

Economic Burden and Health-Related Quality of Life Among Older People with Dementia Living at Home and Their Informal Caregivers in the Milan Metropolitan Area

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BACKGROUND

- ❑ Dementia is a leading cause of dependency and mortality in older populations. The number of people living with **dementia worldwide** is above **55 million**, and nearly 10 million new cases are diagnosed each year (WHO). In **Italy**, **1.3 million** people lived with **dementia** in 2018, but this number is expected to increase up to **1.5 million** cases by 2025 [1].
- ❑ The **Italian national costs** of **dementia** are estimated to be **€15.6 billion** per year, of which **≈80%** are incurred **by families** [1]. Dementia causes a **significant impairment** of health-related **quality of life (QoL)** of people affected but also of their **caregivers**, who experience physical, emotional, and financial **problems** from long-term and intensive caring tasks [2].
- ❑ In **Milan**, where the number of residents living with dementia was estimated at about **28,600** people in 2022, a range of **public interventions** are provided to support the home care of older and/or severely disabled residents including both **in-kind services** (e.g., home health and social care, daycare centres, and meeting centres) and **monetary transfers**.

RESEARCH OBJECTIVES

This study investigates the **socioeconomic burden** and **quality-of-life (QoL)** of people with **dementia** and their **informal** (unpaid) **caregivers** in the **Milan** metropolitan area.

METHODS

A cross sectional survey was conducted between January and April 2023 using a **self-administered caregiver questionnaire**. The questionnaire was composed by two sections: a) a **35-item cost-of-illness** questionnaire aimed to quantify the consumption of health and social care resources and the related dementia's costs including family's **out-of-pocket costs** and caregiver's **productivity losses** in the last 12 months; b) a **quality-of-life (QoL)** section including the **EQ-5D-5L (proxy version)** about the person with dementia, applying the Italian scoring algorithm to convert caregiver's responses to the descriptive system onto an index value [3], and the **CarerQoL-7D** on caregiving situation, applying UK tariffs to calculate care-related utility scores [4]. A generalized linear model (**GLM**) was used to identify the variables associated with costs (gamma distribution) and QoL (normal distribution).

RESULTS

A total of **107 questionnaires** completed by **family caregivers** were collected. Most **caregivers** were **female (68%)**, **children** of the care recipient (**65%**), and **employed (68%)**; their mean age was **59.1±11.8 years**. **86%** of caregivers reported a continuous engagement in caregiving; **36%** lived with the care recipient and **33%** within 1 km away from care recipient's house. Most **older people** with dementia were **female (65%)**, with a mean age of **82.2±6.9 years**, and **47%** received support also by a **paid home care worker**.

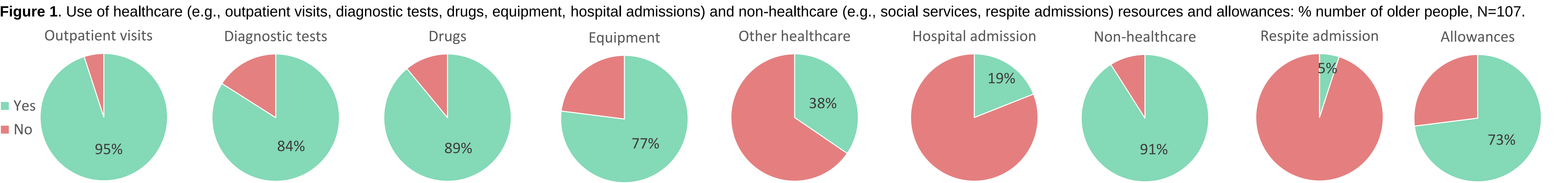


Figure 2. Mean healthcare and non-healthcare service costs (€) by public sector and families compared to mean monetary transfers (€, public and private allowances) in the previous 12 months, N=107.

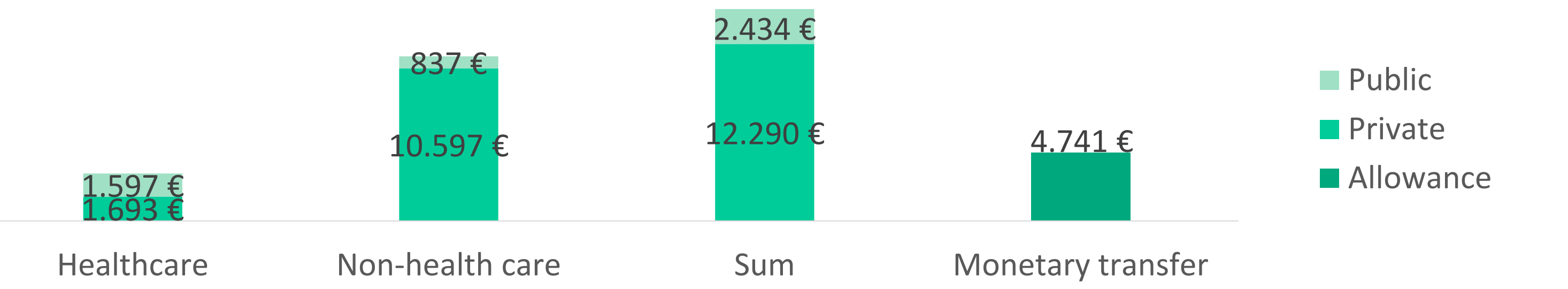


Figure 3. Distribution of levels by EQ-5D-5L dimension for care recipients (proxy-reported), N=107.

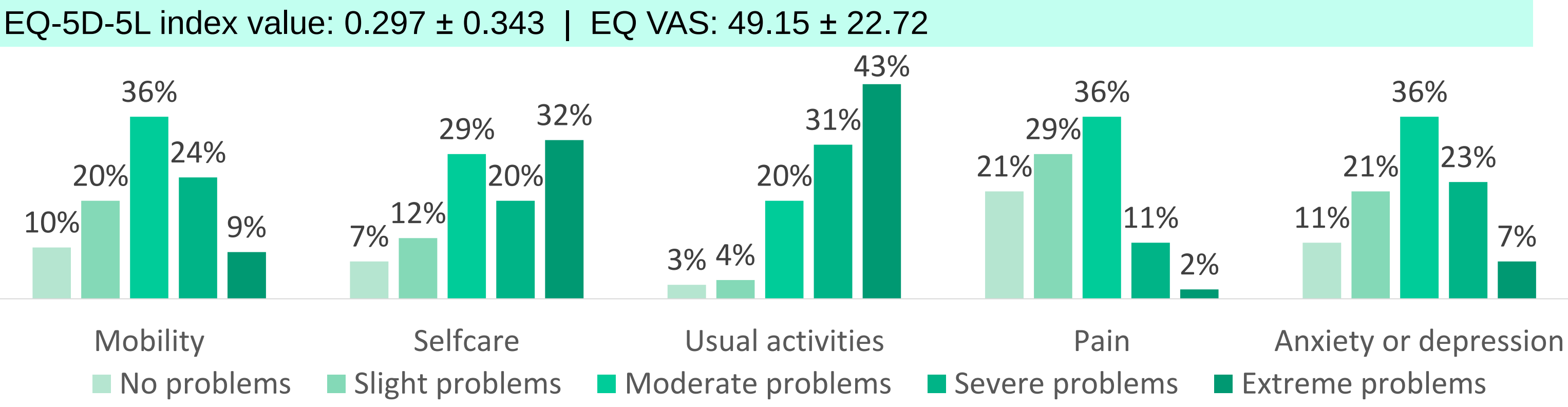
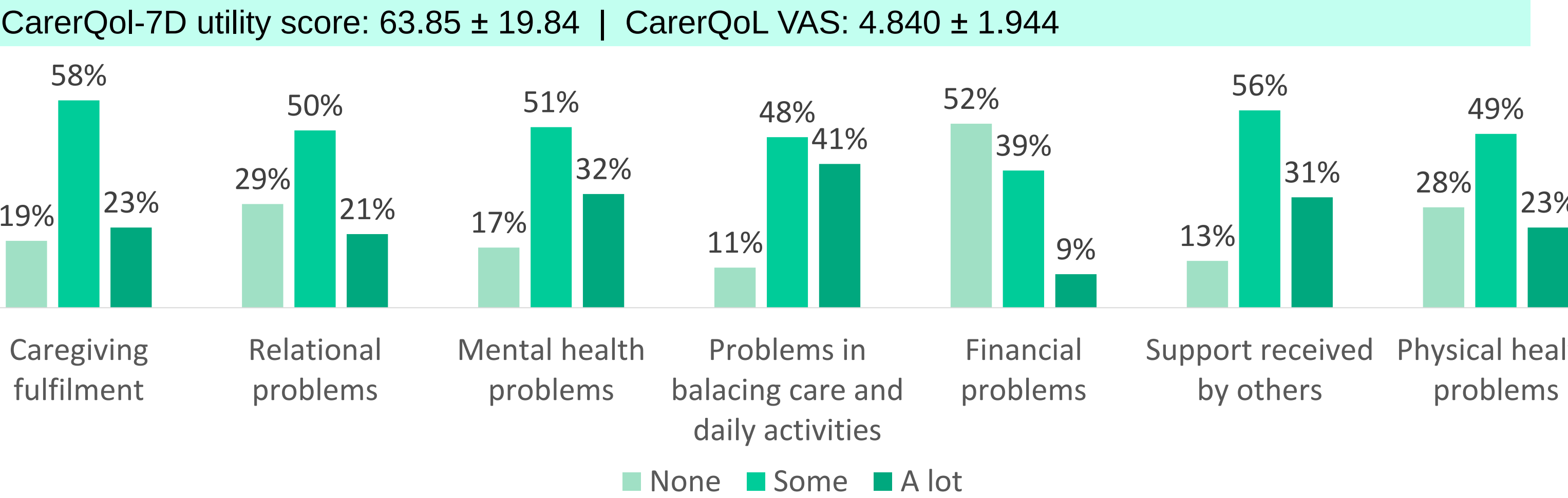


Figure 4. Distribution of responses by CarerQoL dimension for caregivers (self-reported), N=106.



- ❑ Higher levels of **older person's QoL** and higher number of **hours of informal caring** were negatively associated with **total costs**, while **caregiver's age** and **household income** higher than € 40,000 were positively associated with total costs.
- ❑ Higher levels of **older person's QoL** were positively associated with **caregiver's QoL**, while **female caregivers** and those engaged in **continuous caregiving** experienced a worse caregiving situation.

Table 1. GLM (gamma) of total cost (healthcare and non-healthcare).

	Coef.	Robust SE	p-value	95% CI
Care recipient's EQ-5D index value	-14,538.96	3,236.34	0.000***	-20,882.07; -8,195.84
Caregiver's weekly hours of caring	-57.25	22.79	0.012**	-101.92; -12.59
Caregiver's age	169.27	88.87	0.057*	-4.91; 343.45
Caregiver's income: ≥ € 40,000	10,080.71	3,125.78	0.001***	3,954.29; 16,207.13
Constant	8,869.70	4,018.97	0.027**	992.67; 16,746.72
Log-likelihood	-964.90			
AIC	21.08			
BIC	-325.02			

Table 2. GLM (normal distribution) of CarerQoL-7D utility score.

	Coef.	Robust SE	p-value	95% CI
Care recipient's EQ-5D index value	12.18	4.84	0.026**	1.48; 22.89
Caregiver's gender: female	-8.44	3.98	0.033**	-16.21; -0.67
Caregiver's assistance: continuous	-9.07	4.49	0.093*	-17.98; -0.17
Constant	73.91	5.07	0.000***	63.85; 83.97
Log-likelihood	-459.58			
AIC	8.75			
BIC	35,729.95			

AIC: Akaike information criterion; BIC: Bayesian information criterion; CI: confidence interval; Coeff.: Coefficient; SE: standard error; *p<0.10, **p<0.05, ***p<0.01.

DISCUSSION

- ❑ The mean annual economic burden was almost **€ 15,000**, of which the **83.5%** incurred by families. The reduction in caregiver's job productivity was estimated at around **€ 1,755**.
- ❑ The self-reported **caregiving situation** resulted **very difficult** and the **QoL** of **people with dementia**, as proxy-reported by caregivers using EQ-5D-5L, was also **very poor**.
- ❑ The estimated **utility values** could be used in **cost-effectiveness** analyses of new pharmaceutical or social care interventions for dementia patients (and their caregivers).
- ❑ This study showed the complexity of managing **dementia at home**, especially for family caregivers; policy-makers should consider these findings in implementing **long-term policies**.

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