

## ORIGINAL ARTICLE

# The relationship between frailty, functional dependence, and healthcare needs among community-dwelling people with moderate to severe dementia

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## Abstract

This paper examines the healthcare needs of community-dwelling older people living in Porto, Portugal, diagnosed with moderate or severe dementia, linked to functional dependency, cognitive decline, limitations in the activities of daily life, and frailty levels. A sample of 83 participants was recruited. Data were collected between 2013 and 2017. A sociodemographic questionnaire, the Clinical Dementia Rating (CDR), the Barthel Index (BI), the Lawton and Brody Instrumental Activities of Daily Living (IADL) Scale, and the Edmonton Frail Scale (EFS) were used. A set of 26 healthcare needs was defined to support the assessment. The Pearson chi-square or Fisher's exact test (as appropriate) was used to examine the association of the needs (unmet and met) with the levels of dementia and frailty. Participants were diagnosed previously with moderate or severe dementia and benefited from a structured home-care program. There was a high number rated as "severe dementia," "fully dependent," "severely or fully dependent in the activities of daily living (ADL)," and "severe frailty." There were statistically significant differences among needs identified in people with moderate or severe dementia and moderate or severe frailty. The most prevalent healthcare needs in the sample were food preparation, medication/taking pills, looking after their home, toilet use, sensory problems, communication/interaction, bladder, bowels, eating and drinking, memory, sleeping, and falls prevention. In particular, the study identifies a set of needs that are present simultaneously in both frailty and dementia stages. This study underlines that despite well-structured home-care programs for people with dementia, unmet health needs remain. Timely healthcare needs assessment may help professionals to avoid fragmented care and to tailor quality-integrated interventions, including the emotional and psychological balance of the caregiver.

## KEYWORDS

activities of daily living, dementia, family caregiving, frailty, functional dependence, health needs assessment

## 1 | INTRODUCTION

The increasing longevity and the progressive dependence of people with dementia is a worldwide concern (Prince et al. 2015; Winblad et al., 2016). The number of people currently living with dementia is estimated as 47.7 million and is expected to reach 75.63 million by 2030 and 135.46 million by 2050 (WHO, 2015). Dementia is a term for a clinical syndrome characterised by progressive acquired global impairment of cognitive skills and ability to function independently (Sheeman, 2012).

From an early stage, people with dementia need progressively more support to continue their activities of daily living (ADL) and their own safety and integrity (Muders, Zahrt-Omar, Bussmann, Haberstroh, & Weber, 2015). This loss of functional capacity is accompanied by reduced capacity to perform instrumental activities of daily living (IADL) and by an increasing frailty (Abreu, Rodrigues, Sequeira, Pires, & Sanhudo, 2017).

Frailty is associated with dementia when a high level of cognitive declines is present; this explains the importance of adjusting for baseline cognition in studies examining the association between frailty and dementia outcomes (Gray et al., 2013). There is evidence to support the notion that frailty may precede dementia (Boyle, Buchman, Wilson, Leurgans, & Bennett, 2010) and also for the notion that mild dementia may precede the development of frailty (Raji, Snih, Ostir, Markides, & Ottenbacher, 2010).

Frailty is described as one of the most challenging expressions of ageing that decreases the quality of life and independence of older adults in the self-care and in the ADL (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2016). Older frail people also experience dramatic decline in physical and mental functions and have poorer outcomes after even apparently minor stressors such as mild physical disorders and anxiety, as shown in several studies (Pialoux, Goyard, & Lesourd, 2012).

There is no standard definition for frailty (Rodríguez-Mañas et al., 2012), but generally accepted components include muscle weakness, fatigue, slowness, low physical activity, and unintended weight loss (Fried et al., 2001; Kalyani, Varadhan, Weiss, Fried, & Cappola, 2012). "Frail" does not mean comorbidity or disability, so this term cannot be chosen to describe older people in general (Walston et al., 2006).

The increase in dementia prevalence calls for new interventions, involving social and political decision-makers (Burla, Rego, & Nunes, 2014). There is a consensus on the need to provide more compassionate and higher quality care to people with dementia and to avoid unnecessary hospital admissions.

The incidence and prevalence of dementia are strongly age dependent (Sheeman, 2012). Many people show varying levels of behaviour disturbance, dependence, and frailty at some point in the dementia syndrome, and evidence is growing that some of the health needs of the person are related to comorbidities and later life conditions, rather than the dementia itself (Crowther, 2015). Care provision from health professionals and family members increases as the condition progresses, however not all needs are consistently met (Van derPloeg, Bax, Boorsma, Nijpels, & VanHout, 2013).

### What is known about this topic

- Evidence has shown that the quality of dementia care is often suboptimal after diagnosis;
- A comprehensive assessment of the healthcare needs is indispensable to decisions related to the provision of care;
- Avoiding hospital stays in older people leads to a reduction in hospital-acquired infection and premature death.

### What this paper adds

- This is one of the first studies providing a detailed examination of the level of needs of people with moderate to severe dementia with particular reference to functional dependency instrumental activities of daily living (IADL) and frailty;
- Timely healthcare needs assessment helps professionals to avoid fragmented care and to tailor quality-integrated interventions including the emotional and psychological balance of the caregiver.

Need can be defined for our purposes as a state where help (or more help) with specific difficulties is seen to be required by the care professional making the assessment, taking into account the views of the person assessed (or their advocate) (McWalter et al., 1994). The relationship between met and unmet needs and quality of life is commonly accepted; unmet needs can be divided into subjective, objective, personal, and societal needs (Scholzel-Dorenbos, Meeuwssen, & Olde Rikkert, 2010). Subjective needs are those experienced by the person and their caregivers, for example, the need for comfort and compassion; however, objective needs are objectively diagnosed needs, for example, in patients with clear signs of neglect.

Late stage dementia can also be called "advanced dementia" (Aminoff, 2014; Tolson et al, 2017), "severe dementia" (Sampson, 2010), or "end stage of dementia" (Potter, Fernando, & Humpel, 2013). The care provided in the later stages of dementia is often fragmented and people may die because of unrecognised and untreated symptoms and needs, thereby experiencing considerable apathy and suffering (Jones et al., 2016). The strong association between apathy and people's abilities to complete basic ADL is evident in this phase. The assessment of needs and dependence in perform ADL must be comprehensive and include not only physical but also social and psychological functioning (Miranda-Castillo et al., 2010).

A health needs assessment is a staged process (Cavanagh & Chadwick, 2005), conducted by a care professional, which begins with the identification of specific difficulties, accounts for the presence and efficacy of current help, recognises perceived need, and finally specifies the type of intervention required to meet those needs (Meaney, Croke, & Kirby, 2005).

Health needs assessments are a key health strategy, which should be used; (a) to provide evidence about a population on which to plan services and address health inequalities, (b) provide an opportunity to engage with specific populations and enable them to contribute to targeted service planning and resource allocation, and (c) provide an opportunity for cross-sectoral partnership working and developing creative and effective interventions. Health needs assessments are important activities to promote rationalisation of resources in the integrated continuous care networks (Brewin, 2001; Koike & Furui, 2013).

This paper examines the healthcare needs of community-dwelling older people living in Porto, Portugal, diagnosed with moderate or severe dementia. Specific objectives are:

1. to assess the functional dependency and the living skills of the persons with moderate and severe dementia;
2. to identify the unmet needs of the persons with moderate and severe dementia;
3. to investigate whether unmet needs are linked to frailty levels.

## 2 | MATERIALS AND METHODS

This study is part of a larger project (DRIVE-C) focused on caring for people with dementia at home, in the Porto District of North Portugal (<https://www.esenf.pt/pt/i-d/projetos-internacionais/drive-c/>). The study was completed over 3 years (2014–2017). The findings related to family caregivers are presented elsewhere (Abreu, Tolson, Jackson, & Costa, 2018).

### 2.1 | Settings and participants

A cross-sectional survey design was undertaken with dementia caregivers and/or individuals with dementia who were invited to complete a multicomponent battery of tools. Eighty-three persons with moderate or severe dementia living in Porto, along with their family caregivers, were recruited. The recruitment strategy was negotiated with the healthcare team, according to the clinical situation of the recipients of care and motivation to cooperate in the study. Visits were scheduled according to the caregivers' availability.

Inclusion criteria for this study were: (a) persons diagnosed with moderate or severe dementia by a physician using the Clinical Dementia Rating (CDR); (b) having an initial clinical assessment performed by the multidisciplinary team; and (c) having the support of the local Integrated Community Care Team that provides long-term care.

### 2.2 | Data collection

The following instruments were used in the study: a sociodemographic questionnaire, the Barthel Index (BI), the Lawton and Brody IADL Scale, and the Edmonton Frail Scale (EFS).

The sociodemographic questionnaire was used to collect data from the person with dementia, the caregiver, and the context of care.

The BI (Mahoney & Barthel, 1965) is widely used in clinical practice and research to assess the degree of dependence (functional status) in ADL, with scores from 0 (high dependence) to 100 (high independence). This index is used to assess the functional capacity of the person and to determine the level of dependence overall and for each activity. The BI was validated for the Portuguese population by Araújo, Pais Ribeiro, Oliveira, Pinto, and Martins (2007). The Portuguese version shows very good psychometric properties (Cronbach Alpha = 0.96) and interitem correlations (*r*) between 0.66 and 0.93 (Araújo et al., 2007).

The IADL Scale is an appropriate instrument to assess independent living skills (Lawton & Brody, 1969). The scale assesses eight tasks (the ability to use the telephone, shop, prepare food, handle finances, do housework, take medication, do laundry and travel) related to functional skills necessary to live independently in the community. Each activity is scored from 1 to 3 or 1 to 4, depending the activity with a higher score associated with greater ability. Some of the reasons behind its widespread use are its easy application and interpretation, low cost, it does not require specialised personnel for its application, and takes a short time to complete (Araújo, Pais Ribeiro, Oliveira, Pinto, & Martins, 2008).

The EFS assesses nine domains of frailty (cognition, general health status, functional independence, social support, medication usage, nutrition, mood, continence, and functional performance) in older people (Rolfson, Majumdar, Tsuyuki, Tahir, & Rockwood, 2006). The total score ranges from 0 to 17 with higher scores representing greater levels of frailty. Severe frail and non-frail participants were defined according of the EFS score from not frail (0–5); vulnerable (6–7); mild frailty (8–9); moderate frailty (10–11); and severe frailty (12–17). The scale was validated in 2012 for the Portuguese population by Martins, Carvalho, Cordeiro, and Pinheira (2012) showing good psychometric properties. Martins et al (2012) calculated the reference values for the Portuguese average population. It had a value of 0.97 for Cronbach's alpha and a reliability threshold of 0.94 for test–retest reliability (95% confidence interval, 0.90–0.96).

The CDR, developed by Hughes, Berg, Danziger, Coben, and Martin (1982), is a numeric scale commonly used by psychogeriatric ward staff to quantify the severity of symptoms of dementia. The Portuguese version was validated by Garret et al. (2008).

The health needs assessment was developed based on the Care Needs Assessment Pack for Dementia (CarenapD—McWalter et al., 1998). The CarenapD tool is used worldwide in needs assessment. We had to choose which tool or strategy gave the most robust opportunity to measure the needs of the people who we are trying to assess. As the assessment was integrated in the period of care delivery, our option was to use a set of needs that were documented in the clinical records, which facilitated the provision of continuum-based dementia care that better meets the individual needs of persons with dementia. A set of needs was added to the traditional list: interaction, breathing, cutaneous integrity, mood, memory, confusion, usual sleep, emotional management, recognising familiar people, and make decisions and plans.

**TABLE 1** Sociodemographic characteristics of the person with dementia and the family caregivers (N = 83)

Variables	Person with dementia (n = 83)	Family caregiver (n = 83)
Age (mean)	79.95 (Range 50–95) (SD: 7.46)	60.64 (Range 25–87) (SD: 13.74)
Gender		
Male	28 (33.7%)	11 (13.3%)
Female	55 (66.3%)	72 (86.7%)
Education level		
Less than primary school	15 (18.1%)	4 (4.8%)
Completed primary school	66 (79.5%)	63 (75.9%)
Completed secondary school	1 (1.2%)	9 (10.8%)
Bachelor degree or more	1 (1.2%)	7 (8.4%)
Employment/occupation		
Employed		20 (24.1%)
Retired (age)		18 (21.7%)
Unemployed		15 (18.1%)
Retired (disability)		15 (18.1%)
Domestic work		12 (14.5%)
Other		2 (2.4%)
Student		1 (1.2%)
Relationship of family caregiver with the person with dementia		
Wife/husband		30 (36.1%)
Son/daughter		30 (36.1%)
Father/mother		7 (8.4%)
Other		7 (8.4%)
Son-in-law/ daughter-in-law		4 (4.8%)
Brother/sister		3 (3.6%)
Grandson/ granddaughter		2 (2.4%)
Time of caregiving (months)		
Less than 6		23 (27.7%)
6–11		27 (32.5%)
12–23		6 (7.2%)
24–35		9 (10.8%)
36–47		6 (7.2%)
48 and more		12 (14.5%)

The health needs assessment was reviewed systematically throughout the study, using two different raters (both mental health nurses) who work closely with the family caregivers and the recipients of care.

As data from the people with dementia were collected and rated by two researchers, establishing rigorous methods for assessing

the reliability (consistency) and validity (accuracy) of data was important. There are not standard published methods for assessing interrater reliability. We decide to collect data from people who are continually cared for by the healthcare team. The researchers (raters) made their observations and discussed the results with the family nurse. To ensure accuracy, only the participants who have the same evaluation from the researchers were included in the study. For judgement items, the entries had to agree exactly—this was the requirement to transfer the values to the database. The two researchers concurred on all reviews of all items.

The final list that was adopted in this study includes 26 needs encompassing four domains of functioning that are specific and relevant to that individuals with dementia: environmental needs, physical needs, psychological needs, and social needs. The care need status indicated for each item is defined as unmet need or independent/no need.

## 2.3 | Statistical analysis

The data analysis was performed using SPSS version 24.0 (Statistical Package for the Social Sciences; SPSS Inc., Chicago, IL). The frequencies of needs (unmet and met) were compared between participants with moderate/severe dementia and moderate/severe frailty, using the Pearson chi-square test. If the contingency table included at least one cell with expected frequency less than five, then the Fisher's exact test was used. Univariate tests used an unadjusted 5% significance interval.

## 2.4 | Ethical considerations

The study was approved by the human subjects' review boards (Institutional Review Board ULS-33/2014/RS) and was conducted in accordance with the principles of the Declaration of Helsinki (2013). Participants (persons with dementia) or the family caregivers provided consent to participate in the study. Participants were informed of the content and purpose of the study. Taking part in the research or otherwise did not interfere with any treatment or drug administration. Data anonymity, confidentiality, and the right to withdraw from the study at any time were guaranteed.

## 3 | FINDINGS

Table 1 summarises the sociodemographic characteristics of the study sample (persons with dementia and their caregivers). The sample comprised of 83 people formally diagnosed with moderate or severe dementia living in the community (mean age 75.95 years, range 50–95). The majority were women (66.3%) and most had completed primary school (75.9%). Caregivers were also mostly women (86.7%) with a mean age of 60.64 years; 60.2% of caregivers had been caring for their relative for less than 12 months of caring. However, 14.5% had cared for their relative for at least 48 months.

	CDR (stage of dementia)		
	Moderate (n = 30)	Severe (n = 53)	Total (n = 83)
Person with dementia	n (%)	n (%)	n (%)
Types of dementia			
Alzheimer's disease	12 (40.0%)	21 (39.6%)	33 (39.8%)
Under assessment	12 (40.0%)	15 (28.3%)	27 (32.5%)
Vascular dementia	6 (20.0%)	4 (7.5%)	10 (12%)
Frontotemporal	0	5 (9.4%)	5 (6%)
Mixed dementia	0	5 (9.4%)	5 (6%)
Other	0	2 (3.7%)	2 (2.4%)
Dementia with Lewy bodies	0	1 (1.8%)	1 (1.2%)
Total	30 (100.0%)	53 (100.0%)	83 (100.0%)

Note. CDR: Clinical Dementia Rating.

**TABLE 2** Stage and types of dementia of the patients (N = 83)

Instruments and categories	Dementia stage (CDR)		
	Moderate (n = 30)	Severe (n = 53)	Total (n = 83)
Barthel Index			
Independent (>90–100)	0	0	0
Slightly dependent (60–90)	13 (43.3%)	0	13 (15.7%)
Moderately dependent (40–55)	8 (26.7%)	8 (15.0%)	16 (19.3%)
Severely dependent (20–35)	5 (16.7%)	7 (13.3%)	12 (14.5%)
Fully dependent (<20)	4 (13.3%)	38 (71.7%)	42 (50.6%)
Total	30 (100%)	53 (100%)	83 (100%)
Lawton and Brody ADL			
Independent	0	0	0
Moderately dependent	0	0	0
Severely or fully dependent	30 (100%)	53 (100%)	83 (100%)
Total	30 (100%)	53 (100%)	83 (100%)
EFS			
Not frail (0–5)	–	–	0
Vulnerable (6–7)		0	0
Mild frailty (8–9)		0	0
Moderate frailty (10–11)	25 (83.3%)	14 (26.4%)	36 (43.3%)
Severe frailty (12–17)	5 (16.7%)	39 (73.6%)	44 (53.3%)
Total	30 (100%)	53 (100%)	83 (100%)

Note. ADL: Activities of Daily Living; BI: Barthel Index; CDR: Clinical Dementia Rating; EFS: Edmonton Frail Scale.

**TABLE 3** Functionality, frailty, and dementia stages (N = 83)

Table 2 shows the severity of disease and types of dementia of the sample participants. The diagnosis was made by a local physician during the first month and was stored in the person's clinical record, which is regularly updated through a multidisciplinary approach. The table emphasises the number of patients with severe dementia (63.9%). By far the most common type of dementia is Alzheimer's

disease (39.8%), followed by vascular dementia (12.0%), but there were also a high number of persons whose dementia diagnosis is still being assessed (32.5%). Among the people with severe dementia (last CDR stage), 39.6% were diagnosed with Alzheimer's disease.

Table 3 shows the functional decline and frailty of the participants, measured by the BI, IADL Scale, and EFS. The table

compares results between persons who have moderate with those who have severe dementia. Classifying people with dementia according to their functional level (BI) demonstrates that there was a concentration in the “fully dependent” group (50.6%). Individuals who are fully dependent and people and those who are severely dependent (14.5%) need expert and sometime intensive support from their caregivers as they are unable to independently perform instrumental daily living activities.

The EFS assessed cognitive impairment, dependence for ADL, burden of illness, self-perceived health, depression, weight loss, medication issues, incontinence, social support, and mobility. After

scoring the reported EFS, as shown in the Table 3, 44% of people with dementia had severe and 36% moderate frailty. Table 3 includes also a table to show the relation between frailty and the severity of dementia. As can be observed, 73.6% of those with severe dementia also have severe frailty. However, 16.7% of people with moderate dementia also have severe frailty.

Table 4 shows the relationship between the frailty level of the 83 persons with dementia and the 26 needs, classified as unmet or independent/no need. In general, people with severe frailty had higher rates of unmet needs. Of particular note is that all severely frail participants had unmet needs for food preparation, medication/taking

**TABLE 4** Chi-square test of independence for needs and frailty (N = 83)

	Moderate frailty (n = 39)		Severe frailty (n = 44)		
Domains/needs	Unmet need n (%)	Independent/no need n (%)	Unmet need n (%)	Independent/no need n (%)	p-value
Environmental needs					
Accommodation	0 (0%)	39 (100%)	32 (72.7%)	12 (27.3%)	<0.001
Looking after home	27 (69.2%)	12 (30.8%)	43 (97.7%)	1 (2.3%)	<0.001
Food preparation	30 (76.9%)	9 (23.1%)	44 (100.0%)	0 (0%)	0.001 <sup>[1]</sup>
Asking for social support	26 (66.7%)	13 (33.3%)	15 (34.1%)	29 (65.9%)	0.003
Toilet use	29 (74.4%)	10 (25.6%)	43 (97.7%)	1 (2.3%)	0.002
Money use	17 (43.6%)	22 (56.4%)	39 (88.6%)	5 (11.4%)	<0.001
Physical needs					
Senses: vision, hearing	32 (82.1%)	7 (17.9%)	43 (97.7%)	1 (2.3%)	0.023 <sup>[1]</sup>
Communication and interaction	0 (0%)	39 (100.0%)	43 (97.7%)	1 (2.3%)	<0.001
Daytime activities	11 (28.2%)	28 (71.8%)	41 (93.2%)	3 (6.8%)	<0.001
Mobility	9 (23.1%)	30 (76.9%)	38 (86.4%)	6 (13.6%)	<0.001
Bladder	24 (61.5%)	15 (38.5%)	43 (97.7%)	1 (2.3%)	<0.001
Bowels	24 (61.5%)	15 (38.5%)	43 (97.7%)	1 (2.3%)	<0.001
Eat and drink	27 (69.2%)	12 (30.8%)	43 (97.7%)	1 (2.3%)	<0.001
Breathing	10 (25.6%)	29 (74.4%)	40 (90.9%)	4 (9.1%)	<0.001
Medication, taking pills	38 (97.4%)	1 (3.6%)	44 (100.0%)	0 (0%)	0.470 <sup>[1]</sup>
Falls prevention	34 (87.2%)	5 (12.8%)	40 (90.9%)	4 (9.1%)	0.728 <sup>[1]</sup>
Cutaneous integrity	12 (30.8%)	27 (69.2%)	41 (93.2%)	3 (6.8%)	<0.001
Psychological needs					
Mood	37 (94.9%)	2 (5.1%)	39 (88.6%)	5 (11.4%)	0.439 <sup>[1]</sup>
Memory	29 (74.4%)	10 (25.6%)	43 (97.7%)	1 (2.3%)	0.002
Confusion	28 (71.8%)	11 (28.2%)	39 (88.6%)	5 (11.4%)	0.052
Usual sleep	37 (94.9%)	2 (5.1%)	40 (90.9%)	4 (9.1%)	0.679 <sup>[1]</sup>
Emotional management	6 (15.4%)	33 (84.6%)	44 (100.0%)	0 (0%)	<0.001
Taking part in activities	6 (15.4%)	33 (84.6%)	43 (97.7%)	1 (2.3%)	<0.001
Talking about feelings	14 (35.9%)	25 (64.1%)	37 (84.1%)	7 (15.9%)	<0.001
Social needs					
Recognizing familiar people	21 (53.8%)	18 (46.2%)	15 (34.1%)	29 (65.9%)	0.070
Making decisions and plans	8 (20.5%)	31 (79.5%)	27 (61.4%)	17 (38.6%)	<0.001

Note. Using chi-squared test except for <sup>[1]</sup> which use Fisher's exact test.



**TABLE 5** Chi-square test of independence for needs and stages of dementia ( $N = 83$ )

	Moderate dementia (n = 30)		Severe frailty (n = 53)		
Domains/needs	Unmet need n (%)	Independent/no need n (%)	Unmet need n (%)	Independent/no need n (%)	p-value
Environmental needs					
Accommodation	5 (16.7%)	25 (83.3%)	27 (50.9%)	26 (49.1%)	0.002
Looking after home	18 (60.0%)	12 (40.0%)	52 (98.1%)	1 (1.9%) <sup>[1]</sup>	<0.001 <sup>[1]</sup>
Food preparation	21 (70.0%)	9 (30.0%)	53 (100.0%)	0 (0%)	<0.001 <sup>[1]</sup>
Asking for social support	15 (50.0%)	15 (50.0%)	26 (49.1%)	27 (50.9%)	0.934
Toilet use	20 (66.7%)	10 (33.3%)	52 (98.1%)	1 (1.9%)	<0.001 <sup>[1]</sup>
Money use	11 (36.7%)	19 (63.3%)	45 (84.9%)	8 (15.1%)	<0.001
Physical needs					
Senses: vision, hearing	25 (83.3%)	5 (16.7%)	50 (94.3%)	3 (5.7%)	0.108
Communication and interaction	5 (16.7%)	25 (83.3%)	38 (71.7%)	15 (21.3%)	<0.001
Daytime activities	9 (30.0%)	21 (70.0%)	43 (81.1%)	10 (18.9%)	<0.001
Mobility	7 (23.3%)	23 (76.7%)	40 (75.5%)	13 (24.5%)	<0.001
Bladder	15 (50.0%)	15 (50.0%)	52 (98.1%)	1 (1.9%)	<0.001
Bowels	15 (50.0%)	15 (50.0%)	52 (98.1%)	1 (1.9%)	<0.001
Eat and drink	18 (60.0%)	12 (40.0%)	52 (98.1%)	1 (1.9%)	<0.001 <sup>[1]</sup>
Breathing	7 (23.3%)	23 (76.7%)	43 (81.1%)	10 (18.9%)	<0.001
Medication, taking pills	29 (96.7%)	1 (3.3%)	53 (100.0%)	0 (0%)	0.361 <sup>[1]</sup>
Falls prevention	25 (83.3%)	5 (16.7%)	49 (92.5%)	4(7.5%)	0.273 <sup>[1]</sup>
Cutaneous integrity	9 (30.0%)	21 (70.0%)	44 (83.0%)	9 (17.0%)	<0.001
Psychological needs					
Mood	27 (90.0%)	3 (10.0%)	49 (92.5%)	4(7.5%)	0.699 <sup>[1]</sup>
Memory	20 (66.7%)	10 (33.3%)	52 (98.1%)	1 (1.9%)	0.000 <sup>[1]</sup>
Confusion	19 (63.3%)	11 (36.7%)	48 (90.6%)	5 (9.4%)	0.003 <sup>[1]</sup>
Usual sleep	27 (90.0%)	3 (10.0%)	50 (94.3%)	3 (5.7%)	0.663 <sup>[1]</sup>
Emotional management	5 (16.7%)	25 (83.3%)	45 (84.9%)	8 (15.1%)	<0.001
Taking part in activities	5 (16.7%)	25 (83.3%)	44 (83.0%)	9 (17.0%)	<0.001
Talking about feelings	3 (10.0%)	27 (90.0%)	48 (90.6%)	5 (9.4%)	<0.001
Social needs					
Recognising familiar people	11 (36.7%)	19 (63.3%)	25 (47.2%)	28 (52.8%)	0.354
Making decisions and plans	3 (10.0%)	27 (90.0%)	32 (60.4%)	21 (39.6)	<0.001

Note. Using chi-squared test except for <sup>[1]</sup> which use Fisher's exact test.

pills, and emotional management, while 97.7% had unmet needs for looking after home, toilet use, senses, communication/interaction, bladder, bowels, eat and drink, memory, and taking part in activities. However, people with moderate frailty also showed high rates of unmet in some needs such as medication/taking pills (97.4%), mood and sleep (94.9%), falls (87.2%), and senses (82.1%).

The chi-square or Fisher's exact  $p$  values are significant (unadjusted two-sided  $p < 0.05$ ) for 20 from the 26 needs, consistent with a statistically significant association between the variables (needs and level of frailty). Non-statistically significant  $p$ -values were found for medication/taking pills ( $p = 0.470$ ), falls prevention ( $p = 0.728$ ),

mood ( $p = 0.439$ ), confusion ( $p = 0.052$ ), usual sleep ( $p = 0.679$ ), and recognising familiar people ( $p = 0.070$ ). For these, there was a relatively high unmet needs for participants with moderate frailty.

Table 5 shows the relationship between the dementia stage of the 83 persons and the 26 needs, classified also as unmet or independent/no need. From the table, we can observe that, in general, people with severe dementia have, as expected, higher rates of unmet needs. The following examples are prominent: food preparation, medication/taking pills (100%), looking after home, toilet use, bladder, bowels, eat and drink, memory, senses and usual sleep (94.3%), mood and falls prevention (92.5%). People

with moderate dementia also have unmet needs. Examples include medication/taking pills (96.7%), mood and sleep (90.0%), senses and falls (83.3%).

Chi-square or Fisher's exact  $p$  values (as appropriate) are significant ( $p < 0.05$ ) for 19 of the 26 needs, consistent with a statistically significant association between the variables (needs and stage of dementia). Non-statistically significant  $p$ -values were found for asking for social support ( $p = 0.934$ ), senses ( $p = 0.131$ ), medication/taking pills ( $p = 0.361$ ), falls prevention ( $p = 0.273$ ), mood ( $p = 0.699$ ), usual sleep ( $p = 0.663$ ), and recognising familiar people ( $p = 0.354$ ). Unmet needs can be found in both groups providing evidence that people with moderate dementia also show unmet needs.

## 4 | DISCUSSION

The main purpose of this study was to examine the care needs of community-dwelling older people diagnosed with moderate or severe dementia. Specific objectives were to assess the functional dependence, living skills, and frailty and to identify met and unmet care needs.

The sociodemographic characteristics of our study participants with dementia and their caregivers are in line with those indicated in similar studies, namely, the mean age of the recipients of care and that from the caregivers. There is a concentration on "severe dementia."

The most common type of dementia in the sample is Alzheimer's disease. The proportion of people with Alzheimer's disease in this study is higher than others reported in similar researches carried out in Portugal (Nunes et al., 2010). There is a substantial number of people yet to have a specific diagnosis. Diagnosis of dementia is a complex medical and social practice; physicians search for robust evidence to make the diagnosis, which has still associated stigma and often cause emotional distress and anxiety (Dhedhi, Swinglehurst, & Russell, 2014).

This study showed that there was a concentration of persons that are "fully dependent" (50.6%). The study showed also that 44% of people with dementia had severe and 36% moderate frailty. Frailty is described as one of the most challenging expressions of ageing that decreases the quality of life and independence of older adults in the self-care and in the IADL (Clegg et al., 2016; Pialoux et al., 2012).

Our study found strong evidence that frailty among older people correlates with the advanced dementia stage and the capacity to perform the IADL, which is in itself a requirement to benefit from quality, competent, and compassionate care. When trying to calculate the relation between frailty and the severity of dementia, it can be observed that 73.6% of people with severe dementia have severe frailty too.

The assessment of functionality, IADL, and frailty demonstrates differences even between people with moderate and later stages of dementia. People may have complex physical and psychological symptoms in addition to the symptoms derived from cognitive decline due to comorbidities. In people with advanced dementia, timely cases of institutionalisation are accepted to deal with exacerbations

(comorbidities) or to allow rest for caregivers. However, on a daily basis, comfort, interaction, proximity, and sensory interventions are essential, which require a biopsychosocial assessment instead of a neuropsychiatric one. Professionals should perform a full biopsychosocial assessment of assets, strengths, needs, and preferences of the person with dementia (Holmerova et al, 2016). One relevant finding in this study is the relativity of a symptom-based appraisal, rather than one based on real needs, related to memory, confusion, talking about feelings, meals (eat and drink), toilet, communication, elimination, mobility, mood and cutaneous integrity, among others.

Even when dementia is recognised in the primary care setting, research indicates that the quality of dementia care is suboptimal after diagnosis (Pimlott et al., 2009). Some of the needs in persons with dementia are frequently underestimated, for example, accommodation, breathing, falls prevention, cutaneous integrity, taking part in activities, talking about feelings, and making decisions and plans. Frequently, needs assessment separates the evaluation of different people (professionals, family caregiver, and person with dementia) (Callahan et al., 2006; Johansson, Eklund, & Gosman-Hedstrom, 2010). The assessment of needs should be taken into account the past life experiences, cultural background, preferences, and identities (Holmerova et al, 2016) and joint together the recipient of needs, the caregivers, and the professionals (Dinand, Nover, Holle, Zischka, & Halek, 2016).

It is recognised in this study that frailty should be seen as a multidimensional syndrome (Wou & Conroy, 2013) affecting the physical and mental function of the persons in different ways. Cognitive (Buchman, Schneider, Leurgans, & Bennett, 2008) and emotional impairment (Buchman et al, 2014) resulting from ageing had been frequently reported in the frail older people while many of the screening tools determine only physical deficits as a proxy measures of frailty (Heuberger, 2011).

Significant differences were found when trying to evaluate some needs from people with moderate and severe dementia.  $P$  values were significant ( $p < 0.05$ ) for 19 of the 26 needs, consistent with a statistically significant association between the variables (needs and stage of dementia). For the group with severe dementia, the most frequently identified needs were food preparation, medication/taking pills, looking after home, toilet use, senses, communication/interaction, bladder, bowels, eat and drink, memory, senses, usual sleep, and falls prevention. In those with moderate dementia, the most frequent care needs were medication/taking pills, mood and sleep, senses and falls. Globally, the pattern of needs show by people with severe dementia shows a decline in functionality and memory, but indicates a considerable capacity to interact and communicate, which facilitate ensuring a knowledge of individuals' opinions and preferences for decision-making. People with moderate dementia manifest some capacities that can contribute to their quality of life, delay memory, and physic decline (accommodation, asking for social support, communication, daytime activities, mobility, sphincter functioning, emotional management, taking part of activities, talking about feelings, recognising relatives, and making decisions and plans).

We found in this study that 16.7% of people with moderate dementia were also diagnosed with severe frailty. Concerning the



needs assessment, the concept of "severe dementia" is clearly a limiter in matter of frailty. As an alternative, the expression of "advanced dementia," encompassing people with severe dementia and people with moderate dementia but who also have severe frailty, would be more consistent and facilitating optimal care delivery.

Findings show that the set of 26 needs used in this study was useful to sustain an appropriate understating of the health status of the recipient of care and support the assessment as a process, acknowledges changes over time. To know the preferences, talk about feelings, respect the identity, how to stay comfortable, respect requests for help or facilitating participation in simple activities can make a difference when caring for people with advanced dementia.

In line with previous studies (Miranda-Castillo Woods & Orrell, 2013; Van der Ploeg et al., 2013; Van der Roest et al., 2007), our study showed a high number of healthcare needs, as described. Additionally, the study identifies a set of needs that are present simultaneously in frailty and advanced dementia stages. These are important findings to be taken into account for health and social care workers, because both the professional groups are essential to palliative, end of life and bereavement care.

Van der Ploeg (2013) identifies in their study needs such as "accommodation," "money," "benefits," "medication management," "incontinence," "memory problems," "inadvertent self-harm," "company," and "daytime activities." Miranda-Castillo et al. (2013) found accommodation, looking after home, food, self-care, mobility, continence, drugs, psychotic symptoms, information, deliberate self-harm, abuse/neglect, behaviour, alcohol, intimate relationships, money, and benefits. Van der Roest et al. (2007) emphasises the daytime activities (understood as any activity that allows persons with dementia to occupy themselves such as social, stimulation, or leisure activities) as the need most unmet. Chung (2006) found that the unmet need that was more evident in his study was the social interaction item of "taking part in activities", and three behavioural items related to memory and emotion, including "repetitive questioning," "restlessness/agitation," and "swings of mood."

Healthcare professionals tend to consider often that the way people indicate their needs is objective. However, this assessment is subjective and depends on previous experiences, expectations, and resources provided to people with dementia to their caregivers. These 83 persons with moderate or severe dementia are known to the integrated continuous care network and receive adequate health and social care related to their condition, but some needs remain unmet. Unmet needs are difficult to define and hard to measure, particularly in people's own homes.

Caring for dependent people with dementia at home is complex due to dementia-related changes including cognitive decline, difficulties in understanding and communication, impaired decision-making, and high levels of comorbidities and mental health issues, and sometimes complex social and spiritual-related circumstances (Tuffrey-Wijne et al., 2016). However, quality home-care services may prevent the deterioration of care needs level when compared with non-home-care services users (Koike & Furui, 2013). The inadequacies in the needs assessment and

management of dementia are associated with higher rates of avoidable hospitalisation and earlier use of long-term care facilities (Phelan, Borson, Grothaus, Balch, & Larson, 2012; Van der Roest et al., 2009). One important reason is that, at home, it is easier to preserve some small activities, interactions, live in a friendly context, and preserve some memories. This can explain why some care needs in our study show a low number of people who are fully dependent, for example, recognising familiar people, mobility, daytime activities, and asking for social support. Mobility can be easier at home. In other way, hospitalised persons tend to show higher levels of confusion.

Severe frailty and unmet needs can point out a singular opportunity for palliative care interventions to lessen suffering for dementia patients who tend to have low quality of life and high caregiver burden (Hanson et al., 2016; Zalski et al., 2014).

Van der Steen et al. (2014) highlight that dementia may be prolonged in time and that severe disability can go on for years. The care needs assessment and identifying factors that place people with dementia at risk for frailty may help professionals to tailor interventions to the recipients of care and their caregivers.

#### 4.1 | Limitations of the study

The generalisability of the results is subject to certain limitations, typical of such studies, wherever they are carried out. As the identification of needs was articulated with the care delivery and, consequently, more time-consuming to both the person with dementia and his/her family caregiver, it is possible that persons with the most severe dementia or physical disabilities dropped out of the study. Besides that, our study showed that the use of two raters (for data collection and classification) was very complex due to data consuming and the exclusion of the observations for which there was no agreement.

#### 4.2 | Recommendations for further research

Based on this study, future research should benefit from: (a) using of a larger sample size; (b) assessing specific individual needs and providing continuum-based dementia care to better meet the individual needs of persons with dementia; (c) include in the study spiritual needs as meditators of adjustment, self-confidence, and better interact with a supportive environment. Needs assessment offers an opportunity to more fully understand the experiences of the persons with dementia and their families; one recommendation that makes sense after this study is to choose and use needs assessment tools that opens the communication channel between the recipients of care/family caregivers and the professionals.

### 5 | CONCLUSION

This is one of the first studies to provide a detailed examination of the identification of needs of frailty people with moderate to severe

dementia residing in the family home, with particular reference to functional dependency and IADL. Taking a comprehensive approach to understanding needs arising from such domains in tandem with psychosocial and spiritual needs is an important step towards developing therapeutic and caring strategies to support both the individual and family carers.

Evidence has shown that planning for advanced dementia is often not undertaken (Holmerova et al., 2016; Tolson et al., 2016), due to a lack of consistent information. A comprehensive assessment of the healthcare needs is indispensable to decisions related to the provision of quality care. Conducting a comprehensive healthcare needs assessment can prevent fragmented care and promote comfort and well-being.

The challenge of a comprehensive health care needs assessment cannot be underestimated; when professionals believe that all changes affecting the person are related only to dementia, fundamental health needs can easily be missed (Holmerova et al., 2016). An appropriate care needs assessment can also facilitate the emotional and psychological balance of the caregiver.

## CONFLICT OF INTEREST STATEMENT

The authors report no conflict of interest.

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## AUTHORS' CONTRIBUTIONS

W.A. designed the study, carried out the data collection, designed, and wrote the drafts of the manuscript. H.S. contributed significantly to the statistical analysis. W.A., D.T., G.A.J., N.C., and H.S. contributed to the construction and contents of the manuscript. All authors discussed the results and contributed to the final manuscript.

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