

Costs of Informal Caregiving in Dementia

Custos Associados à Prestação Informal de Cuidados a Pessoas com Demência



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ABSTRACT

Introduction: From a perspective that considers the costs borne by the informal caregiver and the care-recipient, this study quantifies and values the use of health and social services, and the time dedicated to caregiving in dementia situations.

Material and Methods: Sociodemographic information and use of services was obtained from 123 caregiving dyads. Costs with informal care were evaluated and valued considering the Health Sector (health services), Patient/Family Sector (time of caregiving) and Other Sectors (social services, continuous care, other private services). Costs with health and social services considered the paying person; the Patient/Family Sector was valued through the proxy-good method. The costs were calculated per month and the value for 100 dyads.

Results: The total cost of informal care was €61 982.2/month per 100 dyads. The Patient/Family Sector value (€44 030.0/month) contributed with 71.0% of the total costs, Other Sectors with 20.8% (€12 887.4/month), and the Health Sector with 8.2% (€5064.8/month).

Discussion: The obtained value per dyad (€619.8/month) represents 77.5% of their monthly income (median = €800.0; interquartile range = 679.0), which can limit the decision of continuing the care provision at home. Considering the values presented for this specific sample, it is estimated that the exemption of fees in the Health Sector and/or benefits in social services may contribute to a downward estimate of the costs.

Conclusion: Regardless of the complexity in estimating the costs associated with informal caregiving in dementia, this paper provides some insights on the burden they can represent for the family income.

Keywords: Caregivers; Cost of Illness; Dementia; Health Care Costs

RESUMO

Introdução: Sob a perspetiva dos custos assumidos pelo cuidador informal e pessoa cuidada, este estudo pretende quantificar e valorar a utilização de serviços de saúde e sociais, assim como o tempo dedicado aos cuidados prestados em situações de demência.

Material e Métodos: Recolheram-se informações sociodemográficas e de utilização de serviços de 123 díades de cuidados. Os custos foram estimados considerando: Setor Saúde (serviços de saúde), Doente/Família (tempo de cuidados) e Outros (serviços sociais, cuidados continuados, outros privados). A avaliação dos custos do Setor Saúde e Outros Setores considerou a pessoa pagadora; para o Setor Doente/Família aplicou-se o método do bem-substituto. Calculou-se o custo mensal para os utilizadores e o valor para 100 díades.

Resultados: O custo total dos cuidados informais foi de €61 982,2/mês por 100 díades. O valor do Setor Doente/Família (€44 030,0/mês) contribui com 71,0% do custo total; os Outros Setores com 20,8% (€12 887,4/mês), seguido do Setor da Saúde com 8,2% (€5064,8/mês).

Discussão: O valor obtido para cada díade (€619,8/mês) representa 77,5% do seu rendimento mensal (mediana = €800,0; amplitude interquartil = 679,0), o que pode condicionar a continuidade dos cuidados em casa. Em face aos montantes apresentados para esta amostra, estima-se a presença de isenção de taxas moderadoras no Setor Saúde e/ou benefícios na comparticipação das respostas sociais e, como tal, uma estimativa em baixa dos gastos apresentados.

Conclusão: Apesar da complexidade na estimação dos custos associados aos cuidados informais na demência, este artigo ilustra o peso significativo que estes podem alcançar para as famílias.

Palavras-chave: Cuidadores; Custos de Cuidados de Saúde; Custos de Doença Demência

INTRODUCTION

An estimated 50 million people are currently affected by dementia worldwide, with an estimated 82 million in 2030 and almost three times as many (152 million) by 2050. There are almost 10 million new cases of dementia each year worldwide. Approximately €700 billion are the estimated global costs, corresponding to over 1% of the globally produced wealth, including healthcare expenditure, social support and informal care (e.g., loss of income / productiv-

ity).^{1,2} Different EU27 studies have estimated that the costs related to informal care correspond to over 55% of total dementia-related costs.^{3,4}

Informal care refers to regular unpaid care (although informal caregivers may receive some type of nominal payment or social benefit)⁵ provided by someone within the patient's social network, namely a family member, friend and/or neighbour.⁶ In Portugal, even though there are few

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population-based studies with national representativeness, there are some epidemiological data collected in the Northern region showing the relevance of dementia in terms of magnitude.⁷ An estimated 160,287 patients over 60 years of age were affected by dementia in 2013, corresponding to 5.9% of the national population within the same age group, according to the study by Santana *et al.*⁸ According to the OECD's "Health at a Glance 2017" report,⁹ an estimated 205,000 patients were affected by dementia in Portugal with a corresponding number of primary caregivers and families at increased risk of physical burden and psychological distress. This reality will have contributed to the official recognition of the need to develop a national plan for dementia considering not only the needs of patients but also of their caregivers,¹⁰ as well as to the discussion and proposal for the creation of the statute of the informal caregiver.

A 53% increase in the capacity of social responses aimed at older people has been found between 2000 and 2013 in Portugal, corresponding to 95,700 new places, from which 52,700 refer to home care (a 108% growth),¹¹ showing an increasing relevance of supporting this population at home, assuming that this will be associated with family care. However, the awareness of the relevance of informal care in economic terms is more recent in Portugal¹² and is often estimated in terms of the amount that would be charged by a professional (e.g., family helper) in case there was no informal caregiver (IC).³

The role of ICs often means quitting from work or reducing the working hours, moving away from their usual residence or accommodating care recipients (CR) in their own home. These changes usually have a major impact on the family budget. Nevertheless, there are few national studies aimed to understand the scope of this problem at the individual, family and economic levels of society.¹³ Methodological constraints have impaired a sound estimate of the costs, particularly as regards the identification of the best way to analyse the time spent in this activity (e.g., occasional support in activities of daily living *versus* permanent support). In fact, the assessment of costs does not seem to be consensual among researchers, nor is it easy to operationalise, especially when ICs are also responsible for different tasks for the whole household (e.g. domestic care tasks).

This study is part of a community intervention project called "Cuidar de Quem Cuida" (CQC) - empowerment for the intervention with informal caregivers of patients with dementia, with a wide geographical scope (10 municipalities from the Metropolitan Area of Porto: Espinho, Gondomar, Maia, Paredes, Porto, Póvoa do Varzim, Santo Tirso, Trofa,

Vila do Conde, Vila Nova de Gaia).¹⁴ Among other objectives, this is a project aimed to obtain the profile of health and social support service utilisation by the caregiving dyads involved. Considering the relevance and urgency of accounting for the economic costs underlying the caregiver activity,^{4,12,13,15-18} this study aimed to extend the knowledge available in our country in this area, by quantifying and valuing the informal care provided to patients with dementia living in the community. From the perspective of costs assumed by the IC-CR dyad, the expenditure related to health services and social responses were taken into account, as well as those related to the time spent in care provision. In addition, the study showed the socio-demographic profile of IC and CR, in addition to the profile of the services used by these caregiving dyads.

MATERIAL AND METHODS

Population

ICs of patients with dementia living in the community were included in the study and were referred to by the organisations involved (municipalities, NGOs and healthcare services) in the CQC project.¹⁹ The participants were directly approached by the organisations' staff as regards their interest in participating in the project. ICs who were in charge of patients with cognitive impairment underlying dementia (Alzheimer's disease or other dementia) and living in the community (in one of the municipalities of the Metropolitan Area of Porto) were included. ICs of CRs living in residential care facilities for the elderly, as well as formal caregivers were excluded from the study. Those who agreed to participate were subsequently approached by the technical team of the CQC project to confirm their inclusion/exclusion criteria, to clarify any doubts about the project and the participation in the study. The selection method may have had an influence on the characteristics of the sample, namely due to the expected social and financial vulnerability of the participants. Therefore, the options and patterns of health service access and utilisation may be different from the profile of the general population.

A total of 140 participants from 219 that were identified as potential beneficiaries of the CQC project were included in the study; the remaining 79 were not included mainly due to lack of availability (e.g., with work schedules incompatible with the schedules of the psychoeducational program sessions). From 140 ICs, 16 participants had dropped out from the study due to lack of availability and health problems (both ICs and CRs) and one incomplete questionnaire was excluded from the analysis. A final sample of 123 ICs was considered. Ethical approval for this study was obtained

from the Ethics Committee of the ICBAS.UP (no. 101/2015) and of the *ARS Norte* (no. 39/2015) and all the underlying ethical and data protection issues were ensured.

Data collection and analysis

All ICs were assessed prior to their participation in the psychoeducational program through a structured interview, including IC's socio-demographic data (gender, age, education, monthly income of the dyad, degree of kinship, co-residence with CRs) and of CRs (gender, age). The degree of the patients' cognitive impairment was assessed by trained technicians by using the Global Deterioration Scale (GDS) to evaluate the degree of severity of dementia.²⁰ The dyad's health and social service utilisation (emergency attendances, scheduled consultations, incontinence products, utilisation of formal social responses and number of hours of informal care) was assessed through the Questionnaire on Resource Utilisation in Dementia (RUD),²¹ considering the 30 days prior to the interview date. The costs associated with informal care were estimated according to the proposal by Drummond *et al.*,²² in which four economic components were assessed (health costs, patient/family costs, other costs and productivity losses); the following three components have been considered:

- Health costs: hospital emergency episodes, emergency episodes in primary care settings, family medicine consultations and hospital specialty consultations (i.e., internal medicine, neurology, psychiatry, orthopaedics), regarding both ICs and CRs. These services were valued taking into account the costs described by the current applicable legislation as regards user fees (hospital emergency episode: €18.0; emergency episode in primary care settings and GP (general practice) consultations: €4.5; hospital specialty consultations: €7.0).²³⁻²⁵ The costs associated with incontinence products used by CRs were also accounted for. A market survey was carried out and seven products (adult diapers) including white-label products, from two of the main hypermarket chains were considered, corresponding to an average unit value of €0.56.
- Patient/family costs: costs related to the time spent in care provision. The number of hours of care provision in basic activities of daily living (BADL) (e.g., eating, dressing, mobility) and instrumental activities of daily living (IADL) (e.g., medication management, laundry and household chores), as well as supervisory care. A proxy-good method assessing informal care time through labour market costs of the nearest

activity (shadow prices) has been used,²⁶⁻²⁸ considering similar professional categories to ICs working in an institutional setting (i.e., residential facilities for the elderly). Therefore, as regards BALDs and supervision, personal caregivers were considered, with an average salary of €3.54/hour at the time of data collection (2014/16); for the evaluation of IADLs, a general services assistant (GSA) average income was considered (€3.06/hour).²⁹

- Other costs: the costs described by the participants regarding social support services were considered, including home support services (HSS), day centres (DC), temporary shelter services (TSS) or long-term care units (LTCU). The costs with private formal care (PFC) services provided by professionals at home were also considered.

The Productivity Loss component was not considered as only 31 ICs (25%) had an occupation and a reduction in working hours to care for the patient with dementia was only described by three from these (2.4%).

The costs of healthcare and social services were considered from the perspective of the payer (dyad) and not the costs to society or to a specific entity (e.g., National Health Service, Social Security). As regards the Health sector, the costs with medication, treatment or medical devices (e.g., wheelchairs and adjustable beds) were not considered, as only the level of utilisation was available with the instrument used to collect information (and not the costs with their acquisition/utilisation).

Descriptive analyses (mean, standard deviation, median, interquartile range, absolute and relative frequency) were performed for all variables, according to their nature. Median and interquartile range were used as an asymmetric distribution has been found. Within each economic assessment component and for each variable included, monthly costs were only calculated for users of that service and, as in other studies, these were referred to 100 IC-CR dyads.²⁸ Finally, the total cost per sector was calculated per each 100 IC-CR dyads. All the analyses were obtained by use of the Statistical Package for the Social Sciences® (SPSS) software, version 22.

RESULTS

Participants

The descriptive analysis showed that mostly female ICs were included in the study (n = 101; 81.5%), with a 57.4 mean age (SD = 11.4 years; range 26-82), mostly with four years of education (n = 42; 37.8%), followed by those with 5-9 years (n = 36; 32.4%). A low monthly income has been

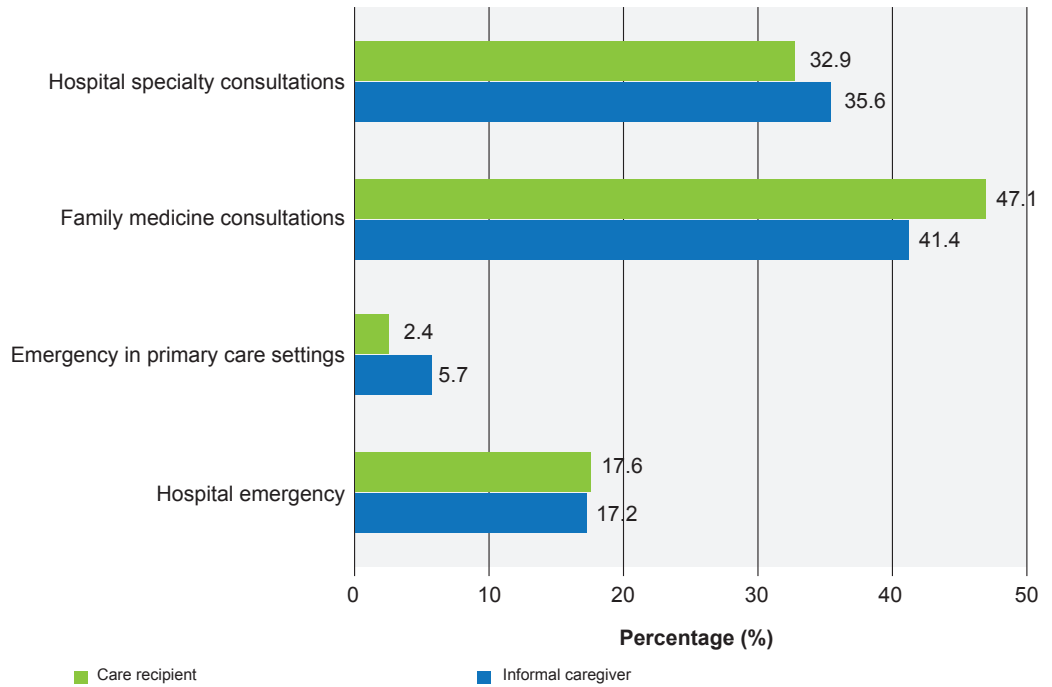


Figure 1 – Characteristics of monthly health services utilisation (%) by the dyad

found, with 40% of the ICs (n = 44) earning no more than €530, followed by caregivers who did not earn any income (n = 33; 30%). As regards the degree of kinship, mostly adult children of elderly patients have been found (n = 77; 62.1%), followed by spouses (n = 31, 25%); mostly family members were among the ICs included in the study (n = 89, 71.8%).

Mostly female patients (n = 87; 70.2%), mean age 82.2 (SD = 7.8 years; range 52-95), with end-stage dementia (n

= 82; 66.1%) and therefore extremely or fully dependent patients were included in the study.

Health service utilisation, informal care time and social responses

Health service utilisation by ICs and CRs, social service utilisation by CRs and informal care time (previous 30 days) are shown in Fig. 1, 2 and 3, respectively.

Hospital emergencies were three times more frequently

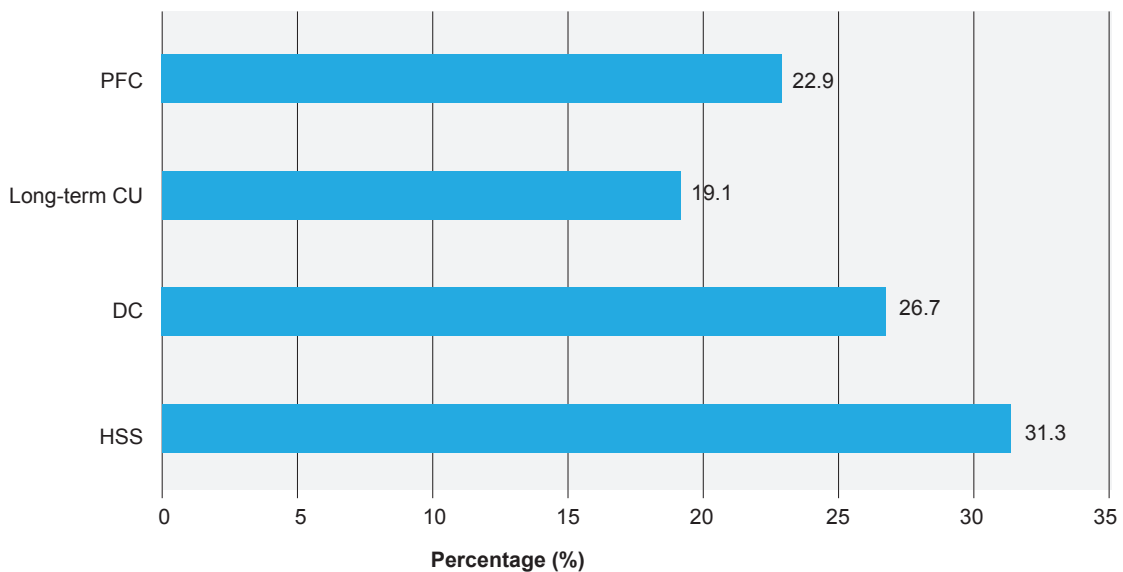


Figure 2 – Characteristics of monthly social services utilisation (%) by CRs

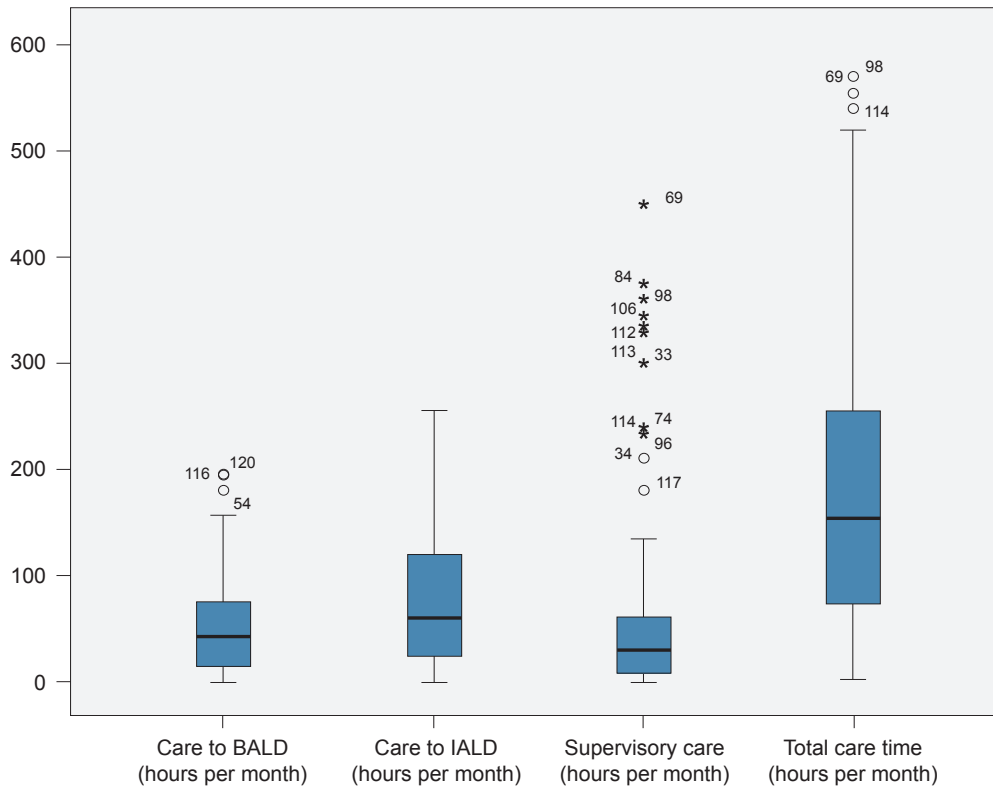


Figure 3 – Characteristics of care provision (hours per month) by type of care

Table 1 – Monthly costs for IC and CRs (€) regarding health costs, by using the proxy good method

	Users		Per 100 ICs
	n	median (IQR)	
Informal caregivers			
Hospital emergency	15	18.0 (18.0)	219.5
Emergency in primary care settings	5	9.0 (4.5)	36.6
Family medicine consultations	36	4.5 (0.0)	131.7
Hospital specialty consultations	31	7.0 (7.0)	176.4
Total health costs			564.2
	Users		Per 100 CRs
	n	median (IQR)	
Care recipients			
Hospital emergency	15	18.0 (18.0)	219.5
Emergency in primary care settings	2	4.5 (0.0)	7.3
Family medicine consultations	40	4.5 (0.0)	146.3
Hospital specialty consultations	28	7.0 (0.0)	159.3
Diapers	87	56.1 (33.6)	3968.1
Total health costs			4500.6

Table 2 – Monthly costs (€) for ICs in Patient/Family cost component, by use of the proxy good method

	Per 100 IC
Type of support	
BADL	15,050.0
IADL	18,360.0
Supervisory care	10,620.0
Patient / Family cost component	44,030.0

used by ICs and seven times more by CRs when compared to emergencies in primary care settings. General practice consultations were more frequent than hospital specialty consultations (Fig. 1). ICs mostly attended internal medicine (n = 5; 5.7%) and psychiatry (n = 5; 5.7%) whereas CRs mostly attended neurology (n = 16; 18.8%) and psychiatry consultations (n = 7; 8.2%).

As regards social response utilisation (Fig. 2), 41 CRs were mostly attended HSS (31.3%), followed by DCs (n = 35; 26.7%). None of the patients used any TSS.

As regards informal care time (Fig. 3), 153.8 hours/month were spent by ICs (IQR = 180.0) and mostly regarding IADL (median = 60 hours; IQR = 96.4), followed by BADL (median = 42.5 hours; IQR = 61.5) and supervisory care (median = 30.0 hours; IQR = 52.1).

Costs associated with informal care

Monthly costs in health component for both ICs and CRs are shown in Table 1. Hospital emergency services were usually the most expensive (€219.5/month per 100 ICs) and were used by 15 ICs over a 30-day period, at a cost of €18.0/month per user. Specialty consultations were used by 31 ICs at a cost of €7.0/month per user and represent the second highest expenditure in healthcare, with €176.4/month per 100 ICs. Regarding CRs, incontinence products, with costs of €56.1/month, were the most significant cost (78.3%) and 70.7% of the patients required the use of these

products. The remaining 21.7% of the costs were related to emergency episodes and medical appointments (€5.3/month). A total monthly cost of €5,064.8 has been found as regards the health component.

Monthly patient/family costs for ICs are shown in Table 2, including BADL, IADL and supervisory care. The total costs per 100 IC corresponded to €44,030.0/month, mostly regarding IADL (approximately €18,360.0/month) and BADL (€15,050.0/month).

As regards the other sectors (Table 3), monthly costs corresponded to the costs supported by the patients or their families regarding the support provided by social responses, private formal support and long-term care. A total of €12,887.4/month per 100 IC-CR dyads were spent and costs associated with DC corresponded to the greatest amount (€4,552.5/month and an individual value of €160.0/month), considering the users of this service, followed by costs associated with HSS, with a total of €131.5/month (€4,383.3/month per 100 IC-CR dyads). At the other extreme, no costs were associated with long-term care. The highest individual value (around €180.0/month) has been found regarding PFC services.

DISCUSSION

This study allowed for the identification of the socio-demographic profile and health care and social service utilisation by the participants in a community intervention project aimed at ICs of patients with dementia. Middle-aged women, direct descendants of the CRs with low education levels and low monthly income mostly provided care to CRs, who were mostly elderly women affected by end-stage dementia and living with ICs. The ICs profile was in line with those described by the 2018 European Commission report³⁰ and other scientific papers, such as the one by Alves *et al.* (2018),³¹ showing that mostly family members (spouses and offspring) aged 45-65, living with CRs, with low education levels and low incomes look after Portuguese CRs.

Table 3 – Monthly costs (€) for CRs regarding other costs, by using the proxy good method

Type of support	Users		Per 100 CRs
	n	median (IQR)	
HSS	41	131.5 (131.0)	4,383.3
DC	35	160.0 (59.0)	4,552.5
Long-term CU	25	0.0 (0.0)	0.0
PFC	27	180.0 (190.0)	3,951.2
Other costs - total			12,887.4

General practice and family medicine consultations were more frequently sought after than hospital specialties, particularly in the case of CRs. Nevertheless, the fact that only the 30 days prior to the interview were considered for the assessment of the levels of health services utilisation is worth mentioning, as this could represent a limitation for the interpretation of the results.

A regular follow-up of CRs by neurology and psychiatry, with the support of family medicine is worth mentioning, while ICs frequently attend psychiatric care. The need for this care is not clear even though it is probably due to the levels of overload/burnout, anxiety and depression associated with care provision (e.g. its duration, illness severity, degree of psychological and social support received), according to some studies in this area.^{12,13,18} Hospital vs. primary care was the best option for both elements of the dyad. Without questioning any urgency underlying dementia, this option was very clearly found in this study and the fact that the costs of hospital emergency care are more than three times higher than primary care is worth mentioning and the political effort to improve the access, adequacy and performance of primary care have improved in recent years.³²

Dementia is a degenerative and progressive disease and care provision scenario found in this group of ICs recruited in the community, mainly living with CRs, allowed anticipating the constraints underlying social, psychological and certainly financial burden associated with informal care. In fact, ICs in this study showed a high dedication to care provision (50% of the ICs provided 153.8 hours of care/month), which is in line with other studies describing a higher number of hours of care when there is cohabitation with CRs and when patients with dementia are involved.³³ In this study, 44,030.0 Euros/month (per 100 ICs) were the total costs regarding the patient/family component, 71.0% of the global costs, showing the relevance of accounting for the IC's time spent in the different tasks related to care provision. The fact that different European studies have described informal care as directly related to the number of hours of care provision and corresponding to the largest share of costs in treatment and care of people with dementia is worth mentioning, in addition to the fact that these tend to be usually not accounted for in health economic evaluations.^{3,4}

Health costs component represented only 8.2% of the overall costs and 78.3% of these were related to incontinence products. This is an important daily cost, which is borne entirely by the dyad. As for the remaining costs with health services, a higher value than what has been found for the health component was expected, in line with other

studies carried out in this context, such as for example a reference to a 25% increase in health services utilisation due to looking after patients with Alzheimer's disease.²⁸ However, this result may be partly explained by the fact that costs with medication, treatment or even the purchase of medical devices or other support products were not considered in this study. In addition, the fact that this was a group of participants with low income, it is expected that many of these people are exempt from paying user fees, reporting low expenses in this sector.

As regards long-term care, we can see that although most people benefit from HSS and/or DC, PFC services still explain the high values in this sector, representing 20.8% of the total costs with informal care (12,887.4/month per 100 CRs). PFC represented the highest individual value (€180.0/month), which is entirely borne by patients. There is clearly a need for 'extra' support that is not being met by the typical social responses, nor by long-term care, either by the frequency of care or by the type of service. It is also clear that people's willingness to pay for this service shows how important it is for their well-being.

As regards total costs of informal care from the perspective of the IC-CR dyad, which was the main objective of this study, the assessment was based on the expenses with health services, other social services and time spent on care provision and reached €61,982.2/month for 100 IC-CR dyads, or €619.8/month per dyad.

Even though this is apparently a low value, 619.8 EUR/month represents 77.5% of the monthly income of the IC-CR dyads (median = 800.0 EUR; IQR = 679.0), with a major impact on the decision of continuity of care by ICs instead of the institutionalisation of CRs. The family's decision to assume this responsibility is closely related to the balance between gains and losses. For instance, if appreciation and commitment with looking after someone who is significant have been identified as gains, on the other hand, it means giving up the opportunity to produce, as well as giving up the income and added value or, in the case of retired people, giving up their leisure time and the development of a set of expected activities, such as the investment in family relationships aimed at caring for the younger generations.

The great heterogeneity underlying informal care makes its economic assessment a challenge. It is worth mentioning the fact that data related to costs were self-reported (particularly caregiver's time spent in BADL, IADL and supervisory care), which could be conditioned by several factors (e.g., biased by the performance of joint activities due to the fact of living together).⁵ In addition, the generalisation of these results should be carefully considered, as this

was a group of participants recruited by social or health response professionals and IC-CRs unconnected with these institutions were not included. Therefore, a different profile of ICs with different social and financial conditions could show another pattern of access and health and social services utilisation, as well as another financial strain associated with care provision (considering the hiring of formal caregivers). Finally, since different methodologies and variables have been adopted by the different studies carried out in this area, any direct comparison of the meaning of costs of informal care found in this study with those described in the literature would be inaccurate.

CONCLUSION

In this study, €619.8/month were the costs of informal caregiving, based on the expenditure on certain health services, other social services and time spent on care provision.

The complexity and heterogeneity of informal care prevented from presenting it with its real monetary value and most likely with an underestimated one. Nevertheless, this study represents a contribution to the recognition of the financial burden for families of caregivers of patients with dementia, calling for the awareness of society and political agents to the significance of the costs of informal care. Given the current relevance of this topic, this methodology should be extended to other caregivers in future research.

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HUMAN AND ANIMAL PROTECTION

The authors declare that the followed procedures were according to regulations established by the Ethics and Clinical Research Committee and according to the Helsinki Declaration of the World Medical Association.

DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

CONFLICTS OF INTEREST

The authors declare that there were no conflicts of interest in writing this manuscript.

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