Needs for Care and Service Use in Dementia: Baseline Assessment of Portuguese Participants in the Actifcare Cohort Study

Necessidades de Cuidados e Recurso aos Serviços na Demência: Avaliação Inicial da Coorte Portuguesa no Estudo Actifcare

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ABSTRACT

Introduction: People with dementia and their relatives should have timely access to formal care in the community. The EU-Actifcare project analysed access to and use of formal services, as related to unmet needs for care. We describe the cohort study implementation and baseline results in Portugal, with a focus on needs for care and service use assessments.

Material and Methods: Our convenience sample consisted of 66 dyads of community-dwelling people with mild to moderate dementia and no significant use of formal services, and their informal carers. Measures included the Camberwell Assessment of Need for the Elderly and Resources Utilization in Dementia.

Results: People with dementia had unmet needs (mean 1.1; SD 1.7), mainly regarding company (23%), psychological distress (20%), and daily activities (14%). Family caregivers spent 150 minutes/day (median) providing support, and 44% had psychological distress unmet needs. Problems with access to or use of formal services, when present, were frequently due to attitudes or lack of knowledge of any or both members of the dyad.

Discussion: The recruitment process was challenging, since the inclusion criteria were restrictive. Not claiming generalizability, we recruited a typical sample of Portuguese people with mild to moderate dementia and no significant formal community support. Levels and type of unmet needs found in some participants would call for formal support, were it not for problems regarding access or use.

Conclusion: There are difficulties regarding timely access and effective use of formal care in dementia, along with relevant unmet needs.

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

RESUMO

Introdução: As pessoas com demência e os seus familiares deveriam ter acesso atempado a cuidados formais na comunidade (centros de dia, apoio domiciliário). O projecto EU-Actifcare investigou o acesso/utilização destes serviços em países europeus. Descrevemos a implementação do estudo de coorte e a avaliação inicial em Portugal, com foco nas necessidades de cuidados e recurso aos serviços.

Material e Métodos: Selecionámos uma amostra de conveniência de 66 pessoas com diagnóstico de demência ligeira a moderada (residindo na comunidade sem cuidados formais relevantes) e respetivos familiares-cuidadores. A avaliação (clínico-funcional e social) incluiu os instrumentos *Camberwell Assessment of Need for the Elderly* e *Resource Utilization in Dementia*.

Resultados: Identificámos necessidades não-cobertas dos doentes (média 1,1; DP = 1,7), principalmente de companhia (23% dos casos), sofrimento psicológico (20%) e atividades diárias (14%). Os familiares-cuidadores dedicavam 150 minutos/dia (mediana) à prestação de cuidados e 44% apresentavam necessidades não-cobertas de sofrimento psicológico. Quando havia problemas de acesso/utilização dos serviços de saúde e sociais na comunidade, estes estavam frequentemente relacionados com recusa ou desconhecimento de utentes/familiares.

Discussão: A seleção dos participantes não foi fácil, pela especificidade dos critérios adotados. Não almejando representatividade nacional, recrutámos uma amostra típica de pessoas em estádios ligeiros a moderados de demência, em serviços e regiões diferentes. Nalguns casos, encontrámos necessidades não-cobertas e repercussões familiares que já justificariam respostas de serviços na comunidade, não fossem os problemas de acesso/utilização.

Conclusão: Na área das demências, existem dificuldades no acesso atempado e utilização efectiva de cuidados formais, coexistindo com uma cobertura menor de necessidades específicas.

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Palavras-chave: Acesso aos Serviços de Saúde; Cuidadores; Demência; Determinação de Necessidades de Cuidados de Saúde; Portugal

INTRODUCTION

Increasing prevalence of dementia has been found with global ageing, reaching an estimated 131.5 million people by 2050 and a huge disease burden.[1] In Portugal, an estimated 160,287 patients above the age of 60 with dementia have been found in 2013,[2] which could be an even higher number considering the Portuguese prevalence recently obtained by the 10/66 method - Dementia Research Group (9.23%; 95% CI 7.80 – 10.90).[3]

Multiple biopsychosocial needs are involved in dementia, involving different complex entities.[4,5] Responses from health promotion to the different levels of prevention are included in this concept of 'health needs'.[6] In health service research, a 'need (for care)' is an issue to which an 'adequate' intervention exists, i.e. an evidence-based response which could potentially meet (satisfy), fully or in part, such 'need'.[4,5] Internationally, needs assessment in dementia is becoming increasingly relevant.[7] Unmet needs within different psycho-geriatric disorders have also been described in Portugal.[8–10] In addition, most patients have family support, presenting with their own needs:[11] objective and subjective burden[12] and psychological distress,[12,13] as it has also been documented in Portugal.[14,15]

Suboptimal service response has been found.[16,17] An earlier diagnosis would improve healthcare to many patients and families.[18] Despite the attempts to implement timely diagnosis, important constraints remain, frequently due to the normalisation of symptoms or lack of information.[19,20] The search for diagnosis or access to care is also delayed by stigmas, leading to family burnout and premature institutionalisation.[18,21] In addition, failures in referral to secondary healthcare (neurology, psychiatry) and in inter and intradepartmental liaisons are worth mentioning.[16,22,23]

Service research has been focused on early or late-stage dementia rather than in middle-stage, in which a timely access and regular utilisation of community services are crucial (e.g. home care). When informal care is no longer sufficient, needs related to the clinical progression of patients can be met, with an improved quality of life of patients and family, reducing family burden and associated costs or delaying institutionalisation.[24,25] There are however problems related to formal care access and regular utilisation.[20,26]

Service utilisation is analysed by the Andersen Model[27] which was recently updated.[28,29] Access to formal care depends on the interaction between individual as well as contextual determinants. The former include factors predisposing people to use (e.g. sociodemographic, beliefs), enabling factors (e.g. financial resources, health insurance, waiting lists) and those related to patient and family needs (perceived or evaluated). The contextual level is easily divided into predisposing factors (e.g. sociodemographic, cultural), enabling (e.g. health, service and equipment expenditure, health policies) and related to environmental needs / population indicators (e.g. life expectancy, mortality, levels of disability). Inter-factorial dynamics is particularly complex in conditions such as dementia, due to progressively changing needs.

In line with other studies,[30] the Actifcare project (*ACcess to TImely Formal Care*) within the European Union Joint Programme Neurodegenerative Disease /JPND (2014 - 2017) was inspired by the Andersen model. It was focused on middle-stage dementia (transition from informal care, when this becomes suboptimal, to combinations between those and community formal care e.g., home care, day care centres).[31] The study was focused on formal service access and utilisation in eight European countries (Germany, Netherlands, Ireland, Italy, Norway, Portugal, United Kingdom and Sweden), including the evaluation of unmet needs and quality of life of patients and their families. The availability, accessibility and service utilisation within the different countries were also analysed.[31] Different components (work packages-WPs) were included in this global project: WP2 (literature review; qualitative study of patients', informal caregivers' and healthcare professionals' experiences, as well as political and administrative perspectives), WP3 (longitudinal cohort study on formal care access / utilisation), WP4 (cost-efficiency analysis based on WP3), WP5 (identification of best-practice strategies and recommendations).[31]

Predisposing and enabling factors and constraints to formal care utilisation throughout one year within these eight countries were analysed by the longitudinal study (WP3), in addition to the participants' needs and quality of life.[31] The study was aimed at the initial assessment (baseline) of the Portuguese cohort included in the study, focused on needs for care and service access/utilisation.

MATERIAL AND METHODS

Design

The general protocol of the EU-Actifcare project is available at www.actifcare.eu, including the methodology of the cohort study (WP3)[31]: this was a longitudinal, observational, six and twelve-month follow-up study. Only the initial assessment of the group of participants was described in the study, as well as the specific characteristics of the study implementation in Portugal.

Participants

Dyads of patients with dementia and their main informal caregivers were selected.

Inclusion criteria: patients diagnosed (DSM-IV-TR) according to the assistant physician,[32] with early to middle-stage dementia (score 1 or 2 in Clinical Dementia

Rating-CDR scale);[33] score < 25 in Mini Mental State Examination (MMSE) scale[34]; unpaid (informal) caregiver with a regular contact with the patient (at least once a week); need for formal care over the subsequent year, according to the assistant physician's subjective evaluation (allowing for the inclusion of a significant number of patients presenting in a transition stage for formal care). 'Community formal care' was defined as home care or day care services (e.g. centres) or any other regular support (at least once a week) from paid professionals or other caregivers.

Exclusion criteria (patients): alcohol-related persisting dementia, Huntington's disease (any subtype was reported, whenever present); relevant formal care due to dementia at that moment or over the past six months (community or institutional care for family relief).

Exclusion criteria (patients/caregivers): severe language, hearing or literacy impairment; relevant comorbidity (e.g. severe mental disease or other, developmental disorder).

The recruiting of at least 50 dyads per country was anticipated by the EU-Actifcare protocol, 400 in total. Whenever a national representativeness was not ensured, convenience samples should prevent from reproducing any nationwide atypical situations. In Portugal, anticipating the presence of recruiting constraints due to the restrictive characteristics of study inclusion criteria (mentioned above), we linked up with primary care, neurology and psychiatry outpatient clinics, private services and non-profit organisations (e.g. Alzheimer Portugal) in different regions (Lisbon, south bank of the Tagus, Cascais, Evora, Mora, Gouveia).

Measures

The study variables and evaluation instruments are shown in Table 1.[31] Portuguese versions of different instruments were already validated,[31] while the preliminary validity data of the remaining instruments were not described in the study, nor any data on each dyad's quality of life, interpersonal relationship, social support and locus of control (Table 1).

Assessment of patients with dementia

Data from two interviews were mainly described in the study, focused on the assessment of needs and description of service utilisation: Camberwell Assessment of Need for the Elderly (CANE)[4,5] and Resources Utilization in Dementia (RUD).[35] The presence of (un)met needs for care, according to a 'patient-centred' approach, is assessed by the CANE interview, including 24 domains (biological, psychological or social) and allowing for the comparison between the perspective of needs of patients, informal caregivers and professionals (these are considered into a fourth score which is obtained by researchers / assessors). There are absent, unmet or met needs within each domain. Total score is obtained by adding up the scores regarding items in which needs are recorded.[8] This instrument has shown robust validity and reliability (test-retest, inter-observer),[5] with internationally confirmed psychometric properties.[7,36] In Portugal, the instrument was translated,[8] validated[9] and used in service research.[10,14] The perspectives of needs of patients, informal caregivers and assessors were considered in this study.

Formal and informal care utilisation in dementia are measured by the RUD interview, which was translated into 58 different languages.[35] As regards informal care utilisation, data on the time spent by the family-caregivers in care provision / supervision were obtained. The instrument has shown good psychometric properties (face validity, reliability).[35] The evaluation of formal care access / utilisation was supplemented with an ad hoc check-list,[31] in addition to patient's clinical and functional characteristics: dementia severity,[33] cognitive status,[34] neuro-psychiatric symptoms[37], comorbidities[38] and functional status[39] (Table 1).

Assessment of informal caregivers

Information needs and those related to psychological distress were assessed (two items in CANE interview specific for caregivers)[4,5] and resource utilisation (RUD).[35] The presence of symptoms of anxiety and depression was also assessed (Table 1): anxiety and depression symptoms,[40] disease-related family burden,[41] perseverance time[42] and sense of coherence.[43] Symptoms of depression and/or anxiety were quantified by the Hospital Anxiety and Depression Scale (HADS) and internationally validated cut-offs in 'depression' and 'anxiety' subscales were considered: ≥ 11 (probable case) and ≥ 8 (possible case).[40,44] These cut-offs were not strictly validated in Portugal[45] and were used with limitations.

Procedures

Training of interviewers

Ten interviewers (clinical psychologists) were selected and four training sessions on the administration and scoring of the instruments (videos, role-play sessions) were carried out, focused on the CANE interview and in inter-observer agreement. Information was provided at the recruiting locations.

Study pilot

A study pilot (n = 5) was carried out in Lisbon, allowing for the improvement of the Portuguese versions of the instruments and aimed at procedure coordination.

Fieldwork activity

Interviews were scheduled at the patient's home or any other convenient place, in which privacy and comfort were ensured. These were separately conducted with the patient and family-caregiver (including different moments together, whenever adequate and divided in two moments in order to reduce evaluation overload).

Quality control

Data were collected according to the European protocol and were monitored by the national fieldwork coordination (MJM, MGP) and quality control of entered data into the

Table 1 – Instruments used in the cohort study

Instrument	Variable	Respondents[a]	Author (year) / Portuguese version (year) and national validity reference
Sociodemographic and clinical characteristics of the patients with dementia			
Sociodemographic questionnaire	Sociodemographic data	1,2	*Grupo de Trabalho Actifcare em Portugal* (2015)
Clinical Dementia Rating (CDR)	Dementia severity	1,2	Morris (1993) / *Grupo de Estudos de Envelhecimento Cerebral e Demência* (2008)
Mini Mental State Examination (MMSE)	Cognitive status	1	Folstein *et al* (1975) / Guerreiro *et al* (1994); Portuguese version obtained from Psychological Assessment Resources, via MAPI Research Trust – PROQOLID (2014)
Neuropsychiatric Inventory Questionnaire (NPI-Q)	Neuropsychiatric symptoms	2	Kaufer *et al* (2000) / Adapted from the *Grupo de Estudos de Envelhecimento Cerebral e Demência* (2008); online approval obtained from the website http://www.npitest.net/ (2014)
Charlson Index	Comorbidity	4	Charlson *et al* (1994) / *Grupo de Trabalho Actifcare em Portugal* (2015)
Lawton Instrumental Activities of Daily Living (IADL)	Instrumental activities of daily living	2	Lawton & Brody (1969) / Araújo *et al* (2008)
Physical Self-Maintenance Scale (PSMS)	Activities of daily living	2	Lawton & Brody (1969) / Araújo *et al* (2008)
Service access and utilisation			
Checklist of service utilization	Access and reasons for (no) utilisation of services	1,2	*Grupo de Trabalho Actifcare em Portugal* (2015)
Resources Utilization in Dementia (RUD) 5.0[b]	Service utilisation	1,2	Wimo *et al* (2013) / Portuguese version obtained online from the website http://rudinstrument.com (2015)
Needs for care, quality of life, quality of the relationship			
Camberwell Assessment of Need for the Elderly (CANE)	Needs for care	1,2,4	Reynolds *et al* (2000) / Gonçalves-Pereira *et al* (2007); Fernandes *et al* (2009)
EQ-5D-5L / EQ-VAS	Health-related quality of life	1,2,3	Brooks (1996) / Ferreira *et al* (2013)
DEMQOL-U / DEMQOL- Proxy-U	Quality of life of patients with dementia	1,3	Mulhern *et al* (2013) / *Grupo de Trabalho Actifcare em Portugal* (2015)
Quality of Life-Alzheimer's Disease (QOL-AD)	Quality of life of patients with dementia	1,3	Logsdon *et al* (1999) / Bárrios *et al* (2013)
CarerQoL-7D / CarerQoL-VAS	Quality of life of caregivers	2	Brouwer *et al* (2006) / *Grupo de Trabalho Actifcare em Portugal* (2015)
ICEpop CAPability Measure for Older People (ICECAP-O)	Capability/quality of life of caregivers and patients with dementia	1,2,3	Coast *et al* (2008) / *Grupo de Trabalho Actifcare em Portugal* (2015)
Positive Affect Index (PAI)	Quality of the relationship between caregivers and patients with dementia	1,2	Bengtson & Schrader (1982) / *Grupo de Trabalho Actifcare em Portugal* (2015)
Symptoms of anxiety and depression, overload and social support of caregivers			
Hospital Anxiety and Depression Scale (HADS)	Anxiety and depression	2	Zigmond & Snaith (1983) / Pais-Ribeiro *et al* (2007); Portuguese version obtained from GL Assessment, via MAPI Research Trust – PROQOLID (2014)
Relative Stress Scale (RSS)	Disease-related family burden	2	Greene *et al* (1982) / Grupo de Trabalho Actifcare em Portugal (2015)
Lubben Social Network Scale (LSNS-6)	'Perceived' social support	2	Lubben, 1988 / Ribeiro *et al* (2012)
Perseverance time	Single question[d]	2	Kraijo *et al* (2014) / *Grupo de Trabalho Actifcare em Portugal* (2015)
Locus of control and sense of coherence of caregivers			
Locus of Control Behaviour Scale (LOC)[c]	Locus of control	2	Craig *et al* (1984) / *Grupo de Trabalho Actifcare em Portugal* (2015)
Orientation to Life Questionnaire (SOC-13)	Sense of coherence	2	Antonovsky (1987) / Saboga-Nunes (1999)

[a] Patients with dementia (1); informal caregivers/family (2); informal caregivers (as a proxy, giving an opinion on the status of the patient with dementia or giving the response that patients would give) (3); researchers/interviewers (4); [b] Application of selected items; [c] Instruments only used on the first evaluation; [d] '*Se a situação de cuidados se mantiver tal como está, quanto tempo será capaz de continuar a prestar cuidados?*' ('In case that the current situation remains unchanged, how long would you be able to keep on taking care of the patient?')

MACRO system (WP3 coordination/Bangor University). A data randomised cross-check was involved in a second level of quality control (European): data from each centre was checked by another centre, until a final consensus was reached.

Statistical analysis

An exploratory analysis of the interesting variables was carried out, followed by an inferential study using non-parametric (Kruskall-Wallis, Mann-Whitney, chi-square) or parametric tests, according to the conditions of applicability. Kappa coefficients (-1 to +1) were obtained for each item of the CANE interview (the agreement between the perspective of unmet needs of patients and informal caregivers was considered, while the perspective of interviewers was not). Depending on the value of Kappa, a poor (K < 0.20); slight (0.21 – 0.40); fair (0.41-0.60); good (0.61-0.80) or excellent (K > 0,81) level of agreement was considered.[46] A 0.05 level of significance has been considered. Statistical Package for the Social Sciences/SPSS, v23.0 for Windows software was used.

Ethical and formal aspects

An informed consent has been obtained from patients and caregivers. The study was approved by the different Ethics Committee of the involved institutions (*NMS/Faculdade de Ciências Médicas*; *Centro Hospitalar de Lisboa Ocidental*; *ARS Lisboa e Vale do Tejo*; *ARS Alentejo*) and by the *Comissão Nacional de Proteção de Dados*. Agreements were made with Alzheimer Portugal, *Santa Casa da Misericórdia de Mora*, *Hospital do Mar-Luz Saúde* and *Associação de Beneficência Popular de Gouveia*.

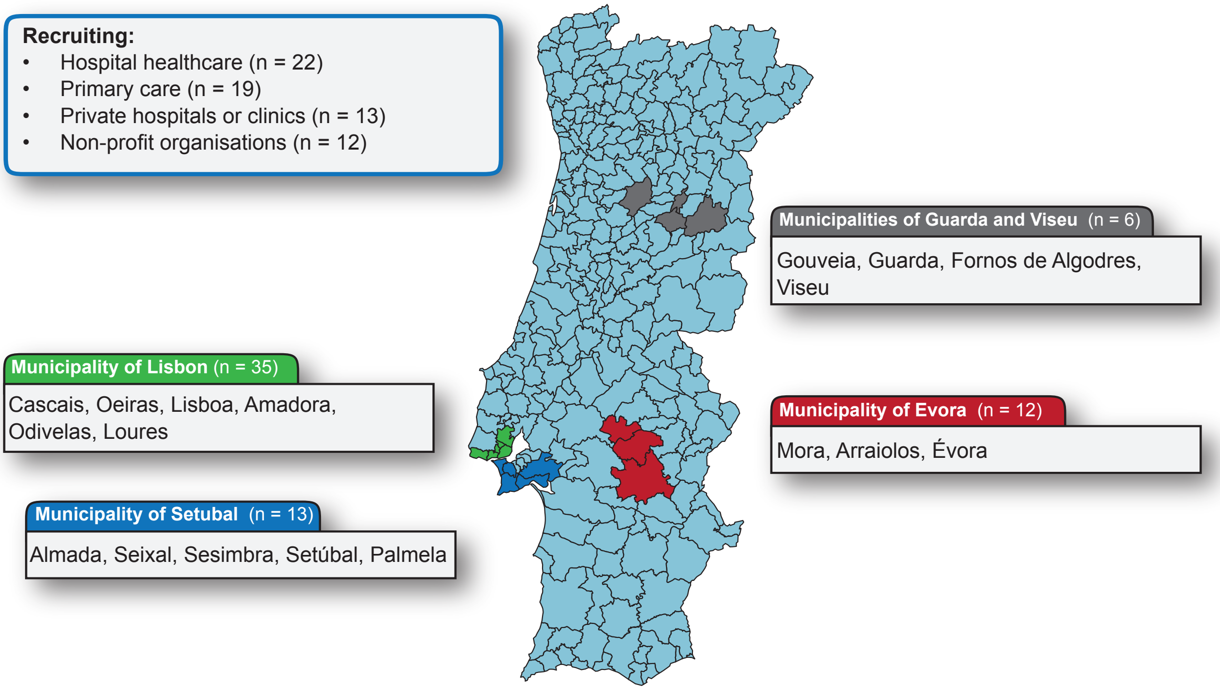
RESULTS

Demographic and clinical characteristics

In total, 66 dyads of patients with dementia and caregivers were included in the study, following the exclusion of 17 that did not comply with inclusion criteria. The participants lived in 18 different municipalities and were selected from outpatient clinics of family medicine, neurology and psychiatry (mainly public, even though also from private institutions) or non-profit organisations (Fig. 1).

Characteristics of the Portuguese participants are shown in Table 2 and were compared with the global sample of the EU-Actifcare[47] (mean age of 77.3 has been found, range 57-91, 2/3 female and 45.5% with basic education, 12.1% secondary and 12.1% high education). Most patients were diagnosed with Alzheimer's disease (37.9%) while most (89.4%) patients presented with early-stage (mild) dementia (CDR 1). Comorbidity was found in 41 patients (62.1%), e.g. diabetes: 20 (30.3%); peptic ulcer: 6 (9.1%); coronary heart disease: 5 (7.6%); peripheral vascular disease: 5 (7.6%). Caregivers were aged between 35 and 91 (mean 64.9), mostly female (around 2 thirds), spousal (60.6%) and/or living with the patient (84.8%). Some illiterate patients were found (13.6%), while 48.5% had basic education, 16.7% secondary and 21.2% high education.

When HADS was applied to caregivers, 6 (9.1%) presented with depression and anxiety, 7 (10.6%) with depression and no anxiety and 3 (4.5%) with anxiety and no depression (probable cases: cut-off 10/11). Caregivers with symptoms of anxiety and/or depression (16 patients; 24.2%) have described higher family burden, when compared to the remaining 50 (RSS: median 50.2 *vs.* 28.2; *p* < 0.001). No significant differences were found as regards



Recruiting:
- Hospital healthcare (n = 22)
- Primary care (n = 19)
- Private hospitals or clinics (n = 13)
- Non-profit organisations (n = 12)

Municipalities of Guarda and Viseu (n = 6)
Gouveia, Guarda, Fornos de Algodres, Viseu

Municipality of Lisbon (n = 35)
Cascais, Oeiras, Lisboa, Amadora, Odivelas, Loures

Municipality of Evora (n = 12)
Mora, Arraiolos, Évora

Municipality of Setubal (n = 13)
Almada, Seixal, Sesimbra, Setúbal, Palmela

Figure 1 – Participant recruiting and regional distribution

Table 2 – Sociodemographic and clinical characteristics of the patients with dementia and their family / informal caregivers: Portuguese and non-Portuguese participants in EU-Actifcare

Patients with dementia	**Portuguese participants (n = 66)**	**Non-Portuguese participants (n = 385)**[a]	***p*-value**
Age, years, mean (SD)	77.3 (6.2)	77.8 (8.1)	0.516
Gender: female, n (%)	41 (62.1)	205 (53.2)	0.228
Education, years, mean (SD)	6.4 (6.1)	10.4 (3.8)	0.001
Types of dementia, n (%)			0.169
Alzheimer	25 (37.9)	193 (50.4)	
Vascular	8 (12.1)	44 (11.5)	
Mixed	7 (10.6)	49 (12.8)	
Dementia with Lewy Bodies	2 (3.0)	4 (1.0)	
Other	4 (6.1)	23 (6.0)	
Unspecified	20 (30.3)	72 (18.7)	
CDR categories 1 / 2, n (%)	59 (89.4) / 7 (10.6)	295 (76.6) / 80 (20.8) / 10 (2.6) sem informação	0.052
MMSE, mean (SD)	17.8 (4.8)	19.2 (4.9)	0.033
NPI total score, mean (SD)	6.8 (5.5)	7.9 (5.5)	0.139
Comorbidity (Charlson), mean (SD)	1.8 (0.9)	1.6 (0.7)	0.110
None, n (%)[b]	25 (37.9)	194 (51.1)	
Low comorbidity, n (%)[b]	31 (47.0)	131 (34.5)	
High comorbidity, n (%)[b]	10 (15.2)	55 (14.5)	
Sem informação	0	5 (1.3)	
IADL, mean (SD)	3.7 (2)	3.4 (1.9)	0.190
PSMS, mean (SD)	3.7 (2)	3.7 (1.8)	0.935
Informal caregivers			
Age, years, mean (SD)	64.9 (15.0)	66.7 (12.9)	0.318
Gender, female, n (%)	44 (66.7)	255 (66.4)	0.967
Educação, anos, média (DP)	9 (6.3)	12.4 (3.8)	0.001
Cohabitation with patients with dementia, n (%)	56 (84.8)	267 (69.5)	0.011
Relationship with patients with dementia, n (%)			0.447
Spouse / marital status	40 (60.6)	248 (64.4)	
Son, daughter	20 (30.3)	117 (30.4)	
Other family (e.g. daughter-in-law, sister)	6 (9.1)	20 (5.2)	
Anxiety (HADS), mean (SD)	6.5 (3.9)	6.2 (3.8)	0.452
Depression (HADS), mean (SD)	6.4 (4.4)	4.5 (3.4)	0.001
Total RSS, mean (SD)	22.3 (11.5)	21.1 (10.8)	0.432
Emotional distress	10.5 (4.8)	9.2 (4.9)	0.038
Social distress	7.3 (5.3)	7.6 (4.8)	0.318
Negative feelings	4.4 (2.9)	4.4 (2.9)	0.262
Perseverance time, n (%)			0.544
Less than 1 week	0	0	
More than 1 week, less than 1 month	0	5 (1.3)	
More than 1 month, less than 6 months	4 (6.3)	19 (5.0)	
More than 6 months, less than 1 year	7 (11.1)	30 (7.9)	
More than 1 year, less than 2 years	7 (9.5)	59 (15.6)	
More than 2 years	48 (73.0)	265 (70.1)	
SOC-13, mean (SD)	64 (11.1)	67.7 (10.9)	0.012

CDR: Clinical Dementia Rating Scale; MMSE: Mini Mental State Examination; NPI: Neuropsychiatric Inventory; IADL: Instrumental Activities of Daily Living; PSMS: Physical Self-Maintenance Scale; HADS: Hospital Anxiety Depression Rating Scale; RSS: Relative Stress Scale; SOC-13: Sense of Coherence Scale-13. [a] Unpublished data. Note: Data in Kerpershoek. Vugt, Wolfs, *et al.* (2017)[47] refer to the global EU-Actifcare sample (n = 451) [b] Charlson index – none: 0-1 conditions; low comorbidity: 2 conditions; high comorbidity: ≥ 3 conditions.

the needs of corresponding patients. As regards caregivers' needs, a significant association between needs of 'psychological distress' has been found (which was not found as regards 'information on dementia') and probable anxiety and/or depression (*p* = 0.004).

Needs for care

Total needs for care and differences between perspectives

The perspectives of unmet needs (item by item) of patients and caregivers are shown in Table 3. No or poor agreement between those two perspectives has been found in most items. Fair of good levels of agreement were only found in 'feeding', mobility/falls', 'vision/hearing/communication', 'personal care' and 'care to other people'. Unmet needs most frequently described by the patients regarded 'psychological distress' (19.7%), 'information' (18.2%), 'memory' (18.5%), 'companion care' (18.5%) and 'vision/hearing/communication' (16.7%), while those most frequently described by caregivers regarded 'activities of daily living' (27.3%), 'psychological distress' (15.2%), 'companion care' (15.6%), 'memory' (12.1%) and 'social benefits' (12.1%).

A comparison between the perspectives of total needs of patients, caregivers and assessors is also shown in Table 3. No significant differences were found regarding unmet needs. Lower met needs (and total) were described by patients, when compared to caregivers and assessors (*p* < 0.001). Unmet needs per person ranging between 0 and 8 have been described by assessors (>2 were described by 9 (13.6%) participants.

Assessors' integrative perspectives on needs for care

Assessors' perspectives on patients and caregivers' needs for care (item per item) are shown in Table 4. More

Table 3 – Unmet needs for care (perspectives of patients with dementia and informal caregivers) and total needs for care (including the perspectives of assessors)

Unmet needs, n (%)	Patients with dementia	Informal caregivers	Kappa agreement[a]	*p*-value[b]
Housing	1 (1.5)	1 (1.5)	-0.016	0.865
Household care	2 (3)	1 (1.5)	0.357	< 0.001
Eating	0 (0)	1 (1.5)	0.643	< 0.001
Personal care	1 (1.5)	0 (0)	0.507	< 0.001
Care to other people	0 (0)	0 (0)	0.476	< 0.001
Activities of daily living	4 (6.1)	18 (27.3)	0.224	0.001
Memory	12 (18.5)	8 (12.1)	0.041	0.470
Vision / hearing / communication	11 (16.7)	4 (6.1)	0.572	< 0.001
Mobility / falls	2 (3)	2 (3)	0.626	< 0.001
Continence care	5 (7.8)	5 (7.8)	0.359	< 0.001
Physical health	1 (1.5)	4 (6.2)	0.061	0.333
Medication / harmful substances	1 (1.5)	3 (4.6)	0.203	0.012
Psychotic symptoms	1 (1.5)	2 (3)	0.134	0.052
Psychological distress	13 (19.7)	10 (15.2)	0.312	< 0.001
Information (on dementia and treatment)	12 (18.2)	4 (7)	0.039	0.721
Personal safety (parasuicidal behaviour)	2 (3)	1 (1.5)	0.313	0.001
Personal safety (unintentional exposure)	2 (3)	1 (1.5)	0.299	0.002
Abuse / neglect	0 (0)	0 (0)	--	--
Behaviour	0 (0)	2 (3)	--	--
Alcohol	0 (0)	0 (0)	--	--
Companion care	12 (18.5)	10 (15.6)	0.288	0.003
Intimate relationships	5 (7.7)	3 (4.6)	-0.064	0.564
Financial management	0 (0)	1 (1.5)	0.261	0.003
Social benefits	1 (1.5)	8 (12.1)	0.029	0.733
Total needs, mean (SD)	Patients with dementia	Informal caregivers	Assessors	*p*-value[c]
Unmet needs	1.3 (1.8)	1.4 (1.4)	1.1 (1.7)	0.238
Met needs	5.0 (2.6)	8.0 (2.7)	7.7 (2.8)	< 0.001
Global needs (met or unmet)	6.3 (2.7)	9.4 (3.0)	8.9 (3.1)	< 0.001

[a] The kappa coefficient was obtained for each item in order to assess the agreement between patients with dementia and caregivers regarding unmet needs of the patients. [b] *p*-value refers to the differences between the perspectives of patients and caregivers regarding unmet needs (item by item). [c] *p*-value refers to the differences between the perspectives of patients, caregivers and assessors regarding total unmet, met and global needs (Kruskal-Wallis test).

frequent unmet needs of patients (mean 1.1; SD = 1.7) regarded 'companion care' (22.7%), 'psychological distress' (19.7%) and 'activities of daily living' (13.6%). Even though no unmet needs were described by 33 (50.0%) patients, the presence of at least three unmet needs was described by 9 (14.0%). Almost half of the caregivers in our cohort described unmet needs regarding 'psychological distress' (43.9%), even though these were only described by assessors in 12.1% of the patients as regards 'information' (Table 4). From their own perspective, unmet needs regarding 'psychological distress' and 'information' were described by 25.8% and 19.7% of caregivers, respectively.

Formal and informal care utilisation

In total, 44 of the patients (66.7%) did not use any formal services during the month preceding the interview (e.g. nursing / home care, home-delivered meals, day care centre), while the remaining (33.3%) have used formal care according to the inclusion criteria (e.g. nursing / home care, due to other conditions; old maid providing no significant support to dementia-related disability) (Table 5).

The hypothesis of using some kind of formal care as defined in the protocol was considered by 20 (30.3% of the total) from the 44 'non user' patients. The reason most frequently given for non-utilisation was patient refusal (33.4%), caregiver's or both, mainly regarding day care centres, home-delivered meals or temporary hospitalisation or admission to a nursing home. Reluctance to care was described by participants due to the lack of quality and association with "dependence" and "decline" (sic). Unawareness (25.8%) was also described by some patients and/or caregivers regarding service utilisation, to which some interest would be assigned, as admitted in the interviews: e.g. temporary hospitalisation / admission to a nursing home, support group for caregivers, cognitive stimulation. The remaining reasons (40.8%) for non-utilisation were distributed

Table 4 – Needs for care of patients with dementia and informal caregivers, according to the integrating perspective of assessors

	Identified needs			
Items / domains	No need	Met need	Unmet need	No information
Needs of patients with dementia, n (%)				
Housing	65 (98.5)	1 (1.5)	-	-
Household care	10 (15.2)	55 (83.3)	1 (1.5)	-
Eating	11 (16.7)	53 (80.3)	1 (1.5)	1 (1.5)
Personal care	26 (39.4)	39 (59.1)	-	1 (1.5)
Care to other people	59 (89.4)	6 (9.1)	1 (1.5)	-
Activities of daily living	37 (56.1)	19 (28.8)	9 (13.6)	1 (1.5)
Memory	-	61 (92.4)	3 (4.5)	2 (3.0)
Vision / hearing / communication	47 (71.2)	11 (16.7)	4 (6.1)	4 (6.1)
Mobility / falls	45 (68.2)	18 (27.3)	2 (3.0)	1 (1.5)
Continence care	47 (71.2)	9 (13.6)	5 (7.6)	5 (7.6)
Physical health	2 (3.0)	62 (93.9)	1 (1.5)	1 (1.5)
Medication / harmful substances	7 (10.6)	52 (78.8)	2 (3.0)	5 (7.6)
Psychotic symptoms	57 (86.4)	5 (7.6)	1 (1.5)	3 (4.5)
Psychological distress	37 (56.1)	12 (18.2)	13 (19.7)	4 (6.1)
Information (on dementia and treatment)	57 (86.4)	-	2 (3.0)	7 (10.6)
Personal safety (parasuicidal behaviour)	61 (92.4)	1 (1.5)	2 (3.0)	2 (3.0)
Personal safety (unintentional exposure)	25 (37.9)	31 (47.0)	4 (6.1)	6 (9.1)
Abuse / neglect	63 (95.5)	-	1 (1.5)	2 (3.0)
Behaviour	55 (80.3)	8 (12.1)	1 (1.5)	2 (3.0)
Alcohol	64 (97.0)	-	2 (3.0)	-
Companion care	43 (65.2)	5 (7.6)	15 (22.7)	3 (4.5)
Intimate relationships	61 (90.9)	1 (1.5)	2 (3.0)	2 (3.0)
Financial management	6 (13.6)	58 (87.9)	1 (1.5)	1 (1.5)
Social benefits	44 (66.7)	4 (6.1)	2 (3.0)	16 (24.2)
Needs of informal caregivers, n (%)				
Needs of information	51 (77.3)	3 (4.5)	8 (12.1)	4 (6.1)
Psychological distress	24 (36.4)	11 (16.7)	29 (43.9)	2 (3.0)

among different categories (e.g. waiting time; unavailability; distance; financial constraints).

The support provided by local services to deal with these problems (CANE/section III) was frequently lower than what was considered by assessors as required, in patients with most common unmet needs ('companion care', 'psychological distress' and 'activities of daily living'). For instance, no support was provided to patients describing unmet needs for 'activities of daily living', even though small-moderate assistance would be required by 88.8% of these. It is worth mentioning that 49 (74.2%) patients had attended medical consultation(s) over the past month (which was not considered as 'formal care' in this project).

Finally, as regards informal care, a 60-minute mode and 150 minutes/day median have been found (mostly to assist daily living instrumental activities: 93 minutes/day). Even though at least one informal caregiver was involved with 54 of the patients (81.8%), most main caregivers (57.6%) described as having ensured more than 80% of patient's care.

DISCUSSION

The EU-Actifcare project was focused on service access and utilisation, including day care centres or home care. An observational study involving an accurately selected significant European sample was included, from a tendentially systemic point of view, with patients with dementia and caregivers. A comprehensive evaluation of needs and service utilisation by a subgroup of Portuguese patients with early-stage (mild) to middle-stage dementia living in the community has been described.

Main results and comparison with other studies

From the assessors' perspective, the participants presented, on average, with one unmet need, mainly regarding 'companion care' (22.7%), 'psychological distress' (19.7%) and 'activities of daily living' (13.6%) (suggesting the presence of suboptimal informal care and/or a partial indication for formal care as services could respond within these domains). Most frequently found unmet needs in non-Portuguese participants in the sample of the EU-Actifcare[47] regarded 'activities of daily living' (32.1%), 'companion care' (28.7%) and 'memory' (15.1%), while Portuguese patients' met needs mainly regarded 'physical health' (93.9%), 'memory' (92.4%) and 'financial management' (87.9%). Lower met needs regarding 'physical health' (65.4%) and 'memory' (82.6%) while similar met needs regarding 'financial management' (83.2%) were found in non-Portuguese

Table 5 – Formal and informal care utilisation

Formal care utilisation[a]	
No formal care utilisation, n (%)	44 (66.7)
Formal care utilisation, n (%)	22 (33.3)
Nursing services at home	3 (4.5)
Home care	16 (24.2)
Home-delivery meal services	5 (7.6)
Day care	-
Transports (healthcare-related)	-
Others	1 (1.5)
Informal caregiver utilisation[a]	
Time spent by caregivers, minutes/day, median (range)	
Activities of daily living	13 (0 - 240)
Instrumental activities of daily living	93 (6 - 300)
Supervision	16 (0 - 480)
Total	150 (6 - 870)
Other informal caregiver involved, n (%)	
0	12 (18.2)
1	25 (37.9)
2	14 (21.2)
3 or more	15 (22.7)
Level of contribution in care provision[b], n (%)	
21% - 40%	1 (1.5)
41% - 60%	5 (7.6)
61% - 80%	22 (33.3)
81% - 100%	38 (57.6)

[a] Over the past 30 days; [b] Assessment of the level of contribution of the main caregiver (among all the involved informal caregivers) who was interviewed

participants. However, the comparison of the levels of needs between the different participant countries in the EU-Actifcare was limited by the fact that convenience samples were used, in line with what happened with the comparison of other results in our study between the participating countries or with the comparison of the levels of need with results from other studies.

Our findings were generally in line with international studies, e.g. by Miranda-Castillo *et al.*, in which more frequent unmet needs regarded 'activities of daily living' (50.7%), 'companion care' (39.5%) and 'psychological distress' (30.9%)[48] while it is worth mentioning that only 5% of our patients presented with unmet needs regarding 'memory' (these were almost always met), which is usually higher in patients with dementia admitted to day hospitals,[4] hospitals[49] or nursing homes[4,50,51] (or even in geriatric populations with heterogeneous neuropsychiatric diagnoses).[52] In other national studies, unmet needs mainly regarded 'psychological distress', 'activities of daily living', 'companion care' and 'memory'[9] or 'psychological distress', 'activities of daily living' and 'benefits'.[10] The use of a specific group of patients in our study (presenting with early to middle-stage dementia, with no formal care within the community) is what makes our results unusual, when compared to literature.

Differences have been found in the assessment of the needs of patients with dementia (when the perspectives of patients and caregivers were compared, for instance).[7,51,53] In this small group of Portuguese patients, this was more significant in 'housing', 'memory', 'physical health', 'information', 'intimate relationships' and 'social benefits'. However, no significant differences were found as regards total unmet needs between patients and caregivers, while almost the double of the average level of needs was found from the caregivers' perspective.[47] This could reflect a simple effect of sampling or an influence of the lower education of caregivers in our group. As regards met needs, significantly higher levels have been found, from the family/caregivers perspective, in line with what has been found in the global sample.[47] Anyway, none of these 'international' comparisons should be overvalued (cf. Limitations). Regardless of the difficult interpretation of some global tendencies (sampling level), important differences between the perspectives of patients, caregivers and assessors have been found, in clinical terms (individual level) and regarding service assessment, warranting systematic evaluations of needs for care.[4]

As regards the needs of caregivers, higher needs regarding 'psychological distress' were found, when compared to what was usually found in national[9,10,14] and international literature[5] (almost half of the patients presented with this type of unmet needs). In addition, only one quarter of the participants presented with 'probable' minor psychiatric morbidity (HADS). Even though a lower difference regarding the rate of needs and psychopathology that was found when 'possible' HADS cases were considered, it is thereby confirmed that the identification of 'needs' is conceptually different from the establishment of clinical diagnoses. The remaining results of these caregivers were also consistent with the assessment of needs. Objective (median care provision of around 150 minutes/day) and subjective burden (total RSS: mean 22.3; SD = 11.5) were found, according to literature.[35,54] Almost one third of the caregivers have described as being unable to keep on taking care of the patients for more than two years, under the same conditions. A lower perseverance time was found in other studies, even though involving groups of more severely affected patients.[55]

In short, untimely access to formal care by a certain amount of participants has been suggested by the level and type of needs. Most participants had not used formal care over the past month and, whenever this occurred, the reasons were not directly linked to dementia. Part of the problems in service access / utilisation was based on negative attitudes of patients and/or family (e.g. refusal, stigmatisation) rather than in structural constraints (e.g. provision and proximity) or organisational (e.g. waiting times or referral), according to this initial assessment of the cohort. Therefore, even with an intentionally selected group of participants with no need for any relevant formal care (CDR < 2) and in many cases with a proven clinical support, unmet needs and problems regarding formal care search, access or utilisation have been found.

Sampling specificities and recruiting constraints

A fairly common community sample in functional and clinical terms was selected, including patients with early to middle-stage dementia. Even though a higher-than-usual percentage of participants with secondary or high education has been found[56], a wide ranging recruitment in geographical, social and service terms has been obtained. Most participants lived in Lisbon and in Setubal, while 27.3% of participants living in the countryside were included, from both urban and rural areas. Significantly lower MMSE scores were found when compared to the remaining participants in the EU-Actifcare. The lower education level of the Portuguese participants could have contributed to this result, with the additional disadvantage of the use of the official translation, which was not specifically adapted to the Portuguese language. Female and spouse caregiver predominance is usual in these populations, particularly in Portugal (where the number of participants living with the patient was, as expected, significantly higher when compared to the remaining countries). In addition, the results of the psycho-social and psychopathological assessment have also confirmed the internal validity and in part the external validity of the study (cf. previous section).

The small size of the group of participants (n = 66) was not related to recruiting problems: the EU-Actifcare was aimed at 50 dyads per country and this number was even exceeded. The team had to deal with the initial constraints (these were expected, due to the national reality of delayed diagnosis of dementia and/or utilisation of formal care). In fact, criteria were intentionally restrictive in order to include patients already diagnosed with dementia while still presenting with levels of disability that did not correspond to an absolute indication for formal care. Delayed diagnosis is a frequent occurrence in Portugal and not always acknowledged by services where patients attend for other reasons (e.g. primary care, medicine/surgery departments).[2,22,23] In addition, many patients with a confirmed diagnosis were excluded from the study due to already being provided with significant formal care for dementia-related problems. Whenever the lack of community responses persisted, with regional disparities (day care centres for dementia or perhaps at a lower level, adequate home care), many patients relied on housemaids as non-qualified formal caregivers or would have been institutionalised.

Limitations of the study

According to the EU-Actifcare protocol,[31] results could not necessarily have been generalized to the Portuguese population of patients with dementia, in line with the remaining countries, not even to the subgroup of patients with early to middle-stage dementia. However, the origin of the participants was diversified, as regards their place of residence, healthcare and social services, in order to reduce the selection bias. This was a relatively typical sample, with a possible bias towards a higher level of education.

The lower literacy of some participants could have compromised the assessment. However, the interviewers were specifically trained and some interviews were divided into close moments, merged with informal interactions aimed at reducing the information overload and preserving data quality. A possible bias regarding the use of the official version of the MMSE is worth mentioning, as discussed above, even though these scores were not used for the analysis.

The small size of our group of participants is a limitation of a comprehensive multivariate analysis. This has been made *vs.* the global sample (451 dyads)[47] and will be in part approached by the Portuguese longitudinal study. The role of regional discrepancies or informal care provision, or even the specific characteristics of early-onset dementia should be approached in further studies.

Study implications in terms of policies and services

The identification of the constraints regarding formal care access and utilisation could have put pressure on the implementation of specific policies. Literature reviews,[57] qualitative approach to patients with dementia, caregivers and professionals,[58] as well as administrators / political decision-makers[59] were involved in the effort of the EU-Actifcare project into the systematisation of these constraints. The results of the longitudinal study are expected to allow for a better understanding on the determinants of service utilisation, enhancing enablers and reducing constraints. Best-practice recommendations have emerged following the project, aimed at improving formal care access / utilisation. Its national applicability should be discussed, namely regarding the role of primary care.[23,60]

A timely access and adequate service utilisation in the community could certainly reduce unmet needs of patients with dementia and their informal caregivers, as well as family burden.

CONCLUSION

Relevant constraints regarding formal care utilisation in the community by patients with early to middle-stage dementia and family / caregivers were suggested by these preliminary findings regarding the Portuguese Actifcare cohort. Unmet needs in specific areas (mainly regarding ‘companion care’, psychological distress’ and ‘activities of daily living’) in addition to significant family burden have been found. With the presence of issues regarding formal care access / utilisation in the community, the implementation of specific best-practice strategies could respond to many needs of this population.

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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 Committees of *NMS/Faculdade de Ciências Médicas*; *Centro Hospitalar de Lisboa Ocidental*; *ARS Lisboa e Vale do Tejo*; *ARS Alentejo*, as well as by the *Comissão Nacional de Protecção de Dados* 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. Informed consents were obtained.

CONFLICTS OF INTEREST

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

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