#### **RESEARCH ARTICLE**



# Health conditions and unmet needs for assistance to perform activities of daily living among older adults with dementia in Chile

Yi Zhou<sup>1,2</sup> | Andrea Slachevasky<sup>3,4,5,6,7</sup> □ | Esteban Calvo<sup>8,9</sup> □

#### Correspondence

Esteban Calvo, PhD, MsPH. Robert N. Butler Columbia Aging Center, Mailman School of Public Health, Columbia University, 722 W. 168th Street, Office 412, New York, NY, USA. Email: esteban.calvo@columbia.edu

Dr Andrea Slachevsky. MD, PhD. Geroscience Center for Brain Health and Metabolism Facultad de Medicina, Universidad de Chile, Avenida Salvador 486, Providencia, Santiago, Chile. Email: andrea.slachevsky@uchile.com

#### **Funding information**

CONICYT, Grant/Award Number: 15150012 and FB0003; Columbia University

**Objective:** This study aims to address gaps in health conditions and unmet needs in daily activities between people with dementia (PWD) and without dementia in a developing country and to identify the variables associated with unmet needs among PWD to guide practitioners and policymakers in dealing with an increased burden of dementia.

**Methods:** Nationally representative data on 4655 Chileans age 60 and over were used to compare health conditions and unmet needs in daily life activities between individuals with (N = 455, 9.6%) and without dementia. Regression analysis was conducted to identify the variables associated with unmet needs among PWD.

**Results:** Overall, PWD had worse health and needed greater assistance in performing daily activities than people without dementia. Among PWD, being male was associated with more unmet needs, in both activities of daily living (ADL) and instrumental ADL. Lower educational level and fewer caregivers were associated with more unmet needs for ADL, while inferior functional ability was associated with more unmet needs for instrumental ADL.

**Conclusions:** The results from this study call for action by practitioners and policymakers to foster caregiver training, increase supportive services, and advance care planning for PWD.

#### **KEYWORDS**

caregiver, dementia, developing country, health condition, older adult, unmet need

### 1 | INTRODUCTION

Global demographic and epidemiological transitions have situated dementia as a critical policy issue. A majority (58% in 2009) of people with dementia (PWD) worldwide resides in low-income and middle-

income countries; this value is projected to increase to 63% in 2030 and 71% by  $2050.^2$  Despite the significance of this issue, limited data have hindered scholarship on dementia in many developing countries. $^{3-6}$ 

Dementia is a leading cause of disability and dependency, which in turn places a heavy burden on families and both the health and

<sup>&</sup>lt;sup>1</sup>Environment and Health Group, Cambridge, MA, USA

<sup>&</sup>lt;sup>2</sup>Harvard T.H. Chan School of Public Health, Boston, MA, USA

<sup>&</sup>lt;sup>3</sup>Geroscience Center for Brain Health and Metabolism (GERO), Santiago, Chile

<sup>&</sup>lt;sup>4</sup>Laboratory of Neuropsychology and Clinical Neuroscience (LANNEC), Physiopathology Program-ICBM, East Neurologic and Neurosciences Departments, Faculty of Medicine, University of Chile, Santiago, Chile

<sup>&</sup>lt;sup>5</sup> Neuropsychiatry and Memory Disorders clinic (CMYN), Neurology Department, Hospital del Salvador and Faculty of Medicine, University of Chile, Santiago, Chile

<sup>&</sup>lt;sup>6</sup>Centre for Advanced Research in Education, Santiago, Chile

<sup>&</sup>lt;sup>7</sup>Servicio de Neurología, Departamento de Medicina, Clínica Alemana-Universidad del Desarrollo, Santiago, Chile

<sup>&</sup>lt;sup>8</sup> Department of Epidemiology and Robert N. Butler Columbia Aging Center, Columbia University, New York, NY, USA

<sup>&</sup>lt;sup>9</sup> Center for Public Policy Research and Laboratory on Aging and Social Epidemiology, Universidad Mayor, Santiago, Chile

social protection systems.<sup>8</sup> The financial and nonpecuniary costs of informal care and traditional health services targeting PWD are substantial, and these will likely grow exponentially in the years ahead unless effective policy reforms and interventions are implemented.

Successful policies and interventions for PWD and their caregivers should respond to these individuals' needs, which are often not well identified and are likely to be greater than for the general adult population. Needs can be objectively diagnosed, but they can also be subjectively experienced by patients and caregivers. Unmet needs are defined as a shortage of resources to meet an explicit request for formal or informal support to perform activities of daily living (ADL) or instrumental ADL (IADL).

The health conditions and unmet needs of PWD are important dimensions to consider when understanding individual and societal capacity to manage longer lifespans. Previous studies on the health conditions and unmet needs of PWD are largely restricted to North America and Europe, and their results may not be generalizable to developing countries with more rapidly aging populations and weaker health and social protection systems. <sup>11-19</sup>

Among developing countries, Chile's population is aging especially rapidly and presents unique pressures associated with an increasing burden of dementia.<sup>3</sup> Life expectancy at birth in Chile is 82 years (85 for female and 80 for male) and has increased by an average of 4.2 years per decade over the last 50 years.<sup>20</sup> Approximately 180 000 Chileans live with dementia, and this number is expected to triple by 2020.<sup>21</sup> Although Chile is now defined as an upper middle-income country, social protection systems remain largely underdeveloped, and as is the case for most of Latin America, an outdated health system has not achieved the complex and multi-disciplinary response required by people with chronic diseases.<sup>22</sup> Available evidence suggests a shortage of public policies for PWD and their caregivers.<sup>23,24</sup>

In the context of the challenges presented by dementia in many countries, this study sought to use nationally representative survey data for Chile to compare health conditions and unmet needs for daily activities between PWD and people without dementia, as well as to identify the variables associated with the number of unmet needs among PWD.

## 2 | METHODS

## 2.1 | Data and sample

We drew nationally representative data for 4766 Chileans aged 60 and over (1851 male and 2915 female) from the *Encuesta Nacional de Dependencia de las Personas Mayores* (or Survey of National Dependency of Older Adults), which collected data between November 2009 and January 2010.<sup>25</sup> The survey contains information about participants' demographic characteristics, cognitive function, health conditions, ADL, social networks, and socioeconomic status. Using probability sampling and stratifying geographically and by population size for urban and rural areas, this survey excluded people from recondite locations and oversampled individuals 80 years and older. After excluding 111 people with missing

#### Key points

- As in numerous developing countries, there are important gaps in health conditions and unmet needs in the activities of daily living between people with dementia (PWD) and people without dementia in Chile.
- Overall, PWD had worse health and greater needs for assistance for performing daily activities than people without dementia.
- Among PWD, being male and having a lower educational level, fewer caregivers, and worse functional ability were associated with more unmet needs.
- Practitioners and policymakers facing the challenges of increased dementia within Chile's aging population should consider comprehensive responses, such as fostering caregiver training programs, increasing supportive services, and advancing care planning for older adults with dementia.

data on cognitive function, our final sample included 4655 subjects. All participants signed an informed consent prior to the survey, and the study was approved by the Chilean National Service for Older Adults.<sup>25</sup>

#### 2.2 | Measurement of dementia

Dementia assessment measured cognitive function by using a short version of the Mini-Mental State Examination (MMSE) and a scale for ADL known as the Pfeffer Functional Activities Questionnaire (PFAQ). The short version of the MMSE contains 6 items (registration, orientation, delayed recall, attention/concentration, visual-spatial ability, and verbal comprehension) with a maximum score of 19 points. The modified MMSE was validated in Spanish for the Chilean context and was deemed psychometrically adequate for assessing a population where nearly 70% of participants had no formal education or only primary education.<sup>26,27</sup> The PFAQ measures IADL, such as handling personal finance, shopping alone, remembering plans, using transportation, or preparing a meal. This questionnaire has been widely used in epidemiological studies to differentiate between people with and without dementia.<sup>28</sup> If a respondent's score was below 13 on the MMSE, the PFAQ was completed by a proxy (ie, knowledgeable informant), usually a caregiver or relative. If the score on the PFAQ was above 5, the study survey was administered to a proxy. People with dementia were defined as those individuals having a modified MMSE score below 13 and a Pfeffer Functional Activities Questionnaire score of over 5.26,27 The combination of these 2 instruments (MMSE and PFAQ) with the indicated cut off values has a sensitivity of 94.4% (95% CI 58.9%-80.3%) and a specificity of 83.3% (95% CI 72.3%-90.7%) for dementia diagnosis.<sup>27</sup>

# 2.3 | Measurement of health conditions and unmet needs

Health conditions were assessed based on comorbidity (of hypertension, Parkinson's disease, diabetes, osteoporosis, heart disease, lung disease, cerebrovascular disease, depression, and cancer), oral health (missing teeth, denture, or implants), other conditions such as falling or incontinence, and hospitalization.

Unmet needs were evaluated by using a basic activities assessment based on the Katz ADL Index and Lawton-Brody IADL Scale, which include activities such as bathing, dressing, toileting, transferring from a chair or from bed and climbing stairs, walking, eating, shopping, cooking, managing medications, using a telephone, performing housework, and managing finances.<sup>29,30</sup>

If the respondent indicated impaired ability to perform ADL and/or IADL, follow-up questions probed further regarding the presence and frequency of assistance. Unmet needs in daily living activities were defined as an expression of the need for support by PWDs reporting impairments in performing ADL and/or IADL ("with difficulty" in the questionnaire) and a lack of assistance ("no assistance at all" or "only sometimes have" in questionnaire). We calculated unmet needs related to ADL and IADL and evaluated the existence of support based on the availability and number of caregivers and daily care time received.

#### 2.4 | Covariates

Sociodemographic variables included gender (female indicated with a 1 and male with a 0), age group (65-69, 70-74, 75-79, 80-84, and >85 years), educational level (no formal education, primary school, and secondary school or higher), living area (urban and rural), ethnical group (indigenous or not), marital status (married or not married including single, divorced, or widow), and annual income in CLP (less than \$155 000, between \$155 001 and \$220 514, between \$220 515 and \$356 164, between \$356 165 and \$539 463, between \$539 464 and \$680 000, between \$680 001 and \$902 635, between \$902 636 and \$1 399 108, and over \$1 399 109). Covariates also included number of caregivers and care time provided, as well as number of chronic diseases, number of medications, and MMSE and Pfeffer scores.

#### 2.5 | Statistical methods

Proportions, means, and standard deviations were calculated for demographic information, health conditions, unmet needs, and number of caregivers and care time provided, to compare PWD and people without dementia. A negative binomial regression model was used to identify which covariates were associated with unmet needs among PWD. All analyses were performed by using Stata 14.0 (StataCorp, College Station, TX).

#### 3 | RESULTS

## 3.1 | Health conditions of people with and without dementia

We identified a total of 445 subjects with dementia, or 9.6% of the sample. Table 1 summarizes characteristics for PWD and people

without dementia. Dementia was more prevalent among people who were older, less educated, poorer, widowed or single, and living in rural areas (P < .05). No gender difference was identified after adjusting for age (P = .331).

Overall, the health conditions of PWD were worse than for people without dementia (see Figure 1). People with dementia more commonly had a history of Parkinson's disease (5.7% versus 1.7%, P < .001) or cerebrovascular disease (8.9% vs 3.4%, P < .001) and a higher occurrence of falling (33.0% vs 25.6%, P < .05), urinary incontinence (25.2% vs 12.2%, P < .001), and fecal incontinence (11.4% vs 1.9%, P < .001). Relative to people without dementia, PWD were more likely to visit the emergency room during the year prior to interviewing (33.6% vs 18.6%, P < .001) and tended to have more missing teeth (77%) and less dental implants (50%).

# 3.2 Unmet needs for assistance in performing activities of daily living

As illustrated in Figure 2, PWD required more assistance with all ADL/IADL than people without dementia, especially for walking, doing housework, using a phone, managing medication, cooking, shopping, climbing stairs, transferring from a chair or from bed, and dressing. Although PWD frequently expressed that their needs were met, a larger fraction of PWD as compared with people without dementia indicated that their needs were not met. On average, PWD had 1.79 ± 0.10 unmet daily needs, while people without dementia only had 0.80 ± 0.02 (P < .001). In ADL, PWD identified 1.01 ± 0.06 unmet needs, while people without dementia indicated 0.67  $\pm$  0.02 (P < .001) unmet needs. For IADL, PWD and people without dementia identified 0.77 ± 0.06 and 0.13 ± 0.01 unmet needs, respectively (P < .001). For both groups, a large portion of unmet needs related to mobility, such as walking, climbing stairs, and transferring from bed or a chair. People with dementia had more unmet needs related to bathing, dressing, transferring from bed or a chair and climbing stairs, walking, shopping, and managing medication.

Only 16.4% of PWD indicated that they had no caregiver, more than half of PWD had only one caregiver, and PWD with more than 2 caregivers providing assistance accounted for less than 10% of individuals. Most caregivers were close family members, with paid professionals accounting for less than 5%. More than half of PWD received 2 to 4 hours of daily care, and 21% of PWD received less than 2 hours of daily care and support.

Based on regression models and adjusting for demographics, socioeconomic variables, and care information (Table 2), we found that women with dementia had a decreased risk of unmet needs relating to ADL (P = .017), IADL (P = .028), and overall daily needs (P = .006). Higher educational level (secondary education or above) was also associated with a lower risk of unmet needs (P = .042). A greater number of caregivers was associated with fewer unmet ADL needs (P = .017) and overall unmet needs (P = .030). Unmet needs related to IADL increased with greater functional impairment as measured by the PFAQ (P = .023).

**TABLE 1** Characteristics of people with dementia (PWD)

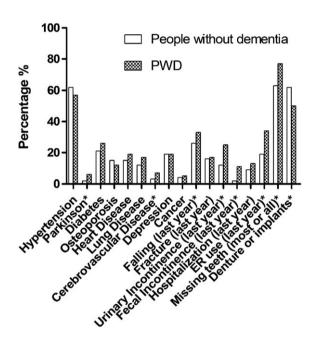
Characteristics	Total <sup>a</sup>	PWD <sup>b</sup>	People Without Dementia	P-value	
Total	4655	445 (9.6%)	4210 (90.4%)		
Gender					
Female	2844	270 (60.7%)	2574 (61.1%)	P = .848	
Male	1811	175 (39.3%)	1636 (38.9%)		
Average age (in years)	72.2 ± 8.5	80.2 ± 8.7	71.1 ± 7.8	P < .001	
Age					
60-64	1059	22 (4.9%)	1037 (24.6%)	P < .00:	
65-69	999	46 (10.3%)	953 (22.6%)		
70-74	890	47 (10.6%)	843 (20.0%)		
75-79	742	58 (13.0%)	684 (16.2%)		
80-84	563	117 (26.3%)	446 (10.6%)		
85 and over	402	155 (34.8%)	247 (5.9%)		
Education					
No formal education	416	106 (23.8%)	322 (7.6%)	P < .001	
Primary education	2114	250 (56.2%)	2572 (61.1%)		
Secondary education or higher	1550	56 (12.6%)	1082 (25.7%)		
Area		, ,			
Urban	3177	267 (60.0%)	2910 (69.1%)	P < .001	
Rural	1478	178 (40.0%)	1300 (30.9%)		
Race	1.70	17.0 (10.070)	1000 (001770)		
Indigenous	352	45 (10.1%)	352 (8.4%)	P = .208	
Nonindigenous	3858	400 (89.9%)	3858 (91.6%)	1 .20	
Marriage	0030	400 (07.770)	0030 (71.070)		
Married	2224	159 (35.7%)	2065 (49.0%)	P < .00:	
Divorced	406	18 (4.0%)	388 (9.2%)	r \ .00.	
Widowed	1515	213 (47.9%)	1302 (30.9%)		
Single	508	55 (12.4%)	453 (10.8%)		
-	308	55 (12.4%)	453 (10.6%)		
Income Less than \$155 000	2330	267 (60.0%)	2063 (49.0%)	P = .002	
Between \$155 000 and \$220 514	919			P00.	
,		73 (16.4%)	846 (20.1%)		
Between \$220 515 and \$356 164 Between \$356 165 and \$539 463	687	55 (12.4%)	632 (15.0%)		
	323	2 (0.5%)	296 (7.0%)		
Between \$539 464 and \$680 000	108	8 (1.8%)	100 (2.3%)		
Between \$680 001 and \$902 635	70	2 (0.5%)	68 (1.6%)		
Between \$902 636 and \$1 399 108	29	0	29 (0.7%)		
More than \$1 399 109	28	2 (0.5%)	26 (0.6%)	5 00	
Average number of caregivers	1.0 ± 1.8	1.3 ± 0.9	0.4 ± 0.7	P < .00	
Average care hours per day	1.0 ± 1.8	3.2 ± 2.4	0.8 ± 1.6	P < .00	
Average number of chronic diseases	1.6 ± 1.2	1.8 ± 1.3	1.5 ± 1.2	P < .00	
Average number of medications	2.6 ± 2.2	2.9 ± 2.3	2.5 ± 2.2	P < .00	
Average MMSE score	14.5 ± 4.3	7.6 ± 3.1	15.6 ± 2.6	P < .00	
Average Pfeffer score	8.9 ± 10.4	17.7 ± 8.3	2.1 ± 5.7	P < .00	
Person who takes care of PWD					
Spouse	-	14.0%	<del>-</del>		
Sons or daughters (or in law)	-	53.9%	-		
Paid caregivers or specialists	-	4.5%	-		
Others	-	27.6%	<del>-</del>		
Number of caregivers					
0	-	16.4%	-		
1	-	50.3%	-		

TABLE 1 (Continued)

Characteristics	Total <sup>a</sup>	$PWD^b$	People Without Dementia	P-value
2	-	24.3%	-	
3 or more	-	9.0%	-	
Hours per day of care by caregivers				
Less than 2 h	-	20.9%	-	
2-4 h	-	55.1%	-	
More than 4 h	-	24.0%	-	

Notes: Mean and standard deviation is reported for all continuous variables.

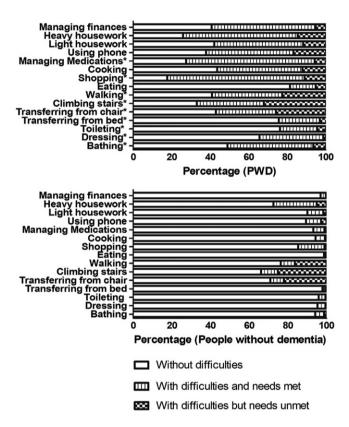
<sup>&</sup>lt;sup>b</sup>PWD, people with dementia. Criteria for diagnosis: MMSE score below 13 and Pfeffer score above 5.



**FIGURE 1** Health conditions among people with and without dementia. PWD, people with dementia. Health conditions included hypertension, Parkinson's disease, diabetes, osteoporosis, heart disease, lung disease, cerebrovascular disease, depression, cancer, falling, bone fracture, urinary and fecal incontinence, hospitalization, emergency room use, missing teeth, and denture or implants for PWD (white) and people without dementia (checked). \*P < .05

#### 4 | DISCUSSION

To our knowledge, this is the first study to address both health conditions and unmet needs related to ADL and IADL among PWD in a Latin American country. Previous studies in Latin America and the Caribbean (LAC) have indicated that the care needs of PWD are higher than those of older adults requiring care due to other medical conditions. Nevertheless, to the best of our knowledge, no published study has addressed unmet needs in PWD in LAC. Previous epidemiological studies in LAC reported a 7.1% prevalence of dementia among older adults, with high variability between countries, ranging from 2% in Brazil 8 to 13% in Venezuela. In our study, we identified 445 PWD, accounting for 9.6% of the sample. However, this estimate should be interpreted with caution; the Encuesta Nacional de Dependencia de las Personas Mayores is not an epidemiological study on dementia prevalence, and there is no current epidemiological



**FIGURE 2** Unmet needs by activities of daily living and instrumental activities of daily living among people with and without dementia. Met and unmet needs for basic and instrumental activities of daily living, including managing finances, heavy housework (eg, cleaning the bathroom, floors, and windows, and waxing), light housework (eg, making the bed, dusting furniture, and washing dishes), using the phone, managing medication, cooking, shopping, eating, walking, climbing stairs, transferring from a chair and from bed, toileting, dressing, and bathing, for people with dementia (PWD) and people without dementia. \*P < .05 for unmet needs

study on the prevalence on dementia in Chile with which to cross validate the estimate.

Another interesting finding of the current study was that PWD had overall worse physical health and oral health conditions. Higher rates of incontinence among PWD may cause emotional and physical discomfort and increase the burden on caregivers. <sup>40</sup> Findings also suggest that PWD had a greater risk of falling and emergency room visits as compared with older adults without dementia. This has been documented in previous

<sup>&</sup>lt;sup>a</sup>Total subjects in this study were 4766. Missing data on MMSE score resulted in the exclusion of 111 subjects.

TABLE 2 Variables associated with the number of unmet needs among people with dementia (PWD)

	Unmet ADL Needs				Unmet IADL Needs				All Unmet Needs			
	β	95% CI		р	β	95% CI		р	β	95% CI		р
Age												
Age group: 60-64 (ref)												
Age group: 65-69	0.28	-0.36	0.91	0.39	0.28	-0.66	1.21	0.56	0.29	-0.31	0.88	0.34
Age group: 70-74	-0.02	-0.68	0.64	0.95	0.01	-0.97	0.99	0.98	0.02	-0.60	0.64	0.96
Age group: 75-79	0.05	-0.58	0.68	0.87	-0.09	-1.02	0.83	0.84	0.01	-0.58	0.60	0.97
Age group: 80-84	0.19	-0.40	0.78	0.52	0.36	-0.50	1.21	0.41	0.28	-0.26	0.83	0.31
Age group: >85	0.26	-0.33	0.85	0.39	0.23	-0.63	1.08	0.61	0.25	-0.30	-0.80	0.37
Gender (male ref)												
Female	-0.29	-0.53	-0.05	0.017*	-0.38	-0.73	-0.04	0.028*	-0.32	-0.54	-0.09	0.006
Education (no formal ed. ref)												
Primary school education	-0.11	-0.37	0.14	0.38	0.33	-0.06	0.72	0.10	0.08	-0.17	0.33	0.53
Secondary school education	-0.42	-0.83	-0.02	0.042*	0.26	-0.31	0.84	0.37	-0.10	-0.47	0.27	0.60
Marriage status (married ref)												
Single, widowed, or divorced	0.20	-0.05	0.45	0.11	0.29	-0.07	0.66	0.12	0.23	-0.01	0.47	0.05
Living area (urban ref)												
Rural	0.03	-0.21	0.27	0.78	0.10	-0.25	0.46	0.57	0.07	-0.15	0.30	0.53
Ethical group (other ref)												
Indigenous	0.10	-0.26	0.46	0.58	0.29	-0.24	0.82	0.28	0.20	-0.14	0.55	0.25
Income	0.04	-0.06	0.14	0.45	-0.12	-0.28	0.04	0.13	-0.02	-0.12	0.07	0.63
Number of caregivers	-0.39	-0.70	-0.07	0.017*	-0.24	-0.67	0.18	0.26	-0.31	-0.59	-0.30	0.030
Care time provided	0.06	-0.06	0.18	0.32	0.01	-0.16	0.17	0.94	0.03	-0.07	0.14	0.54
Number of chronic disease	0.06	-0.04	0.17	0.23	-0.06	-0.21	0.09	0.42	0.02	-0.08	0.11	0.75
Medications	-0.03	-0.09	0.03	0.36	0.02	-0.07	0.10	0.70	-0.01	-0.07	0.05	0.71
MMSE score	-0.01	-0.05	0.03	0.69	-0.03	-0.09	0.03	0.36	-0.02	-0.06	0.02	0.40
Pfeffer score	0.01	-0.01	0.02	0.63	0.03	0.01	0.05	0.023*	0.01	-0.01	0.03	0.07

Abbreviation: ref, reference category.

literature, with one study in particular using data from the US Health and Retirement Study and suggesting that avoidable emergency room visits by PWD occurred mainly among community-dwelling residents as compared with nursing home residents; nursing homes are generally equipped to provide care for challenging situations, while deficiencies in both equipment and training are common among informal caregivers. <sup>41</sup> Worse health conditions and a higher risk of accidents among PWD may be explained by a higher rate of comorbidity and a lack of support and unmet needs in daily life. However, worse health conditions may also result in greater unmet needs, as increased physical and mental efforts are required of caregivers. <sup>42,43</sup> Better care planning is needed for PWD, including assessments of overall health conditions to reduce the occurrence of accidents and hospitalizations, as well as caregiver training programs to provide sufficient knowledge and skills for in-home dementia care solutions.

Another main contribution of this study relates to the documentation of differences between met and unmet ADL and IADL needs among PWD and people without dementia. Unmet needs were particularly high with regard to mobility (eg, transferring from a chair, climbing stairs, and walking). Further studies are required to explain why unmet needs for certain daily activities were slightly higher among people without dementia than PWD (see Table S1). One possible explanation is that PWD were more likely to have a family caregiver; this reliance on family support will face important limitations

in the near future. Another possible explanation is the existence of a generalized lack of support for older adults, especially for mobility. Consistent with previous research, <sup>44</sup> we found a higher rate of falling, emergency room visits, and hospitalization among PWD as compared with people without dementia, which suggests that a lack of support may lead to worse health outcomes among PWD.

Considering these findings, educational programs for informal caregivers with specific emphasis on mobility and supportive devices such as walkers or wheelchairs should be considered as potential interventions. Additionally, primary care doctors should pay closer attention to patients' mobility when performing exams and should provide relevant advice to avoid accidents or hospitalization that could further deteriorate patients' conditions.

Findings also indicated that older male adults tend to have more overall unmet needs, a finding that has rarely been discussed in the literature. One potential explanation may be that men are less likely to express their need for support than women.<sup>45</sup>

Other findings are also of interest. Educational level (as a proxy for socioeconomic status among older adults) and functional ability were associated with unmet ADL and IADL needs, respectively. The relationship between functional ability and unmet needs can be expected, given that people with lower functional ability require more support. An association between low educational level and dementia severity

<sup>\*</sup>P < .05.

has been previously documented both internationally and in Chile and can be attributed in part to reduced access to formal care. <sup>23,46</sup> In addition, the number of caregivers was another important variable associated with unmet needs, both regarding ADL and overall needs. Formal caregivers are rare in Latin American countries, where family systems are strong. Consistent with previous literature, we found that less than 5% of PWD caregivers were paid professionals. <sup>3,22,23</sup> The burden for caregiving lies primarily on family members, and a majority of PWD had one or 2 informal caregivers. However, around 16.4% of PWD had no regular caregiver. In the context of the profound and ongoing demographic changes observed throughout LAC and in particular in Chile, families will face significant challenges for providing care to older adults.

In 2002, the Chilean government launched a national aging public service, known as SENAMA, which seeks to improve quality of life for individuals age 60 and older. And a documented by previous studies, available public long-term care services are limited. Based on our study, formal caregiving provided by institutions or organizations including SENAMA and others (eg, municipalities, health care centers, nursing homes, and educational institutions) also remains limited. Recently, a National Plan for Dementia was developed, combining efforts from experts in neurology, geriatrics, mental health, public policy, and civil society. The plan is expected to be implemented during 2017 in 3 hospitals and several primary care centers in Chile. Developing more and better care programs (eg, long-term care, day care centers, home care programs, and respite care services) will support PWD as their ability to rely on the support of family caregivers decreases into the future.

One limitation of this study relates to the assessment of unmet needs in connection with ADL. Studies in the United States and United Kingdom have considered additional factors, such as medical treatment for other illnesses, well-coordinated postdiagnostic support, and psychological distress. Future studies could address these areas and others such as safety, social interactions, satisfaction with assistance, and mental health status among PWD to plan for improved and holistic interventions and policies in the context of aging societies.

Another limitation relates to the measurement of dementia. Although the assessment used in this study was validated for the Chilean population, limitations persist, particularly surrounding the diagnosis of dementia involving executive function impairment, such as vascular dementia and early stage frontotemporal dementia. <sup>50</sup> Other tests that are more sensitive to Alzheimer and non-Alzheimer dementia, such as the Montreal Cognitive Assessment and Addenbrooke's Cognitive Examination-Revised, were not available or validated in Chile at the moment of data collection. <sup>51-53</sup> As data become available in Chile, further studies could address needs based on the type of dementia. Future studies could also include nutritional status; this factor was excluded from the current study due to too many missing data among PWD.

#### 5 | CONCLUSION

Relative to people without dementia, PWD had worse health and greater needs for assistance in performing ADL and IADL. The growing prevalence of dementia in Chile's aging population, insufficient support for PWD, and increasing health expenditures require comprehensive societal responses. These include a fostering of caregiver training

programs, increased support services, and advancement in care planning for PWD so that unmet needs are addressed and the potential burden upon family caregivers is reduced.

#### **ACKNOWLEDGEMENTS**

This work was supported by the FONDAP Program grant 15150012, Basal Funds for Centers of Excellence Project FB0003 of the Associative Research Program of CONICYT, FONDECYT/Regular/1140107, and the President's Global Innovation Fund of Columbia University. The authors thank Katherine B. Indvik for language review and editing support.

#### **CONFLICT OF INTEREST**

None declared.

#### ORCID

Andrea Slachevasky http://orcid.org/0000-0001-6285-3189
Esteban Calvo http://orcid.org/0000-0002-2382-5553

#### **REFERENCES**

- Ravindranath V, Dang HM, Goya RG, et al. Regional research priorities in brain and nervous system disorders. Nature. 2015;527(7578):S198-S206.
- Prince M, Wimo AMG, Gemma-Claire A, Yu-Tzu W, Prina M. World Alzheimer Report 2015 The Global Impact of Dementia An Analysis of Prevalence, Incidence, Cost and Trends. London: Alzheimer's Disease International (ADI); 2015.
- 3. Custodio N, Wheelock A, Thumala D, Slachevsky A. Dementia in Latin America: epidemiological evidence and implications for public policy. *Front Aging Neurosci.* 2017;9:221.
- Gitlin LN, Fuentes P. The Republic of Chile: an upper middle-income country at the crossroads of economic development and aging. Gerontologist. 2012;52(3):297-305.
- Prince M, Ferri CP, Acosta D, et al. The protocols for the 10/66 dementia research group population-based research programme. BMC Public Health. 2007;7(1):165.
- Shah H, Albanese E, Duggan C, et al. Research priorities to reduce the global burden of dementia by 2025. Lancet Neurol. 2016;15(12):1285-1294.
- Sousa RM, Ferri CP, Acosta D, et al. Contribution of chronic diseases to disability in elderly people in countries with low and middle incomes: a 10/66 Dementia Research Group population-based survey. *Lancet*. 2009;374(9704):1821-1830.
- 8. World Health Organization. Dementia: a public health priority 2012. http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\_eng.pdf?ua=1
- Scholzel-Dorenbos CJ, Meeuwsen EJ, Olde Rikkert MG. Integrating unmet needs into dementia health-related quality of life research and care: introduction of the hierarchy model of needs in dementia. Aging Ment Health. 2010;14(1):113-119.
- Desin P, Caban-Holt A, Abner E, Van Eldik L, Schmitt F. Factors associated with unmet needs among African-American dementia care providers. J Gerontol Geriatr Res. 2016;5(1):267.
- Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. J Am Geriatr Soc. 2013;61(12):2087-2095.
- Calvo E, Williamson JB. Old-age pension reform and modernization pathways: lessons for China from Latin America. J Aging Stud. 2008;22(1):74-87.
- 13. Dempsey L, Dowling M, Larkin P, Murphy K. The unmet palliative care needs of those dying with dementia. *Int J Palliat Nurs*. 2015;21(3):126-133.

- 14. Gorska S, Forsyth K, Irvine L, et al. Service-related needs of older people with dementia: perspectives of service users and their unpaid carers. *Int Psychogeriatr*. 2013;25(7):1107-1114.
- 15. Hancock GA, Woods B, Challis D, Orrell M. The needs of older people with dementia in residential care. *Int J Geriatr Psychiatry*. 2006;21(1):43-49.
- Johnston D, Samus QM, Morrison A, et al. Identification of communityresiding individuals with dementia and their unmet needs for care. Int J Geriatr Psychiatry. 2011;26(3):292-298.
- Orrell M, Hancock GA, Liyanage KC, Woods B, Challis D, Hoe J. The needs of people with dementia in care homes: the perspectives of users, staff and family caregivers. *Int Psychogeriatr*. 2008;20(5):941-951.
- Staudinger UM, Finkelstein R, Calvo E, Sivaramakrishnan K. A global view on the effects of work on health in later life. Gerontologist. 2016;56(Suppl 2):S281-S292.
- van der Ploeg ES, Bax D, Boorsma M, Nijpels G, van Hout HP. A crosssectional study to compare care needs of individuals with and without dementia in residential homes in the Netherlands. *BMC Geriatr*. 2013;13(1):51.
- Economic Comision for Latin American and the Caribbean. Chile: national socio-demographic profile 2016. http://estadisticas.cepal.org/ cepalstat/Perfil\_Nacional\_Social.html?pais=CHL&idioma=english.
- 21. Fuentes P, Albala C. An update on aging and dementia in Chile. *Dement Neuropsychol.* 2014:8(4):317-322.
- 22. Bossert TJ, Leisewitz T. Innovation and change in the Chilean health system. *N Engl J Med*. 2016;374(1):1-5.
- Hojman DA, Duarte F, Ruiz-Tagle J, Budnich M, Delgado C, Slachevsky A. The cost of dementia in an unequal country: the case of Chile. PLoS One. 2017;12(3):e0172204.
- Slachevsky A, Budinich M, Miranda-Castillo C, et al. The CUIDEME study: determinants of burden in chilean primary caregivers of patients with dementia. J Alzheimers Dis. 2013;35(2):297-306.
- 25. SENAMA Gobierno de Chile. Estudio Nacional de la Dependencia en las Personas Mayores 2009.
- Lazo-Porras M, Pesantes MA, Miranda JJ, Bernabe-Ortiz A. Evaluation
  of cognitive impairment in elderly population with hypertension from a
  low-resource setting: agreement and bias between screening tools.
  eNeurologicalSci. 2016;5:35-40.
- Quiroga P, Albala C, Klaasen G. Validation of a screening test for age associated cognitive impairment, in Chile. Revista Medica de Chile. 2004:132(4):467-478.
- Assis Lde O, de Paula JJ, Assis MG, de Moraes EN, Malloy-Diniz LF.
   Psychometric properties of the Brazilian version of Pfeffer's Functional Activities Questionnaire. Front Aging Neurosci. 2014;6:255.
- Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The index of Adl: a standardized measure of biological and psychosocial function. JAMA. 1963;185(12):914-919.
- Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969;9(3 Part 1): 179-186
- Khanassov V, Vedel I. Family physician-case manager collaboration and needs of patients with dementia and their caregivers: a systematic mixed studies review. Ann Fam Med. 2016;14(2):166-177.
- 32. Prince M, 10/66 Dementia Research Group. Care arrangements for people with dementia in developing countries. *Int J Geriatr Psychiatry*. 2004;19(2):170-177.
- Llibre Rodriguez J, Valhuerdi A, Sanchez II, et al. The prevalence, correlates and impact of dementia in Cuba. A 10/66 group population-based survey. Neuroepidemiology. 2008;31(4):243-251.
- Gonzalez FJ, Gaona C, Quintero M, Chavez CA, Selga J, Maestre GE.
   Building capacity for dementia care in Latin America and the Caribbean.
   Dement Neuropsychol. 2014;8(4):310-316.
- 35. Custodio N, Slachevsky A. In: Guajardo Soto G, Tijoux Merino M, Abusleme Lama M, eds. Antecedentes epidemiológicos de las demencias en las personas mayores en Chile y en América Latina. Pp 35-63 in:

- Construcción social de las demencias en las personas mayores en la Región Metropolitana, Chile. Santiago, Chile: SENAMA-FLACSO Chile, Instituto Chileno de Terapia Familiar; 2015.
- Fiest KM, Jette N, Roberts JI, et al. The prevalence and incidence of dementia: a systematic review and meta-analysis. Can J Neurol Sci. 2016;43(Suppl 1):S3-S50.
- Nitrini R, Bottino CM, Albala C, et al. Prevalence of dementia in Latin America: a collaborative study of population-based cohorts. *Int Psychogeriatr*. 2009;21(04):622-630.
- 38. Ramos-Cerqueira A, Torres A, Crepaldi A, et al. Identification of dementia cases in the community: a Brazilian experience. *J Am Geriatr Soc.* 2005;53(10):1738-1742.
- Maestre GE, Pino-Ramirez G, Molero AE, et al. The Maracaibo aging study: population and methodological issues. *Neuroepidemiology*. 2002; 21(4):194-201.
- Landefeld CS, Bowers BJ, Feld AD, et al. National Institutes of Health state-of-the-science conference statement: prevention of fecal and urinary incontinence in adults. Ann Intern Med. 2008;148(6):449-458.
- Feng Z, Coots LA, Kaganova Y, Wiener JM. Hospital and ED use among Medicare beneficiaries with dementia varies by setting and proximity to death. *Health Aff.* 2014;33(4):683-690.
- 42. Bunn F, Burn AM, Goodman C, et al. Comorbidity and dementia: a scoping review of the literature. BMC Med. 2014;12(1):192.
- Poblador-Plou B, Calderon-Larranaga A, Marta-Moreno J, et al. Comorbidity of dementia: a cross-sectional study of primary care older patients. BMC Psychiatry. 2014;14(1):84.
- 44. Miranda-Castillo C, Woods B, Galboda K, Oomman S, Olojugba C, Orrell M. Unmet needs, quality of life and support networks of people with dementia living at home. *Health Qual Life Outcomes*. 2010;8(1):132.
- Kashdan TB, Mishra A, Breen WE, Froh JJ. Gender differences in gratitude: examining appraisals, narratives, the willingness to express emotions, and changes in psychological needs. J Pers. 2009;77(3):691-730.
- Chen R, Lang L, Clifford A, Chen Y, Hu Z, Han TS. Demographic and socioeconomic influences on community-based care and caregivers of people with dementia in China. *JRSM Cardiovascul Dis.* 2016;5. 2048004016652314
- Calvo E, Madero-Cabib I. Envejecimiento Saludable, Activo y Positivo y Su Promoción Entre las Personas Mayores. In: Gerontología Social. Santiago, Chile: Pontificia Universidad Católica de Chile; 2016:49-65.
- 48. Marin PP, Wallace SP. Health care for the elderly in Chile: a country in transition. Aging Clin Exp Res. 2002;14(4):271-278.
- Gajardo J, Abuseleme T. Plan Nacional de Demencias: Antecedentes globales y síntesis de la estrategias chilena. Rev Med Clin Condes. 2016;27:286-296.
- 50. Dubois B, Slachevsky A, Litvan I, Pillon B. The FAB: a frontal assessment battery at bedside. *Neurol.* 2000;55(11):1621-1626.
- Delgado C, Araneda A & Behrens MI. Validation of the Spanishlanguage version of the Montreal Cognitive Assessment test in adults older than 60 years. Neurologia; 2017.
- 52. Munoz-Neira C, Henriquez Ch F, Ihnen JJ, Sanchez CM, Flores MP, Slachevsky CA. Psychometric properties and diagnostic usefulness of the Addenbrooke's Cognitive Examination-Revised in a Chilean elderly sample. Revista Medica de Chile. 2012;140(8):1006-1013.
- Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc. 2005;53(4):695-699.

**How to cite this article:** Zhou Y, Slachevasky A, Calvo E. Health conditions and unmet needs for assistance to perform activities of daily living among older adults with dementia in Chile. *Int J Geriatr Psychiatry*. 2018;33:964–971. <a href="https://doi.org/10.1002/gps.4879">https://doi.org/10.1002/gps.4879</a>