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Needs for Care, Service Use and Quality of Life in Dementia: 12-Month Follow-Up of the Actifcare Study in Portugal

Necessidades de Cuidados, Utilização de Serviços e Qualidade de Vida na Demência: Reavaliação da Amostra Portuguesa no Estudo Actifcare após 12 Meses

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ABSTRACT

Introduction: The intermediate stages of dementia are relatively under-researched, including in Portugal. The Actifcare (ACcess to Timely Formal Care) EU-JPND project studied people with mild-moderate dementia, namely their needs, access to and use of community services (e.g., day centers, home support). In our baseline assessment of the Portuguese Actifcare cohort, the unmet needs of some participants would call for formal support, which was not always accessible or used. We now report the main results of the 12-month follow-up, analyzing changes in needs, service (non)use, quality of life and related variables.

Methods: This was a longitudinal, observational study using a convenience sample of 54 dyads of people with dementia and their family carers. Our main outcomes were the Camberwell Assessment of Need for the Elderly (CANE) and the Resources Utilization in Dementia. Clinical-functional, quality of life, psychological distress and caregiving-related assessments were also used.

Results: At follow-up, the cognitive and functional status of people with dementia declined ($p < 0.001$), and their neuropsychiatric symptoms increased ($p = 0.033$). Considering CANE interviewers' ratings, the total needs of people with dementia increased at follow-up ($p < 0.001$) but not the unmet needs. Quality of life was overall stable. The use of formal care did not increase significantly, but informal care did in some domains. Carers' depressive symptoms increased ($p = 0.030$) and perseverance time decreased ($p = 0.045$). However, carers' psychological distress unmet needs were lower ($p = 0.007$), and their stress and quality of life remained stable.

Conclusion: People with dementia displayed complex biopsychosocial unmet needs. Their cognitive-functional decline over one year was not accompanied by a corresponding increase in any pattern of unmet need, nor of service use. Reliance on informal care (namely supervision) may have contributed to this. Caregiving-related outcomes evolved according to different trends, although stability was almost the rule. Primary carers were even more present at follow-up, without an apparently heavier toll on their own needs, burden, and quality of life. Overall, this longitudinal study comprehensively assessed Portuguese community-dwelling people with dementia. Despite the lack of generalizability, participants' needs remained overall stable and partly unmet over one year. Longer follow-up periods are needed to understand such complex processes.

Keywords: Caregivers; Dementia; Health Services Accessibility; Needs Assessment

RESUMO

Introdução: As fases intermédias da demência têm sido menos investigadas. O projecto EU-JPND Actifcare (ACcess to Timely Formal Care) estudou as necessidades de pessoas com demência ligeira-moderada e o acesso/utilização de serviços na comunidade (v.g., centros de dia, apoio domiciliário). Na avaliação inicial da subamostra portuguesa, as necessidades não cobertas de alguns participantes exigiram apoio formal, nem sempre disponível ou procurado. Apresentamos agora resultados do estudo longitudinal (12 meses), analisando necessidades, utilização dos serviços, qualidade de vida e variáveis relacionadas.

Métodos: Estudo longitudinal de uma amostra de conveniência (54 díades doente/familiar-cuidador). Além dos principais instrumentos (Camberwell Assessment of Need for the Elderly - CANE, Resources Utilization in Dementia), foram realizadas avaliações complementares: clínico-funcionais, qualidade de vida, sofrimento psicológico, experiência de cuidar.

Resultados: No *follow-up*, o estado cognitivo e funcional das pessoas com demência piorou ($p < 0,001$) e os sintomas neuropsiquiátricos aumentaram ($p = 0,033$). O total de necessidades aumentou ($p < 0,001$), mas o total de necessidades não cobertas e a qualidade de vida permaneceram estáveis. A utilização de cuidados formais não aumentou significativamente, mas os cuidados informais sim (nalguns domínios). Os sintomas depressivos dos familiares-cuidadores aumentaram ($p = 0,030$), diminuindo o tempo de perseverança ($p = 0,045$). Porém, as suas necessidades não cobertas de sofrimento psicológico foram menores ($p = 0,007$), enquanto o *stress* e a qualidade de vida permaneceram estáveis.

Conclusão: Estas pessoas com demência apresentavam necessidades biopsicossociais complexas e não cobertas. O declínio cognitivo-funcional ao longo de um ano não foi, aparentemente, acompanhado por um aumento de necessidades não cobertas, nem da utilização de serviços. A maior utilização dos cuidados informais (supervisão) pode ter contribuído para tal. A análise das dimensões da experiência de cuidar sugere tendências não inteiramente uniformes, embora a estabilidade fosse quase a regra. Os familiares-cuidadores 'primários' estavam ainda mais presentes no *follow-up*, sem que isso pareça ter alterado as suas próprias necessidades, sobrecarga e qualidade de vida. Em suma, apresentamos uma análise longitudinal abrangente de uma amostra comunitária de famílias de pessoas com demência ligeira-moderada. Não sendo os resultados generalizáveis, ao fim de um

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ano as necessidades dos participantes mantiveram-se globalmente estáveis e parcialmente não cobertas. Para compreender processos tão complexos, necessitamos de estudos com tempos de seguimento maiores.

Palavras-chave: Acessibilidade aos Serviços de Saúde; Avaliação das Necessidades; Cuidadores; Demência; Prestação de cuidados

INTRODUCTION

Dementia is a major public health problem. Its global burden of disease substantially increased in recent years and will most probably continue to increase likewise.¹ The number of people with dementia worldwide is estimated to reach 131.5 million by 2050.² In Europe, the enormous economic costs associated with dementia tend to follow a North-South gradient, with Mediterranean countries more reliant on informal, family care.^{3,4}

Regarding Portugal, knowledge about the prevalence of dementia has improved considerably compared to a decade ago, and fieldwork strongly supports estimates exceeding 200 000 people living in the community with this condition.^{1,5} These are probably underestimates, as they do not include institutionalized people with dementia⁶; furthermore, numbers are expected to increase up to 350 000 in 2050.¹ In a recent study, the global estimated cost of Alzheimer's disease amounted to 2 billion euros in 2018 (1% of the GDP⁶). Informal care represents more than half of these costs⁶ and is a heavy burden on family income.⁴

In Portugal, a Dementia National Strategy was approved.⁷ However, there are complex barriers to its implementation, including poor resources and organization. Some mainly relate to primary health care,⁸ others to secondary and tertiary healthcare, social security and the third sector.⁹ There is a convoluted system of fragmented care which is hard to navigate, because its components are poorly articulated. Regarding community services, as day centers or home care, timely access is difficult and close-to-home care coordination or case management are lacking. Support for carers and families remains inadequate, to say the least.⁹ Like everywhere,¹⁰ stigma additionally contributes to delays in diagnosis and access to care, family exhaustion and premature institutionalization. Mental health stigma and a tendency towards family caregiving obligations seem more influential in Southern Europe than barriers to access and use of services.¹¹ Despite the recognition of these challenges, we know little about patterns of service (under)use by people with dementia and their families, as related to their unmet needs.

In this context, the Actifcare (ACcess to TImely Formal Care) EU-JPND project focused on needs for care, access, and use of services by people living with intermediate stages of dementia in the community and their families. By 'intermediate' we mean mild (beyond immediate postdiagnosis) and moderate stages, still relatively neglected in psychosocial research as compared with more advanced phases. The project included a cohort study of a large sample from

eight European countries,¹² for which a baseline analysis of the Portuguese subsample has been published.¹³ We were interested in analyzing the transition from situations in which people can rely on family informal care only, to more advanced levels of disability where formal community services (e.g., day centers, home care) become necessary to meet emerging needs. At baseline, unmet needs were more frequently psychosocial in nature (e.g., company, psychological distress, daily activities). Some would call for formal support, were it not for problems regarding access or use of community services. Problems with access or use of these services, when present, were frequently due to attitudinal issues or lack of knowledge regarding the condition or available services (influencing levels and types of unmet needs).¹³

We now report the 12-month follow-up results of the same Portuguese cohort, aiming to analyze changes in participants' needs for care, service (non)use, and related clinical, functional, and psychosocial variables over time.

METHODS

Study design

The Actifcare EU-JPND cohort study protocol is available elsewhere,¹² and has been detailed regarding the Portuguese subsample recruitment, study procedures and baseline assessments.¹³ Here, we refer to the 12-month follow-up results.

Ethical considerations

Written informed consent was provided by all participants (persons with dementia and their family carers). Permission was granted by local ethics committees [Comissão de Ética da Faculdade de Ciências Médicas; Comissões de Ética para a Saúde do Centro Hospitalar de Lisboa Ocidental, Administração Regional de Saúde (ARS) de Lisboa e Vale do Tejo and ARS Alentejo] and by the Portuguese data protection authority (Comissão Nacional de Proteção de Dados).

Sample

The EU Actifcare sample was composed of 451 dyads of people with a diagnosis of DSM-IV-TR dementia¹⁴ and their primary (main) family caregivers, henceforth called 'carers'. According to the inclusion criteria, participants should have mild or moderate dementia (Clinical Dementia Rating-CDR),¹⁵ or score below 25 on the Mini Mental State Examination (MMSE),¹⁶ no relevant formal assistance with

personal care relating to dementia (e.g., paid home carer) for the previous six months, and a clinical impression that such formal care would be needed within the 12-month follow-up. People with significant comorbidities (severe somatic/mental disorders or sensory impairments) were excluded.^{12,13} In Portugal, we recruited 66 dyads from different regions and clinical and social settings (primary care, public or private neurology and psychiatry outpatient clinics, and the third sector, including Alzheimer Portugal).

Instruments

Our study assessments were comprehensive. An overview of all variables included may be found in Table 1, along with the corresponding measures and references to original and Portuguese validation studies.^{12,13}

Assessments of people with dementia

Following our baseline report, we remained focused on needs for care and service use, and the corresponding measures: the Camberwell Assessment of Need for the Elderly (CANE)¹⁷ and the Resources Utilization in Dementia (RUD).¹⁸ The CANE interview assesses care needs (unmet, met, or non-existent) across 24 biological and psychosocial domains, allowing for the comparison of users', carers' and interviewers' perspectives on each domain. For each user, a total score is computed by summing up all domains where an existing need is recognized. Its validity and reliability have been documented internationally^{17,19} and in Portugal.²⁰ Regarding RUD, it measures the use of formal and informal care in dementia, and its psychometric properties were also documented.¹⁸ Additionally, an *ad hoc* checklist described access to and use of formal services more in depth.¹²

We also used the Quality of Life-Alzheimer's Disease Scale (QOL-AD),²¹ both self and proxy-rated. Its thirteen domains (physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self, and life overall) are evaluated on four-point Likert scales (poor, fair, good, excellent). Higher scores indicate better quality of life (range 13 - 52). The QOL-AD demonstrated favorable validity and reliability in Portugal.²² Participants' clinical-functional characterization further included: dementia severity,¹⁵ cognitive function,¹⁶ neuropsychiatric symptoms,²³ comorbidity²⁴ and overall functioning²⁵ (Table 1).

Assessment of family carers

We assessed carers' specific needs with the two corresponding items of the CANE interview (information about dementia and psychological distress),¹⁷ use of resources with the RUD,¹⁸ and quality of life with the CarerQoL scale. This last scale was specifically developed to gauge the impact of providing informal care. It consists of seven items, rated on three-point scales; here we used the sum score

(range 0 - 14), with higher scores meaning higher quality of life.^{26,27} Additional assessments included e.g., anxiety and depression symptoms,²⁸ family burden,²⁹ perseverance time³⁰ (Table 1).

Procedures

All interviewers were psychologists with clinical and/or research experience. Reliability training for the study measures has already been reported.¹³

The assessments took place at home or elsewhere, as convenient. They were conducted separately with the person with dementia and their carer. If necessary, conjoint conversations would take place, mainly if the person with dementia felt more secure in the presence of their loved one. Furthermore, interviews would be interrupted due to tiredness or assessment burden, to be completed within short timeframes.

Data analysis

For this longitudinal analysis of our Portuguese cohort, only the 54 dyads completing the 12-month follow-up were considered. Beforehand, the variables' distributional properties were examined, using means with standard deviations (SD) for continuous variables and frequencies with percentages for categorical variables (n, %). The data were tested for normality (Shapiro-Wilk) before all analyses were carried out. Chi-square (with Fisher's correction when necessary) or *t*-Student test were used to analyze socio-demographic and clinical differences between baseline and dropout participants. All variables were compared at baseline and at the 12-month follow-up. In order to compare means, we used specific tests: *T*-tests for related samples; two-way repeated measures ANOVA, with the Bonferroni test for the multiple pairwise comparisons. To analyze categorical variables, we used McNemar or Wilcoxon tests. When the results showed statistically significant differences the effect size (Cohen's *d*) was calculated. A significance level of 0.05 was used. All analyses were performed with Statistical Package for the Social Sciences/SPSS, v28.0 for Windows.

Data availability

The complete dataset is available upon reasonable request to the corresponding author. Consent for dataset availability has not been obtained from participants, but data was anonymized.

RESULTS

After recruitment and baseline assessment, 12 of the 66 dyads of people with dementia and their carers were lost to the 12-month follow-up. Attrition was due to carer withdrawal (not willing to collaborate, stating exhaustion) (six dyads), person with dementia death (four) or

Table 1 – Overview of the EU-Actifcare project instruments specifically used in this longitudinal analysis

Instrument	Variable	Respondents ^a	Author (year) / Portuguese translation (year) and/or reference of validation study in Portugal
Sociodemographic, clinical and functional characteristics of people with dementia			
Sociodemographic questionnaire	Sociodemographic data	1,2	Actifcare Workgroup in Portugal (2015)
Clinical Dementia Rating (CDR)	Dementia severity	1,2	Morris (1993) / <i>Grupo de Estudos de Envelhecimento Cerebral e Demência</i> (2008)
Mini Mental State Examination (MMSE)	Cognitive Status	1	Folstein <i>et al</i> (1975) / Guerreiro <i>et al</i> (1994); Portuguese version obtained from Psychological Assessment Resources, via MAPI Research Trust – PROQOLID (2014)
Neuropsychiatric Inventory Questionnaire (NPI-Q)	Neuropsychiatric symptoms	2	Kaufer <i>et al</i> (2000) / Adapted from <i>Grupo de Estudos de Envelhecimento Cerebral e Demência</i> (2008); online approval obtained from the website http://www.npitest.net/ (2014)
Charlson Index	Comorbidity	4	Charlson <i>et al</i> (1994) / Actifcare Workgroup in Portugal (2015)
Lawton Instrumental Activities of Daily Living (IADL)	Instrumental activities of daily living	2	Lawton & Brody (1969) / Araújo <i>et al</i> (2008)
Physical Self-Maintenance Scale (PSMS)	Activities of daily living	2	Lawton & Brody (1969) / Araújo <i>et al</i> (2008)
Needs for care			
Camberwell Assessment of Need for the Elderly (CANE)	Needs for care	1,2,4	Reynolds <i>et al</i> (2000) / Gonçalves-Pereira <i>et al</i> (2007); Fernandes <i>et al</i> (2009)
Service access and utilization			
Checklist of service utilization	Access and reasons for (no) utilization of services	1,2	Actifcare Workgroup in Portugal (2015)
Resources Utilization in Dementia (RUD) 5.0	Service utilization	1,2	Wimo <i>et al</i> (2013) / Portuguese version obtained online from the website http://rudinstrument.com (2015)
Quality of life and relationship quality			
Quality of Life-Alzheimer's Disease (QOL-AD)	Quality of life of people with dementia	1,3	Logsdon <i>et al</i> (1999) / Bárrios <i>et al</i> (2013)
CarerQoL-7D	Quality of life of carers	2	Brouwer <i>et al</i> (2006) / Actifcare Workgroup in Portugal (2015)
Positive Affect Index (PAI)	Quality of the relationship between carers and people with dementia	1,2	Bengtson & Schrader (1982) / Actifcare Workgroup in Portugal (2015)
Carers' psychological distress, caregiving experiences and social support			
Hospital Anxiety and Depression Scale (HADS)	Anxiety and depression	2	Zigmond & Snaith (1983) / Pais-Ribeiro <i>et al</i> (2007); Portuguese version obtained from GL Assessment, via MAPI Research Trust – PROQOLID (2014)
Relative Stress Scale (RSS)	Disease-related family burden	2	Greene <i>et al</i> (1982) / Actifcare Workgroup in Portugal (2015)
Lubben Social Network Scale (LSNS-6)	'Perceived' social support	2	Lubben, 1988 / Ribeiro <i>et al</i> (2012)
Perseverance time	Single question ^b	2	Kraijo <i>et al</i> (2014) / Actifcare Workgroup in Portugal (2015)
Carers' dispositional variables			
Locus of Control Behavior Scale (LOC) ^c	Locus of control	2	Craig <i>et al</i> (1984) / Actifcare Workgroup in Portugal (2015)
Orientation to Life Questionnaire (SOC-13)	Sense of coherence	2	Antonovsky (1987) / Saboga-Nunes (1999)

^a Respondents: people with dementia (1); informal carers/family (2); informal carers (as a proxy, giving an opinion on the status of the person with dementia or providing an approximate response that person would give) (3); researchers/interviewers (4);

^b In case the current situation remains unchanged, how long would you be able to keep on with caregiving? ('Se a situação de cuidados se mantiver tal como está, quanto tempo será capaz de continuar a prestar cuidados?');

^c Only used in baseline assessments.

institutionalization (one), and carer death (one). In three other dyads, the person with dementia was no longer able to participate in follow-up assessments due to cognitive decline; these were not dropouts since the carer remained willing and able to participate.

We first compared the 12 dyads lost to follow-up and the 54 that could be reassessed after 12 months (Table 2). There were no statistically significant differences between these two groups regarding individuals' demographic and clinical-functional characteristics, dyads' caregiving arrangements, or locus of control (a measure that was only completed at baseline).

Regarding people with dementia who completed the study, mean age was 77 years (SD = 6.4) and around two

thirds (34 participants) were women. More than one third of the sample (20 participants) had a diagnosis of Alzheimer's disease, which was the most frequent dementia subtype, and two thirds (34 participants) had high comorbidity levels with the Charlson Index. Only two lived alone. Regarding carers, mean age was 64 years (SD = 15.1), 35 of them (around two thirds) were women and 32 were spouses of the person with dementia.

Table 3 concerns other clinical, functional, and psychosocial assessments of people with dementia and their carers, showing the corresponding differences between baseline and 12-month follow-up.

There was a decrease in MMSE scores, in Lawton IADL function and in basic ADL function. These differences were

Table 2 – Baseline demographic characteristics, clinical diagnoses of dementia and multimorbidity of participants completing the study versus lost to follow-up

	Completing the study (54 dyads)	Lost to follow-up (12 dyads)	p-value
People with dementia			
Age, years, mean (SD)	76.9 (6.4)	79.1 (5.4)	0.273 ^b
Women, n (%)	34 (63.0)	7 (58.3)	0.737 ^c
Education, years, mean (SD)	6.9 (6.6)	4.4 (2.9)	0.215 ^b
Living alone, n (%)	2 (3.7)	0 (0.0)	0.498 ^c
Type of dementia, n (%)			0.882 ^c
Alzheimer's Type	20 (37.0)	5 (41.7)	
Vascular	6 (11.1)	2 (16.7)	
Mixed (Alzheimer's and Vascular)	6 (11.1)	1 (14.3)	
Lewy Body	2 (3.7)	0 (0.0)	
Frontotemporal dementia	4 (7.4)	0 (0.0)	
Unspecified	16 (29.6)	4 (33.3)	
Comorbidity (Charlson), mean (SD)	3.1 (1.5)	3.0 (1.3)	0.785 ^b
			0.658 ^c
None, n (%) ^a	8 (14.8)	1 (8.3)	
Low comorbidity, n (%) ^a	12 (22.2)	4 (33.3)	
High comorbidity, n (%) ^a	34 (63.0)	7(58.3)	
Family carers			
Age, years, mean (SD)	64.2 (15.1)	68.2 (14.7)	0.408 ^b
Women, n (%)	35 (64.8)	9 (75.0)	0.498 ^c
Education, years, mean (SD)	9.4 (6.5)	7.3 (5.0)	0.300 ^b
Relationship to person with dementia, n (%)			0.884 ^c
Spouse/partner	32 (59.3)	8 (66.7)	
Adult children	16 (29.6)	4 (33.3)	
Other (e.g., son/daughter in law; sibling)	6 (11.1)	0 (0.0)	
Locus of control, mean (SD)	57.3 (6.5)	55.5 (5.4)	0.321 ^b

SD: standard deviation.

^a Charlson index – none: 0-1 conditions; low comorbidity: 2 conditions; high comorbidity: ≥ 3 conditions.

^b t-Student test.

^c Chi square test with Fisher's correction

statistically significant and had moderate effect sizes. Accordingly, seven cases converted from CDR 1 to CDR 2 dementia severity. Neuropsychiatric symptoms increased, but the level of significance and effect size were lower. People with dementia did not report significant differences in their quality of life over time, the same happening with proxy perceptions. Furthermore, when accounting for the interaction between time and respondent in a two-way repeated measures ANOVA, QOL-AD scores were not significantly different at baseline and follow-up ($F = 0.176$, $p > 0.05$).

Regarding carers' assessments (Table 3), depressive

symptoms increased, and perseverance time decreased, but the effect size was modest for both changes. We found no other significant differences between carers' baseline and follow-up assessments.

Table 4 depicts changes in levels of need of people with dementia, according to their own views, their carers' and the interviewers' (overall perspective). The mean total number of needs decreased according to people with dementia ($p = 0.010$) but increased according to both carers ($p = 0.015$) and interviewers ($p < 0.001$). The mean total number of unmet needs decreased according to people with dementia

Table 3 – Clinical, functional and secondary outcome assessments of people with dementia and their family carers: differences between baseline and follow-up (12 months)

	Baseline	Follow-up	p-value	Effect size ^d
People with dementia				
Dementia severity (CDR)			0.016^a	
Category 1, n (%)	50 (92.6)	43 (79.6)		
Category 2, n (%)	4 (7.4)	11 (20.4)		
MMSE (range: 0 - 30)	18.3 (4.8)	16.2 (5.7)	< 0.001^b	0.753
Neuropsychiatric symptoms (NPI-Q) (range: 0 - 12)	6.9 (5.9)	8.4 (4.5)	0.033^b	-0.297
Lawton IADL function (range: 0 - 8)	3.9 (2.0)	2.9 (2.1)	< 0.001^b	0.669
Basic ADL function (PSMS) (range: 0 - 6)	3.9 (1.8)	3.2(1.9)	< 0.001^b	0.580
QOL-AD (range: 13 - 52)	31.1 (5.9)	31.3 (5.7)	0.791 ^b	
Relationship Quality (PAI) (range: 5 - 30)	22.0 (4.6)	21.7 (3.5)	0.567 ^b	
Proxy				
QOL-AD (range: 13 - 52)	29.4 (5.8)	30.1 (6.5)	0.397 ^a	
Family carers				
CarerQoL-7D (range: 0 - 13)	10.2 (2.6)	9.7 (2.3)	0.109 ^b	
Relationship Quality (PAI) (range: 5 - 30)	21.0 (4.6)	20.2 (4.1)	0.114 ^b	
Anxiety symptoms (HADS) (range: 0 - 21)	6.3 (3.7)	6.6 (4.0)	0.477 ^b	
Depressive symptoms (HADS) (range: 0 - 21)	6.2 (4.5)	7.3 (4.4)	0.030^b	-0.309
Subjective burden (RSS) (range: 0 - 60)	21.0 (11.4)	22.8 (10.0)	0.202 ^b	
Social Support (LSNS-6) (range: 0 - 30)	16.3 (4.3)	16.7 (4.7)	0.503 ^b	
Perseverance Time, n (%)			0.045^c	-0.213
Less than one week	0 (0.0)	0 (0.0)		
More than one week but less than one month	0 (0.0)	0 (0.0)		
More than one month but less than six months	2 (3.9)	4 (8.5)		
More than six months but less than one year	5 (9.8)	5 (10.6)		
More than one year but less than two years	5 (9.8)	8 (17.0)		
More than two years	39 (76.5)	30 (63.8)		
Sense of Coherence (SOC-13) (range: 13 - 91)	65.0 (11.2)	67.4 (12.6)	0.078 ^b	

Mean (SD) for all, unless noted otherwise.

CDR: Clinical Dementia Rating Scale; MMSE: Mini Mental State Examination; NPI: Neuropsychiatric Inventory; IADL: Instrumental Activities of Daily Living; PSMS: Physical Self-Maintenance Scale; QOL-AD: Quality of Life-Alzheimer's Disease; PAI: Positive Affect Index; HADS: Hospital Anxiety Depression Rating Scale; RSS: Relative Stress Scale; LSNS-6: Lubben Social Network Scale; SOC-13: Sense of Coherence Scale-13.

^a Related-samples McNemar test;

^b Paired Samples T-test;

^c Wilcoxon test;

^d Cohen's d

Table 4 – CANE ratings by people with dementia, family carers and interviewers (overall perspective): differences between baseline and follow-up (12 months)^a

CANE	Perspective (type of rating)	Baseline (n = 54) Mean (SD)	Follow-up (n = 54) Mean (SD)	Effect	
				Time ^b p-value	Time x perspective ^c p-value
Unmet needs	People with dementia	1.4 (1.9)	0.8 (1.4)	0.029	0.018
	Family carers	1.4 (1.5)	1.0 (1.5)	0.019	
	Interviewers	6.4 (2.8)	5.2 (3.1)	0.775	
Met needs	People with dementia	5.0 (2.7)	4.5 (2.6)	0.251	< 0.001
	Family carers	7.9 (2.6)	9.0 (3.0)	< 0.001	
	Interviewers	9.3 (3.1)	10.0 (3.0)	< 0.001	
Total needs	People with dementia	6.4 (2.8)	5.2 (3.1)	0.010	< 0.001
	Family carers	7.6 (2.8)	9.2 (2.8)	0.015	
	Interviewers	8.8 (3.1)	10.4 (2.4)	< 0.001	

^a The two CANE items on carers' needs are not included here;

^b Paired Samples T-test;

^c Two-way repeated measures ANOVA.

($p = 0.029$) and their carers ($p = 0.019$). In contrast, the total number of unmet needs according to interviewers did not change significantly from baseline to follow-up. The two-way repeated measures ANOVA showed a significant interaction between type of CANE ratings and time, in the unmet ($F = 5.999$, $p = 0.018$), met ($F = 20.394$, $p < 0.001$) and total number of needs ($F = 35.592$, $p < 0.001$), suggesting that changes over time varied depending on the type of rating considered. At follow-up, there were significant differences between people with dementia and carers' ratings (met needs: $p < 0.001$; total needs: $p < 0.001$) and between people with dementia and interviewers' ratings (unmet needs: $p = 0.022$; met needs: $p < 0.001$; total: $p < 0.001$). Carers and interviewers' ratings did not differ significantly at follow-up.

Going into more detail, Table 5 shows the ratings of unmet needs compared to 'no needs' and 'met needs', by domain, now only from the interviewers' integrative perspective. Item-by-item analyses showed no statistically significant differences between baseline and follow-up in any person with dementia need domain. 'Company', 'psychological distress' and 'daytime activities' were the most common unmet needs at baseline. The number of participants with these unmet needs decreased at follow-up ('company' and 'psychological distress') or remained stable ('daytime activities'). On the contrary, the number of participants with unmet needs increased in other domains, namely 'memory', 'medicines', 'mobility' and 'behavior'. Regarding the two carer-related need domains, there was an increase in information and a decrease in psychological distress unmet needs, with the latter being statistically significant.

Finally (Table 6) there was a general trend towards an increase in access/use of formal and informal care. How-

ever, the only statistically significant differences were an increase in time spent in supervision by carers and in their level of contribution to care provision, as primary carers.

DISCUSSION

We conducted a longitudinal study of dyads of community-dwelling people with mild to moderate dementia and their family carers, over one year. This small sample had been recruited to integrate a large cohort from eight countries. Notwithstanding, cross-country comparisons were not a primary aim of the EU project and that is why we undertook this analysis of Portuguese participants. To our knowledge, this is the first study of a Portuguese sample in which needs for care, service use, and quality of life in dementia were comprehensively assessed over time. We additionally considered carers' variables such as anxiety and depressive symptoms and family burden.

As expected, we documented cognitive and functional decline in people with dementia and a relative increase in their neuropsychiatric symptoms. However, regarding needs assessment, total unmet needs did not change significantly at follow-up, according to interviewers. This was a surprising result. First, because unmet needs are more important to consider in health services research than the crude mean of overall needs (met plus unmet), which was significantly higher at follow-up (interviewers' ratings) owing to the met needs' component. Second, in order to rate each CANE item, interviewers take into consideration users' and carers' views, aiming to provide an integrated perspective over each need domain: that is why this specific CANE score is more often reported. That users', carers' and interviewers' views did not exactly coincide is not surprising: research has widely illustrated such discrepancies.^{19,31,32} Our

Table 5 – Frequency of unmet needs and other CANE ratings (interviewers' perspective): differences between baseline and follow-up (12 months)

Need domains	Baseline		Follow-up		p-value ^a
	Unmet needs	No needs/ Met needs	Unmet needs	No needs/ Met needs	
People with Dementia, n (%)					
Accommodation	-	54 (100.0)	1 (1.9)	53 (98.1)	1.000
Looking after home	-	53 (100.0)	1 (1.9)	52 (98.1)	1.000
Food	1 (1.9)	52 (98.1)	1 (1.9)	52 (98.1)	1.000
Self-care	-	53 (100.0)	-	53 (100.0)	1.000
Caring for another person	1 (1.9)	53 (98.1)	2 (3.7)	52 (96.3)	1.000
Daytime activities	9 (16.7)	45 (83.3)	9 (16.7)	45 (83.3)	1.000
Memory	2 (3.8)	51 (96.2)	6 (11.3)	47 (88.7)	0.289
Eyesight/hearing/communication	1 (2.0)	50 (98.0)	2 (3.9)	49 (96.1)	1.000
Mobility	1 (1.9)	52 (98.1)	4 (7.5)	49 (92.5)	0.250
Continence	2 (6.1)	46 (93.9)	-	53 (100.0)	0.250
Physical health	1 (1.9)	52 (98.1)	3 (5.7)	51 (94.3)	0.500
Medicines/drugs	2 (4.0)	48 (96.0)	5 (10.0)	45 (90.0)	0.453
Psychotic symptoms	1 (2.0)	50 (98.0)	-	51 (100.0)	1.000
Psychological distress	11 (22.9)	37 (77.1)	9 (18.8)	39 (81.3)	0.791
Information	2 (4.3)	45 (95.7)	4 (4.3)	45 (95.7)	1.000
Deliberate self-Harm	2 (3.8)	50 (96.2)	-	52 (100.0)	0.500
Accidental self-Harm	4 (8.0)	46 (92.0)	1 (2.0)	49 (98.0)	0.250
Abuse/neglect	1 (2.0)	49 (98.0)	-	50 (100.0)	1.000
Behavior	1 (2.0)	50 (98.0)	4 (7.8)	47 (92.2)	0.375
Alcohol	-	52 (100.0)	-	52 (100.0)	1.000
Company	13 (25.5)	38 (74.5)	7 (13.7)	44 (86.3)	0.180
Intimate relationships	2 (3.8)	50 (96.2)	3 (5.8)	49 (94.2)	1.000
Money	-	52 (100.0)	-	52 (100.0)	1.000
Benefits	2 (5.4)	35 (94.6)	1 (2.7)	36 (97.3)	1.000
Carers, n (%)					
Information	7 (13.7)	44 (86.3)	14 (27.5)	37 (72.5)	0.118
Psychological distress	23 (45.1)	28 (54.9)	12 (23.5)	39 (76.5)	0.007

^a McNemar test

results lend themselves to different interpretations, and it may be that some people with dementia underrated their own unmet needs due to denial or anosognosia. Nevertheless, and somehow unexpectedly, their carers also reported significantly lower levels of total unmet needs at follow-up.

At item/domain level, these people with dementia already displayed a picture of complex biopsychosocial unmet needs at baseline, mainly regarding 'company', 'distress' and 'daily activities'. At follow-up, these remained the three most frequent unmet needs and the overall pattern did not differ significantly, even though 'company' and 'distress' unmet needs decreased slightly. On the contrary, in line with the clinical and functional changes in the sample over time,

the number of 'memory', 'medicines', 'mobility' and 'behavior' unmet needs slightly increased.

Notwithstanding, these changes were not accompanied by significant modifications in formal services' use: only four participants started to use them, definitely less than expected (one of the inclusion criteria was some degree of expectation that the person would require formal support within 12 months). At least partly, more use of informal care may have contributed to this, namely on account of extended supervision time.

Notably, these primary carers reported higher levels of contribution in care provision at follow-up, more than half stating a contribution higher than 80%. In accordance,

Table 6 – Formal and informal care utilization: differences between baseline and follow-up (12 months)

	Baseline	Follow-up	p-value
Formal care^a			
No formal care utilization, n (%)	34 (53.1)	30 (46.9)	0.388 ^c
Formal care utilization, n (%)	20 (45.5)	24 (54.5)	
Nursing services at home, n	1	1	
Home care, n	0	1	
Home-delivery meal services, n	2	3	
Day care, n	0	1	
Transports (healthcare-related), n	0	1	
Other (e.g., housekeeper), n	13	15	
Unspecified, n	4	2	
Informal care^a			
Time spent by carers, minutes/day (mean, SD)			
Activities of daily living	12.3 (17.4)	7.9 (12.0)	0.106 ^d
Instrumental activities of daily living	11.8 (14.7)	14.8 (15.6)	0.229 ^d
Supervision	7.0 (11.5)	15.2 (14.6)	0.001^d
Total	29.4 (25.2)	37.9 (21.3)	0.066 ^d
Other informal carer involved, n (%)			
0	12 (24.0)	11 (22.0)	0.810 ^e
1	18 (36.0)	14 (28.0)	
2	10 (20.)	15 (30.0)	
3	4 (8.0)	8 (16.0)	
4 or more	6 (12.0)	2 (4.0)	
Level of contribution in care provision ^b , n (%)			
21% - 40%	1 (2.0)	0 (0.0)	0.004^e
41% - 60%	3 (6.0)	2 (4.0)	
61% - 80%	16 (32.0)	6 (12.0)	
81% - 100%	30 (60.0)	42 (84.0)	

^a Over the past 30 days;^b Assessment of the level of contribution of the main carer, i.e., the one that was interviewed (among all involved informal carers);^c McNemar test;^d Paired samples T-test;^e Wilcoxon test

although effect sizes were low, carers' perseverance time (their estimate of how long they can continue in this way if the situation remains unchanged) tended to decrease ($p = 0.045$), approaching the low levels reported in other studies³³ while their depressive symptoms tended to increase ($p = 0.030$). Nevertheless, stability was almost the rule concerning other carer-related measures, namely quality of life, burden of care and 'information' unmet needs. Carers' 'psychological distress' unmet needs were even significantly lower at follow-up: although almost half of carers had this type of unmet need at baseline, this decreased to less than a quarter at follow-up. Such a finding remains consistent with higher involvement in caregiving over time, reflecting that more needs are being met by formal and/or informal

support and not a decrease in overall needs.

The analysis of other outcome measures for people with dementia also yielded interesting results. QOL-AD ratings remained stable overall, regardless of being self or proxy-reported. In the longitudinal analysis of the EU-Actifcare large sample, carer's proxy-ratings were significantly lower than self-ratings at all timepoints for the QOL-AD, just like for the ICECAP-O (measuring capability, a construct closely related to quality of life); proxy-ratings declined over time, but self-ratings remained stable. It was concluded that quality of life ratings in dementia must be interpreted with caution and in the context of each caregiving relationship.^{34,35} In the present analysis, restricted to the Portuguese subsample, the usual pattern of significantly worse

proxy reports by carers or other informants^{22,36} was not observed. A recent review suggested there may be stronger agreement on more observable quality-of-life domains e.g., physical health and mobility, than with, for example, anxiety/depression, emotional well-being³⁶ but perhaps this tendency is mitigated when proxies are repeatedly reminded to respond from the person's perspective.³⁷ Other measures related with quality of life, either generic (EQ-5D, ICECAP-O) or disease-specific (DEMQOL), were also considered for EU-Actifcare reports, where cross-validating quality-of-life tools in dementia was also a (secondary) aim. Analyzing the small subsample of the present study, we only reported QOL-AD results, the disease-specific measure with more in-depth documentation of validity and test-retest reliability in Portugal.

The quality of the relationship between persons with dementia and their carers also remained stable, regardless of who rated it (person with dementia or carer). After all, relationship quality obviously contributes to quality-of-life appraisals.

On the whole, our results support previous suggestions that deterioration in quality of life is not inevitable throughout the dementia journey. King et al used other quality-of-life measures (EQ-5D-3L and DEMQOL, both self and proxy-rated) reporting overall stability over one year except for proxy-ratings of the EQ-5D-3L, which declined.³⁵ They argued that, depending on which measure is used, the observed changes may be associated with different factors.³⁵ However, given our small numbers we did not undertake multivariable analyses.

These findings in Portugal must be contextualized in the larger EU-Actifcare cohort study. We previously highlighted that, in comparison with other countries' participants at baseline, Portuguese patient-carer dyads more often shared the same household, mirroring North-South differences in Europe concerning caregiving.¹³ Portuguese participants displayed lower education levels and carers specifically reported lower sense of coherence and more depressive symptoms. However, their sense of coherence scores did not deviate much from findings in similar samples; and their mean levels of depressive symptoms (falling within the 'normal' to 'possible case' range, per international cut-offs) would not represent clinical depression in most cases.

Our study also illustrates the importance of dementia needs assessment,¹⁹ underlining once more the prevalence of psychosocial unmet needs. In a recent Chilean study, for instance, the most frequent unmet needs were again 'daily activities' (39.2%), 'company' (36.1%), and 'memory' (34.9%).³⁸ Coming back to the role of formal support, the EU-Actifcare results on access and use of services align with recent literature documenting limited receipt of support services among people with mild-moderate dementia³⁹ and

inequalities in care structures, including dementia-specific services, throughout Europe.⁴⁰ Overall, we should more systematically consider users and carers' views and priorities, as in value-based healthcare.⁴¹

Another aspect has to do with the interpretation of the scores of the psychosocial measures in our sample, a matter which is not always easy. For instance, QOL-AD ratings were higher than in the Portuguese validation study,²² but this was partly conducted in long-term care. Regarding the absolute values of caregiving-related outcomes, we found no other analyses with, for example, the PAI, RSS or LOC measures (Table 1) in Portugal; a Portuguese study reported higher LSNS-6 scores in older people who were not necessarily carers.⁴² Regarding studies in other countries, the LSNS-6, PAI and RSS scores we report fell within the usual range for similar populations,⁴³⁻⁴⁵ but these carers seemingly displayed a higher locus of control.⁴⁵

It must also be noted that our study was conducted prior to the COVID-19 pandemic: Portuguese research began to unravel the additional impact of such challenges for these vulnerable populations.⁴⁶

Limitations

Our results must be cautiously interpreted. They are not generalizable, not even to the subgroup of community-dwellers with mild or moderate dementia in Portugal. First, our small convenience sample at baseline (66 dyads) was recruited to serve the purposes of the large EU-Actifcare cohort study. Inclusion criteria were deliberately restrictive; for instance, participants could not rely on significant formal care but would be expected to do so after the one-year follow-up.^{12,13} Notwithstanding, the sample was diversified regarding region and context of recruitment (healthcare levels, social services in charge). Despite a certain deviation towards higher education, the sample typicality at baseline was somehow ensured. Second, our analyzable sample was further reduced to 54 dyads, as 12 were lost to follow-up. In seven cases, attrition came from carers' exhaustion or the person's institutionalization: the results could have been different if we had been able to assess them at follow-up. However, we found no significant differences between the analyzable sample and the remaining dyads at baseline.

Although this was an observational study, it may be that some participants found the comprehensive, extended assessment process reassuring and supportive in itself, arguably influencing subjective measurements related to, for example, needs or social support. On the other hand, the use of multiple researchers to collect data potentially introduces variation in measurements,³⁸ and this other source of bias was surely minimized here.

Finally, a one-year follow-up period may be too short to

grasp the complexity of the evolution of dementia, possibly contributing to the stability of many outcomes.

Is this it? Implications of the study

Despite the limitations of the study, we believe our results to be rather important, nonetheless. First, over one year of progressing dementia, these dyads did not worsen most outcomes significantly, including unmet needs, quality of life, or most carers' measures (except depressive symptoms and perseverance time). Therefore, it is often possible to preserve quality of life, even if transiently, and even before launching specific psychosocial interventions.

Second, although their levels remained stable overall, unmet needs did exist at baseline and/or follow-up. The fact that people with dementia have many and complex biopsychosocial needs is also uncontroversial in Portugal.²⁰ Most rely on family carers with their own needs, displaying objective and subjective burden and psychological distress.^{47,48} In this context, the responses of health and social services are still grossly inadequate,⁹ which leads us to a third point.

By assessing clinical-functional and social characteristics, perceived needs, and access to and use of formal services over one year, this study highlights the importance of interventions targeting specific needs, which frequently change over short periods of time. While the evidence base for interventions to enhance timely access and appropriate use of community services remains limited,⁴⁹ they could reduce the unmet needs of people with dementia and their families along with other negative outcomes such as carers' burden and psychological morbidity.

Fourth, many participants were recruited from primary care. The SPICE five-item assessment (focusing on senses, physical ability, incontinence, cognition, and emotional distress domains) was derived from the 24-item CANE specifically for primary care users and, later, tested in Portugal as well.⁵⁰ Although some of the most-rated unmet needs in the present study would not be screened by SPICE, it tackles 'cognition' and 'psychological distress', and perhaps combining it with the two CANE carer items could prove cost-effective in such populations.

Finally, important research gaps should be acknowledged. Future studies should consider longer follow-up periods and larger samples. They should also include people with mild-to-moderate dementia who did not even reach the appropriate clinical services, which frequently happens in Portugal. Assessment bias may be decreased by combining qualitative and quantitative methods, as we did in other EU-Actifcare studies and plan to do regarding ongoing analyses of the Portuguese subsample.

CONCLUSION

This was a longitudinal, observational, and comprehen-

sive analysis of the Portuguese cohort that integrated the larger EU-Actifcare project on community-dwelling people with mild to moderate dementia.

We found a decline in patients' cognitive and functional measures and a slight increase in neuropsychiatric symptoms; this was associated with relatively little additional input from formal services, with the main carer spending more time providing supervision for the person with dementia and taking on greater overall responsibility for care. The significant increase in depressive symptoms may be interpreted as an early sign of role-captivity for these main carers. While the relative stability of quality of life may also be seen in a positive light, our results pertain to a small, albeit typical, convenience sample with some attrition, and arguably longer follow-up periods are needed in this field.

Above all, at our 12-month follow-up, we still found relevant unmet needs in specific areas; these were mainly 'psychological distress', 'daytime activities' and 'company' for people with dementia, and 'information' and 'psychological distress' for their carers. This calls for timely interventions that may be tailored to person-centered assessments of need.

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AUTHOR CONTRIBUTIONS

MGP: Contributed to the design of the EU-Actifcare study. Principal investigator of the Actifcare project in

Portugal. Planned the present study analyses. Drafted the manuscript.

MJM: Contributed to the design of the EU-Actifcare study. Coordinated and conducted the fieldwork in Portugal. Planned and conducted the present study analyses. Drafted the manuscript.

RFA: Planned and conducted the present study analyses. Drafted the manuscript.

AV, CB, LA, TAR: Closely collaborated in the Actifcare study planification and implementation in Portugal, and in fieldwork. Provided relevant contributions to the manuscript.

BW: Designed and coordinated the EU-Actifcare cohort study. Provided relevant contributions to the manuscript.

MdV, FV: Coordinators of the EU-Actifcare consortium. Designed the EU-Actifcare cohort study. Provided relevant contributions to the manuscript.

PROTECTION OF HUMANS AND ANIMALS

The authors declare that the procedures were followed according to the regulations established by the Clinical Re-

search and Ethics Committee and to the Helsinki Declaration of the World Medical Association updated in 2013.

DATA CONFIDENTIALITY

The authors declare having followed the protocols in use at their working center regarding patients' data publication.

COMPETING INTERESTS

The authors declare that no competing interests exist.

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