psychological and legal counselling. Also, caregivers of people with low levels of quality-of-life expressed higher preference for increased home care hours and predominantly of healthcare type. This is not surprising, since the EQ-5D is a standard measure of the self-perceived general health status (in this case, the older person's status as proxy-reported by his/her caregiver). The lower preference expressed by caregivers of females (compared to those caring for a man) for home services of healthcare type can be explained by the fact that caregiving tasks that require physical strength, such as personal hygiene or management of medical devices (e.g., sanitary pads, walkers), are relatively easier if the person being cared for is a woman. This is especially true when the caregiver is a woman, as in two thirds of our sample. Moreover, elderly women are more likely to experience loneliness due to their longer

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life expectancy and the increased value they place on personal relationships.[42] Therefore, they might require more social and psychological support including companionship and recreational pursuits (i.e., the home care of social or mixed type in our experiment). Indeed, in our study higher EQ-5D severity levels of anxiety/depression were reported for female than for male care recipients (34% vs. 26% of severe or extreme problems).

In interpreting the study findings, some limitations should be acknowledged. First, the sample size (n=93) is quite small. Of the 108 caregivers approached, 13.8% returned an incomplete (or empty) questionnaire and were excluded from the analysis. This might be due to participant's difficulties in understanding or accepting the task. However, around one third of DCE studies enroll less than 100 participants,[19] and the literature review informing this experiment retrieved one study enrolling 28 carers only.[24] Second, the sample was recruited through a network of service providers and thus included a high percentage of graduated and/or employed people with privileged access to assistance and more likely to participate in surveys (i.e., selection bias). This issue also affected previous DCEs conducted in comparable countries where, for example, the percentage of participants with third level education was twenty percentage points higher than the national average.[6] Third, as DCEs are conducted through hypothetical scenarios, there is potential for hypothetical bias i.e., the preferences and WTP estimates may not accurately reflect real-life choices or behaviors.[6] Fourth, the design of DCEs usually implies a trade-off between reality and feasibility. In this study, the inclusion of additional attributes (e.g., personalization of care, respite care for caregivers) would create more articulated scenarios but also result in an excessively cognitively demanding choice task. Therefore, the number of selected attributes was aligned to that of previous DCEs in health economics, which included 4-5 attributes in around 40% of cases.[20] Fifth, caregiver's preferences elicited through a cross-sectional survey might change over time following the

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evolution of care recipient's disease (dementia is a progressive disorder) or family situation, or to new public policies in the elderly care.

The literature raised various concerns in relation to the use of DCEs to obtain WTP, as the estimates for marginal WTP are sensitive to variables such as the range specified for the monetary attribute, the presence (or absence) of a zero-cost option, and the econometric model applied [43]. Moreover, these estimates cannot be interpreted as real WTP estimates because they are not related to personal income and respondents are not bound by the choices they make, due to the stated preference or hypothetical nature of the choice task[44,45]. Moreover, this study presented paired scenarios without opt-out or status quo options, which are generally required to ensure that the choices respondents faced were realistic and to derive theoretically reliable estimates of WTP. In the absence of these options, the WTP results are mere estimates of the relative utility of the attribute-levels of services and not an indication of the amount people would pay in the real world [26, 46]. Therefore, they have very limited external validity and should be interpreted cautiously only within the experiment's forced choice context. However, there are several reasons why we did not include an opt-out choice option. In Italy, in the field of home care services for people with dementia, there is no standard of care. Therefore, in the absence of a full understanding of what a status quo/opt-out option would mean to respondents, it was deemed unrealistic or unfeasible to include it. This issue also emerged from many other DCEs that also obtained WTP estimates[26,27,46-52]. For example, Nieboer et al. derived WTP estimates for long-term care services without including an 'opt-out' option because in real life people in urgent need of long-term care are also forced to select one of the available options[26]. In the period 2013-2017, two thirds (64%) of the DCEs in healthcare did not include a status quo/opt-out[20]. Moreover, as the DCE was included in a larger survey and presented 9 choice tasks, adding an opt-out option to each choice task would have increased task complexity and potentially decreased survey response

rate and the accuracy of responses. The inclusion of an opt-out option also decreases statistical efficiency, especially with a small sample (93 respondents), because trade-offs between attribute-levels do not emerge when respondents opt out and the reason for this choice is not acquired. Lastly, it is unknown to what extent estimates for WTP would change in the presence of opt-out or status quo choice options[46].

The aging in place model is prevalent worldwide, also due to the diffusion of technologies such as active/ambient assisted living robots that support independent living at different stages of aging.[53] However, increasing physical disabilities, cognitive impairment and autonomy loss may force older people over time to move to a more supportive environment,[53,54] which is usually a residential care facility. In Italy, only 1.8% of older people live in nursing homes or long-term care facilities,[55] and this proportion increases with age (6.3% above 85 years). The number of long-term care beds (in institutions and hospitals) per 1,000 population aged above 65 years in Italy was 21.8 versus 45.6 on average in OECD34 in 2021,[56] thus is unlikely to satisfy fully the potential demand. In 2022, indeed, in the face of 66,000 nursing home beds there were almost 71,000 older people waiting admission in Lombardy.[57] However, residential care is not the only alternative to home care. In several parts of the world, new care models have rapidly appeared, which indicates that existing ones might not entirely satisfy the complex needs of current and new generations of older people. In Scandinavian countries, the senior housing model aims to provide an affordable, safe and 'age-friendly' environment that encourages and enables residents to be physically and socially active, by promoting well-being and healthy aging.[58] However, there are several barriers to delivering appropriate community environments for people living with dementia. Indeed, as they usually require continuous caregiving, the social housing would displace both the older person and the caregiver, who is often of working age, to satellite towns or suburban neighbourhoods where social connections and access to services and urban

equipment are difficult.[59] The experience of senior housing in Italy is still very limited, and more evidence is required to understand whether it can be considered an effective alternative model to traditional care arrangements.

This study revealed some key messages that might inform current and future policy agenda in Lombardy (and elsewhere). First, it is unrealistic to change a care model that still largely relies on family caregivers but that there is a strong need to support them, as there are social risks associated with prolonged caregiving tasks.[60] Public resources dedicated to home care services should be integrated within the existing social care system to provide also "respite" to family assistants (e.g., more professional home care time translating into more time away from care duties) or adequate training to play their difficult role and navigate within the complex service network (e.g., attending mutual help groups or receiving guidance from professionals). Second, families may be willing to contribute to public expenditure for these additional services, possibly differentiating their monetary contribution based on income levels, although no definitive conclusions can be drawn on the WTP in the absence of a zero-cost status quo option. Third, there is a need for personalizing care support programs according to different caregiving situations (e.g., based on family income and caregiver or care recipient's characteristics), thus progressively abandoning the typical standardized approach to elderly care.

5. CONCLUSION

This study is expected to provide relevant information to policymakers to design public home care services for people with dementia and their informal caregivers according to priorities and values placed on alternative hypothetical interventions. In particular, participants expressed the need for tailored home support, including specialized training for family assistants. The results also suggest looking at the family context as a microcosm where

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composite strategies are devised to balance interdependence, solidarity, and intergenerational obligations. Future research could investigate caregiver's preferences in relation to alternative care settings such as residential care or senior housing.

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Table 1. Attributes and levels.

Attributes	Level 1	Level 2	Level 3
Professional home care hours (per month)	15	30	45
Type of home care	Social	Health	Mixed
Caregiver support group	Not organized	Among caregivers only	With professional support
Family co-payment (per month)	€130	€260	€390

Table 2. Sample's characteristics (n=93).

		Caregiver	Care recipient
Age (mean ± SD; years)		59.0 ± 12.1 (28; 86)	82.2 ± 6.5 (64; 94)
Age group (years)	≤40	4 (4.3)	0
	41-60	59 (63.4)	0
	61-80	26 (28.0)	28 (30.1)
	>80	4 (4.3)	62 (66.7)
	Missing	0 (0.0)	3 (3.2)
Gender			
	Male	30 (32.3)	30 (32.3)

	Female	63 (67.7)	61 (65.6)
	Missing	0 (0.0)	2 (2.1)
Marital status			
	Single	19 (20.4)	3 (3.2)
	Married	66 (71.0)	41 (44.1)
	Divorced	6 (6.5)	3 (3.2)
	Widow/Widower	2 (2.1)	44 (47.3)
	Missing	0 (0.0)	2 (2.1)
Parental status			
	Children ≥ 18 years [1]	59 (63.4)	85 (91.4)
	Children < 18 years [1]	16 (17.2)	/
	No children	22 (23.6)	6 (6.5)
	Missing	0 (0.0)	2 (2.1)

Table 2 (cont.). Sample's characteristics (n=93).

		Caregiver	Care recipient
Educational level			
	Compulsory	7 (7.5)	67 (72.0)
	High school	53 (57.0)	18 (19.4)
	Academic degree (or higher)	33 (35.5)	6 (6.4)
	Missing		2 (2.1)
Employment status			
	Employed	38 (40.9)	/

	Self-employed	15 (16.1)	/
	Pensioner	23 (24.7)	/
	Unemployed / Housewife	6 (6.4)	/
	Other	11 (11.8)	/
Annual household income			
	< €20,000	10 (10.7)	43 (46.2)
	€20,000- €40,000	48 (51.6)	25 (26.9)
	> €40,000	24 (25.8)	2 (2.1)
	Included in caregiver's	/	15 (16.1)
	Prefer not to say	10 (10.8)	6 (6.4)
	Missing	1 (1.1)	2 (2.1)

Table 2 (cont.). Sample's characteristics (n=93).

		Caregiver	Care recipient
Time since diagnosis			
	< 3 years	/	25 (26.9)
	3-6 years	/	31 (33.3)
	> 6 years	/	16 (17.2)
	Unknown	/	20 (21.5)
	Missing	/	1 (1.1)

Chronic conditions	Yes, of which [1]:	54 (58.1)	83(89.2)
	Arthritis	7 (7.5)	18 (19.3)
	Cancer	3 (3.2)	5 (5.4)
	CVD	25 (26.9)	52 (55.9)
	Depression	7 (7.5)	37 (39.8)
	Diabetes	5 (5.4)	16 (17.2)
	No	39 (41.9)	8 (8.6)
	Missing	0 (0.0)	2 (2.1)
CarerQoL-7D tariff		62.59 ± 20.1 (3.1; 95.9)	/
CarerQoL-VAS		4.70 ± 1.91 (0; 9)	/
EQ-5D-5L index value		/	0.279 ± 0.32 (-0.512; 0.855)
EQ-VAS		/	47.62 ± 22.90 (0; 95)

[1] multiple answers allowed

Table 3. Results from mixed logit model.

		Model 1				Model 2			
		Coef.	SE	p-value	95% CI	Coef.	SE	p-value	95% CI
Professional home care hours (per month)	Mean	0.0191	0.007	0.004**	0.0059, 0.0323	0.0065	0.009	0.474	-0.0113, 0.0242
	SD	0.0425	0.010		0.0271,	0.0429	0.010		0.0272,

					0.0666				0.0677
Type of home care									
Social (ref.)									
Health	Mean	0.0131	0.209	0.950	-0.3966, 0.4228	0.3036	0.385	0.431	-0.4516, 1.0587
	SD	1.4953	0.305		1.0024, 2.2304	1.4592	0.308		0.9644, 2.2080
Mixed	Mean	1.0826	0.184	0.000***	0.7210, 1.4442	1.0965	0.188	0.000***	0.7274, 1.4656
	SD	0.4072	0.389		0.0627, 2.6429	0.5103	0.345		0.1356, 1.9197
Caregiver support group									
Not organized (ref.)									
Among caregivers only	Mean	-0.1032	0.145	0.476	-0.3872, 0.1809	-0.1059	0.150	0.481	-0.4001, 0.1883
	SD	0.511	0.29		0.1652	0.543	0.28		0.1957

30

		1	4		, 1.5810	9	4		, 1.5117
With professional support	Mean	0.6392	0.164	0.000***	0.3169, 0.9616	0.1242	0.236	0.599	-0.3388, 0.5873
	SD	0.6735	0.264		0.3119, 1.4543	0.5226	0.291		0.1756, 1.5555

*p<0.05 **p<0.01 ***p<0.001

Table 3 (cont.). Results from mixed logit model.

		Model 1				Model 2			
		Coef.	SE	p-value	95% CI	Coef.	SE	p-value	95% CI
Family co-payment (€ per month)	Mean	-0.0037	0.001	0.000***	-0.0052, -0.0023	-0.0039	0.001	0.000***	-0.0054, -0.0023
	SD	0.0035	0.001		0.0019, 0.0067	0.0039	0.001		0.0021, 0.0071
Age (care recipient) * Professional						0.8171	0.299	0.006**	0.2320, 1.4023
Female (care recipient) * Health						-1.0839	0.438	0.013*	-1.9433, -

31

								0.2246
Low QoL (care recipient) * Hours					0.0280	0.013	0.036*	0.0018, 0.0542
Low QoL (care recipient) * Health					0.9167	0.422	0.030*	0.0888, 1.7445
Log-likelihood	-481.3				-460.0			
AIC	988.6				954.0			
BIC	1050.1				1034.1			

*$p<0.05$ **$p<0.01$ ***$p<0.001$

Table 4. Willingness-to-pay (WTP) estimates.

	Coef.	SE	p-value	95% CI
Professional home care hours (per month)	5.1301	1.906	0.007**	1.3937, 8.8664
Type of home care				
Social (ref.)				
Health	3.5090	56.038	0.950	-106.32, 113.34
Mixed	290.19	60.763	0.000***	171.10, 409.28
Caregiver support group				
Not organized (ref.)				
Among caregivers only	-27.66	38.634	0.474	-103.38, 48.06
With professional support	171.34	49.509	0.001**	74.31, 268.38

** $p<0.01$; ***$p<0.001$