Measuring change in perceived well-being of family caregivers: validation of the Spanish version of the Perceived Change Index (PCI-S) in Chilean dementia caregivers

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Objective: Few instruments evaluate family caregiver perceptions of challenges caring for persons with dementia and improvement or worsening in these areas. To address this measurement gap, we examine psychometric properties of a Spanish version of the 13-item Perceived Change Index (PCI-S), originally validated with English-speaking caregivers.

Methods: Cross-sectional study with 94 caregivers of persons with mild to moderate dementia in Chile. Interviews included caregiver demographics, burden, health perception, distress with behaviours, dementia severity, behavioural symptoms and functionality.

Results: Caregiver mean age was 55.9 (SD ± 14.14) years and mean years caregiving was 3 (SD ± 2.60). The scale had strong internal consistency (Cronbach $\alpha = 0.94$), and inter-observer consistency (CCI = 0.99; 95% CI = 0.95–0.99). Two factors were identified: Management skills ($\alpha = 0.89$), and somatic well-being and affects ($\alpha = 0.92$), explaining 63% of scale variance. Significant associations supporting convergent validity were observed for PCI-S and subscales with caregiver burden ($p < 0.01$), health perceptions ($p < 0.01$), depressive symptoms ($p < 0.01$) and distress with behaviours ($p < 0.01$); and in persons with dementia, functionality ($p < 0.05$), dementia severity ($p < 0.05$) and behavioural symptoms ($p < 0.01$) in expected directions. In logistic regression models, perceived worsening (PCI-S and subscale scores) was associated with more behavioural symptoms (OR = 1.07; 95% CI = 1.03–1.15) and caregiver burden (OR = 1.48; 95% CI = 1.18–1.86); whereas perceived improvement was associated with higher physical functioning (OR = 0.95; 95% CI = 0.91–0.99) in persons with dementia. PCI-S scores were not associated with socio-demographic characteristics reflecting divergent validity.

Conclusions: Spanish version of the 13-item Perceived Change Index and its two-factor solution is a valid and reliable measure with clinical utility to detect improvement or worsening in caregivers concerning daily care challenges. Copyright © 2017 John Wiley & Sons, Ltd.

Introduction

There are an estimated 46.8 million persons with dementia in the world, and this number will exponentially increase more in low and middle income countries in the next 25 years (Prince *et al.*, 2015). In Chile, an upper middle-income country (Gitlin and Fuentes, 2012), there are at least 200 000

cases, corresponding to 7% of the Chilean older-adult population (Fuentes and Albala, 2014). Dementia, a public health priority worldwide, has profound impact on all aspects of daily life of persons with dementia and family members who typically assume long-term care responsibilities. Common clinical features of dementia such as functional decline and behavioural symptoms often trigger need for more hands-on assistance and time caregiving (Di Mattei *et al.*, 2008; Reviews and Wu, 2015). Consequently, caregivers of persons with dementia often have higher rates of depressive symptoms and report more burden than non-caregivers or caregivers of older adults without dementia (Spitznagel *et al.*, 2006; Richardson *et al.*, 2013).

Not surprisingly, caregiver burden has been a primary indicator of well-being in families and a key outcome of intervention studies (Miller, *et al.,* 2012). However, most burden measures reflect global indicators, focus on negative aspects of providing care and do not include the range of caregiver concerns (Black *et al.*, 2013; Porock *et al.*, 2015). Additionally, as dementia caregiving endures for many years (Spitznagel *et al.*, 2006; Prince *et al.*, 2013; Sansoni *et al.*, 2013), evaluating change in perceived well-being is important to discern (Porock *et al.*, 2015). There is a need to develop instruments that capture daily caregiving experiences, enable monitoring of improvement or worsening in areas of concern to caregivers, and which are sensitive to change with disease progression or intervention.

The Perceived Change Index (PCI) is a brief 13-item measure that captures whether caregivers perceive care challenges and their own well-being as improving, worsening or staying the same reflecting back over a 1-month period (Gitlin *et al.*, 2006a). Previous research showed this scale had excellent psychometric properties and was sensitive to change as a consequence of interventions designed to support family caregivers through education and skill-building (Gitlin *et al.*, 2006b; Gitlin *et al.*, 2010a; Gitlin *et al.*, 2010b). Nevertheless, it has not been validated in Spanish or adapted for use in countries other than the USA.

The purpose of this study was to develop a Spanish version (PCI-S) and evaluate its validity for caregivers of persons with dementia in Chile. Specifically, we evaluated internal and inter-observer consistency, and convergent and divergent validity. It is important to advance culturally appropriate and clinically useful measures of well-being for use with diverse families (Owen *et al.*, 2001; Alvira *et al.*, 2015). Furthermore, countries developing national dementia care plans, such as Chile, seek effective measures for evaluating family well-being and service impact.

Methods

A cross-sectional study was conducted with 94 family caregivers living with persons with mild to moderate dementia in Santiago, Chile, and attending an adult-day service, 'Kintun' (Fuentes and Albala, 2014). Caregivers, selected in consecutive order of entry into Kintun between April and July, 2016, fit the following inclusion criteria: caregivers of persons attending Kintun; ≥18 years of age; providing ≥10 weekly hours of care; providing care for ≥1 month prior to study enrolment; and caring for persons ≥60 years old with physician diagnosis of dementia. Caregivers unable to read or caring for persons with severe dementia (e.g. Reisberg's Global Deterioration scale = 7) (Reisberg *et al.*, 1982), were excluded. Literacy was an important criterion, as we sought to test whether the scale could be self-administered. An indication of literacy was determined in the face-to-face interview by asking caregivers their education level and whether they could read and write. We also showed caregivers the instructions for completing the PCI-S, and asked if they understood the statements and could complete independently.

The study was approved by the ethics committee of the Nutrition and Food Technology Institute, INTA, University of Chile.

Semantic validation

A semantic validation of PCI-S was conducted for translating and adapting PCI. A rigorous translation to Spanish was completed by a professional team member, and then the translation was standardised by three experts (geriatrician, occupational therapist and psychologist), who analysed the conceptual equivalence and understanding in the local context applying these criteria: caregiver understanding of scale items, utility of scale for the local population, and theoretical framework of scale and usual needs and problems of caregivers (Cronbach and Meehl, 1955; Hyrkäs *et al.*, 2003). This was followed by further evaluation and revision by a second multi-professional group (geriatrician, psychologist, occupational therapist, nutritionist, physical therapist and social worker), who also analysed its conceptual equivalency and comprehension in the local context. To improve caregiver understanding of scale items, and considering the socio-economic and cultural

background of Chilean caregivers, some modifications to terminology were necessary. This included referring to 'care recipient' (persona al cuidado) as 'family member' (familiar) and 'aregiving' (cuidado) to 'Take care of your family member' (cuidar a su familiar).

The resultant PCI-S was pilot-tested with eight caregivers to evaluate item clarity and acceptability. The pilot confirmed that no further modifications were required.

Procedures

Caregivers were initially contacted by telephone and screened for study eligibility, followed by interviews in Kintun that included the PCI-S. Interviews were of 60–90-min duration with PCI-S taking 3–5 min. Informed consent was obtained prior to interviews by trained professionals of Kintun.

Measures

Instruments were chosen for use in this study which were available in Spanish and previously validated for Spanish speaking populations; selected by Chile's Ministry of Health to evaluate the national-dementia care plan; and which either described the study sample or served as indicators of convergent or discriminant validity.

To describe the study sample, age, gender, relationship to persons with dementia, time caregiving, education and income levels of caregivers were collected. Also, age, gender and income of persons with dementia were obtained from caregivers.

We also considered caregiver characteristics (age, gender, income and education) in association with PCI-S scores and to serve as indicators of discriminant validity. According to the well-being change theory of Diener *et al.* (1999) and Suh *et al.* (1996), well-being is a personal evaluation related to life situations (positive or negative) experienced in a specific moment of time and thus subject to fluctuations. Thus, we reasoned that socio-demographic characteristics reflect stable traits that my influence the experience of caregiving but which would not impact daily fluctuations in appraisals of the caregiving situations.

Persons with dementia

We assessed behavioural symptoms, physical function and disease stage. The Neuropsychiatric Inventory (NPI-Q) (Cummings *et al.*, 2000) evaluates frequency (1 = rarely, 2 = sometimes, 3 = often and 4 = very often) and severity (1 = mild, 2 = moderate and 3 = severe) of 12 behavioural and psychological symptoms (BPSD) as reported by caregivers. A total score is derived by multiplying the frequency and severity scores for each item and summing across items with higher scores indicating greater BPSD.

For function, we used the Alzheimer's Disease Cooperative Study - Activities of Daily Living Inventory (ADCS-ADL) (Galasko *et al.*, 1997). It consists of 23 basic and instrumental activities. Caregivers rate performance within the past month as 4 = independent, 3 = with supervision, 2 = with help in some steps, 1 = with help in all steps, and 0 = does not perform activity.

To classify dementia stage, we used Reisberg's Scale of Global Deterioration (Reisberg *et al.*, 1982) with scores ranging from 1 = without cognitive deterioration, 2 = some cognitive deterioration, 3 = mild cognitive deterioration/mild cognitive impairment, 4 = moderate cognitive deterioration/mild dementia, 5 = moderate/serious cognitive deterioration/moderate dementia, 6 = serious cognitive deterioration/moderate–severe dementia, and 7 = very serious cognitive deterioration/severe dementia.

We anticipated that lower PCI-S scores (perceived worsening) would be significantly associated with more BPSD, lower function and greater cognitive deterioration, demonstrating convergent validity. Using the well-being change theory of Diener *et al.* (1999) and Suh *et al.* (1996), we reasoned that caregivers of people with dementia are involved in managing BPSD, cognitive decline and functional abilities, and that with decline, their abilities to do so may be compromised or influence their perceptions of their own well-being. Taking care of persons with these clinical features can be demanding and require constant adaptation to and appraisal of one's ability to effectively manage daily situations.

Caregiver well-being

Three measures assessed caregiver well-being. We used the 6-item Zarit burden scale (Higginson *et al.*, 2010) measuring subjective burden along a Likert-type scale (0 = never to 4 = almost always). Scores are derived by summing across items with higher scores indicating more burden. The EuroQol-5D Questionnaire (EQ-5D) (Rabin and Charro, 2001), a five-item questionnaire, measures caregivers' perception of their health state. Each item reflects a unique dimension (mobility, personal care, usual activities,

pain/discomfort and anxiety/depression), with three response levels (1 = no problems, 2 = moderate problems and 3 = severe problems). The EQ-5D has an additional analogue visual scale from 1 to 100 reflecting overall self-assessment of health. A higher score indicates better perceived health.

Additionally, we evaluated distress with BPSD using the NPI-Q (Cummings *et al.*, 2000). Caregivers indicate their distress level for each of 12 behaviours using a Likert-type scale (0 = not distressing at all to 5 = Extreme or very severe distress). A total score is derived by adding scores across reported behaviours.

We anticipated that lower scores on PCI-S (perceived worsening) would be significantly associated with greater burden, more distress with BPSD, poorer perceived overall health demonstrating convergent validity.

We also anticipated that PCI-S would be associated with EQ-5D item, anxiety/depression, but not with mobility, pain, or personal care/daily activities items. We reasoned that daily care impacts emotionality versus directly affecting the physical functioning of the caregiver.

Perceived Change Index

The PCI evaluates well-being along 13 dimensions over the past month (Gitlin *et al.*, 2006a). Caregivers rate each item along 5 points (1 = got much worse, 2 = somewhat worse, 3 = stayed the same, 4 = somewhat better or 5 = much better) with scores ranging from 13 to 65. In this study, caregivers completed the scale by themselves and then items were reviewed by the interviewer to address questions or assure no missing data. We purposely chose to use self-administration. We envisioned that if validated, PCI-S could be used in public health programs in which time constraints and clinical high demands on professionals might limit their ability to administer the scale.

A high total score reflects that things are improving (better well-being); a low total score reflects that things are getting worse (poor well-being). The original scale had three subfactors: somatic, affective and ability to manage care challenges.

Data analysis

A descriptive analysis of study variables and PCI-S was performed with the total sample ($N = 94$). To evaluate agreement between two observers, a test of test–retest was conducted in which the scale was administered by

two different evaluators in a group of caregivers ($n = 8$), and the coefficient of intra-class correlation was calculated. For content validity, an exploratory factorial analysis was performed using the method of principal factors axis with varimax rotation, using the percentage of variance explained by factors to evaluate model adjustments. Cronbach's alpha coefficient (α) was used to determine internal consistency of the scale and its dimensions.

Convergent and divergent validity were evaluated in a sub-group of caregivers ($N = 86$) with complete data on scales of interest. Pearson (r) and Spearman (s) correlation between PCI-S score and health characteristics were used. The 25th percentile (p25) of PCI-S was used as a cut-off point to dichotomise the data. The p25 of PCI-S found in the sample was considered as a state of low well-being. Logistic regression analysis was used to determine associations between low perceived well-being (dependent variable) and socio-demographic and other variables related to caregivers and persons with dementia (independent variables). The Hosmer–Lemeshow test was used to show the good adjustment of models analysed. Analyses were conducted using IBM Statistical Package for the Social Sciences Statistics (SPSS), Version 20.0

Results

Sample characteristics

Of 94 caregivers enrolled in the study, most were women (85.1%) with mean age of 55.9 (SD ± 14.14), and median of 12 years of education. Most caregivers had low to medium-low socio-economic level (mean income = CLP$224.218, US$332.41), with women having a monthly mean income less than men (women = CLP$202.330, US$299.96, men = CLP$349.285, US$517.83 mean income; diff = CLP$146.955, US$217.87, *p = 0.04*). Most caregivers were children (57.4%), or spouses (28.8%) of persons with dementia, and provided care for an average of 3 years (SD = ±2.60) (Table 1).

Persons with dementia were on average 79 years (SD = ±7.61). Most were women (61.7%), with a low socio-economic level (mean income = CLP$129.632, US$193.38), and diagnosis of mild (59.2%) or moderate (34%) dementia.

Most persons with dementia were moderately dependent in self-care (mean ADCS-ADL = 38.7, SD = ±14.22); had a mean BPSD score of 21.8 (SD = ±14.03) with most caregivers managing ≥2

Table 1 Background characteristics of caregivers and persons with dementia

	Total sample (*n* = 94)	Sub-group (*n* = 86)
Caregivers		
Sex		
Female % (*n*)	85.1 (80)	86.0 (74)
Male % (*n*)	14.9 (14)	14.0 (12)
Age		
Mean ± SD	55.9 ± 14.14	55.9 ± 14.14
Median IR (p25–p75)	55(44–69)	56 (43–68)
Education years		
Mean ± SD	10.3 ± 3.94	10.3 ± 3.93
Median IR (p25–p75)	12(8–12)	12(8–12)
Years of caregiving		
Mean ± SD	3 ± 2.60	3 ± 2.51
Median IR (p25–p75)	2(1–4)	2(1–4)
Approximate monthly income. (CLP)		
Mean ± SD	224.218 ± 248.307	221.924 ± 241.160
Median IR (p25–p75)	180.000 (78.750–300.000)	180.000 (80.000–300.000)
Relationship to care recipient		
Spouse % (*n*)	28.8 (27)	29.1 (25)
Child % (*n*)	57.4 (54)	55.8 (48)
Other % (*n*)	13.9 (13)	15.2 (13)
Persons with dementia		
Sex		
Female % (*n*)	61.7 (58)	61.6 (53)
Male % (*n*)	38.3 (36)	38.4 (33)
Age		
Mean ± SD	79.0 ± 7.61	78.9 ± 7.66
Median IR (p25–75)	80(73–83)	80(73–83)
Approximate monthly income. (CLP)		
Mean ± SD	129.632 ± 61.020	129.423 ± 59.847
Median IR (p25–p75)	120.000 (80.000–168.500)	120.000 (80.000–166.500)
Dementia severity (GDS-R)		
Mild GDS-R = 4% (*n*)	59.6 (56)	59.3 (51)
[95%CI]	[48.9–69.1]	[48.8–69.8]
Moderate GDS-R = 5% (*n*)	34.0 (32)	34.9 (30)
[95%CI]	[24.5–43.6]	[24.7–45.3]
Moderate–severe GDS-R = 6% (*n*)	6.4 (6)	5.8 (5)
[95%CI]	[2.1–11.7]	[1.2–10.5]

n, number of persons; SD, standard deviation; IR, interquartile range; p, percentile; CLP, Chilean money; %, percentage; GDS-R, Global Deterioration Scale Reisberg; CI, confidence interval.

Table 2 Health variables of persons with dementia and caregivers*

	Mean ± SD	Median IR (p25–p75)	Theoretical range
Persons with Dementia (*n* = 86)*			
Functionality (ADCS-ADL)	38.7 ± 14.22	38.5(27–50)	0–78
BPDS (NPI-Q)	21.8 ± 14.03	19(12.8–26.5)	0–144
Caregivers (*n* = 86)*			
Burden (Zarit-6)	8.5 ± 6.79	8(2–13.3)	0–24
Distress related to BPSD (NPI-Q)	15.8 ± 10.43	15.5(7–23)	0–60
Health Perception (EQ-5D-VAS)	61.8 ± 23.98	60(50–80)	0–100
EQ-5D	No problem %	Slight problem %	Severe problem %
Mobility [95%CI]	75.6 [66.3–84.9]	24.4 [15.1–33.7]	0
Self-care [95%CI]	90.7 [84.9–95.5]	9.3 [3.5–15.1]	0
Daily activities [95%CI]	88.4 [81.4–95.3]	11.6 [4.7–18.6]	0
Pain/discomfort [95%CI]	48.8 [38.4–60.5]	41.9 [31.4–52.3]	9.3 [3.5–15.1]
Anxiety/depression [95%CI]	24.4 [16.3–33.7]	46.5 [36–57]	29.1 [19.8–39.5]

n, number of persons; SD, standard deviation; IR, interquartile range; p, percentile; %, percentage; BPSD, Behavioral and Psychological Symptoms of Dementia; CI, confidence intervals.
*Sample *n* = 86 with all the evaluation battery complete.

behaviours. Mean caregiver burden level was 8.5 (SD = ±6.79), indicating high burden. Distress with BPSD was also high (mean = 15.8, SD = ±10.43). Most caregivers reported somewhat poor health (mean = 61.8; SD = ± 23.98). Regarding EQ-5D, 51.2% of caregivers expressed pain/discomfort, and 75.6% had mild (46.5%) to severe (29.1%) anxiety/depression (Table 2).

Reliability and content validity

A test of test–retest ($n = 8$) demonstrated high inter–observer reliability (CCI = 0.99; IC95% = 0.95–0.99; $p < 0.000$). An exploratory factorial analysis (Table 3) yielded a two-factor solution with eigenvalues >1.00 and factor loadings from 0.52 to 0.88, with an internal consistency of α = 0.94. The first factor of four items reflects the same factor of the original scale, referred to as 'Ability to Manage' (α = 0.89). The second factor, constructed from the remaining nine items, called 'Somatic Well-being and Affects' (α = 0.92), combined two separate factors found for the original scale. The two-factor model explained 63% of variance.

Spanish version of the 13-item Perceived Change Index response patterns

Figure 1 presents distributions for items with mean = 2.7 (SD = ±1.1). The most chosen response was that things were 'worsening a little' in the past month.

'Somatic Well-being and Affects' dimension had a lower mean (Mean = 2.5, SD = ±1.10) than 'Ability to Manage' dimension (Mean = 2.9, SD = ±1.09). Caregivers reported deterioration in having free time (Mean = 2.1, SD = ±1.09), and only slightly higher scores on ability to care for persons with dementia (Mean = 2.9, SD = ±1.11), and understanding behaviours (Mean = 2.7, SD = ±1.22).

Convergent and divergent validity

Evidence for convergent validity was found for negative correlations between PCI-S and caregiver burden ($r = -0.53$, $p < 0.01$), distress with BPSD ($r = 0.54$, $p < 0.01$), and anxiety/depression (EQ-5D; $s = -0.44$, $p < 0.01$) and BPSD (NPI-Q, $r = -0.43$, $p < 0.01$) in expected directions. A positive correlation with caregiver perceived health was also found (EQ-5D-VAS $r = 0.39$. $p < 0.01$) as anticipated (Table 4).

The 'somatic well-being and affects' dimension was positively associated with physical function (ADCS-ADL $r = 0.21$, $p < 0.05$); perceived improvement was associated with caring for persons with greater physical function. Similarly, 'ability to manage' dimension was negatively associated with dementia severity (GDS-R $s = -0.22$, $p < 0.05$), suggesting perceived worsening managing care was associated with greater cognitive deterioration.

Table 5 shows logistic regression analysis for associations between the p25 of PCI-S and socio-demographic and health variables of caregivers and persons with dementia.

Table 3 Rotated factor matrix of PCI-S* ($N = 94$)

In the past month. For each item. Please tell me if you have felt things have become much worse. Become somewhat worse. Stayed the same. Improved somewhat. Or improved a lot.	Factors	
	Ability to manage	Somatic well-being and affects
1. Ability to understand care recipient's behaviour	**0.729**	0.285
2. Ability to manage day-to-day caregiving	**0.883**	0.218
4. Sense of control over the care recipient's problems	**0.800**	0.284
5. Ability to handle new caregiving problems	**0.729**	0.301
3. Feeling overwhelmed	0.479	**0.629**
6. Feeling calm or relaxed	0.532	**0.664**
7. Feeling upset	0.530	**0.631**
8. Your energy level	0.459	**0.581**
9. Feelings of being angry	0.433	**0.643**
10. Things have been going your way	0.592	**0.527**
11. Ability to sleep through the night	0.164	**0.708**
12. Feeling rested	0.179	**0.801**
13. Ability to have time for yourself	0.227	**0.635**
α Cronbach alpha coefficient α = 0.89 α = 0.92		

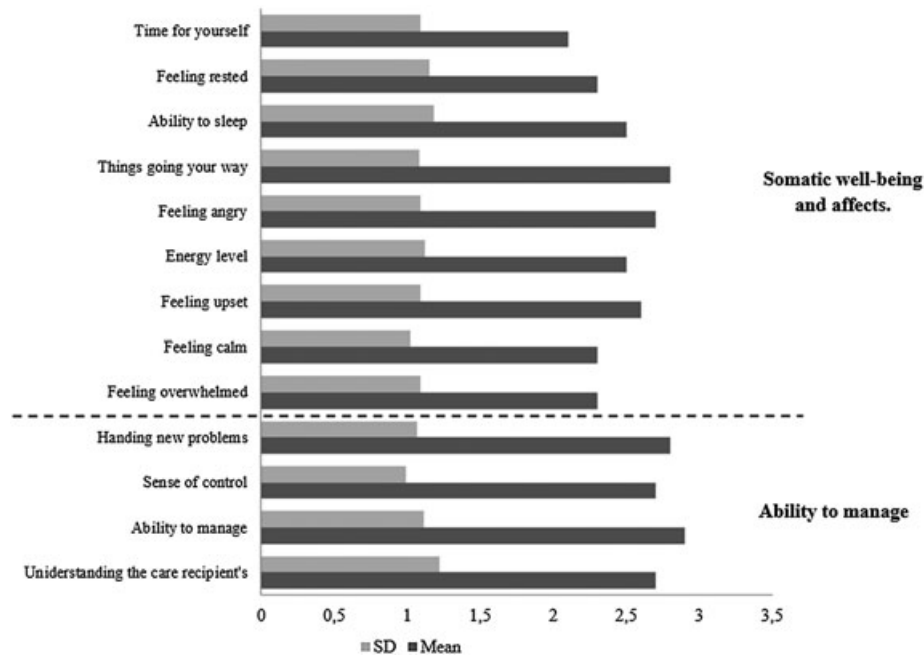*Cronbach α = 0.94 for PCI-S total score.

Figure 1 Score Distribution by item of the PCI-S.

The p25 of the total PCI-S was negatively associated with BPSD (Model 1 OR = 1.07, 95%CI = 1.03–1.15) and burden (Model 2 OR = 1.39, 95% CI = 1.17–1.65; Model 3 OR = 1.48, 95% CI = 1.18–1.86), and positively associated with physical functional (Model 1 OR = 0.95, 95% CI = 0.91–0.99).

The p25 for 'ability to manage' dimension was negatively associated with BPSD (Model 1 OR = 1.07, 95% CI = 1.03–1.12), distress with BPSD (Model 2 OR = 1.11, 95% CI = 1.04–1.19), and burden (Model 2 OR = 1.13, 95% CI = 1.02–1.24; Model 3 OR = 1.13, 95% CI = 1.02–1.25). The p25 for 'somatic well-being and affects' dimension was also negatively related with BPSD (Model 1 OR = 1.07, 95% CI = 1.03–1.13; Model 3 OR = 1.11, 95% CI = 1.01–1.23) and burden (Model 2 OR = 1.41, 95% CI = 1.18–1.69; Model 3 OR = 1.55, 95% CI = 1.19–2.01) and positively with functionality (Model 1 OR = 0.95, 95% CI = 0.91–0.99).

Table 4 Intercorrelation matrix for PCI-S and its two dimensions

	Total PCI-S	PCI-S ability to manage	PCI-S somatic well-being and affects
Persons with dementia (*n* = 86)			
Functionality (ADCS-ADL) (*r*)	0.20	0.14	0.21*
BPDS (NPI-Q) (*r*)	−0.43**	−0.42**	−0.39**
Dementia severity (GDS-R) (*s*)	−0,19	−0,22*	−0,18
Caregivers (*n* = 86)			
Burden (Zarit-6) (*r*)	−0.53**	−0.33**	−0.57**
Distress related to BPDS (NPI-Q) (*r*)	−0.54**	−0.46**	−0.52**
Health perception (EQ-5D-VAS) (*r*)	0.39**	0.30**	0.39**
EQ-5D (*s*)			
Mobility	0.01	0.05	−0.05
Self-care	−0.01	0.04	−0.04
Daily activities	−0.14	−0.15	−0.12
Pain/discomfort	−0.14	−0.07	−0.19
Anxiety/depression	−0.44**	−0.34**	−0.44*

r, Pearson correlation; *s*, Spearman correlation; PCI-S, Perceived Change Index Spanish Version; BPDS, Behavioral and Psychological Dementia Symptoms
*$p < 0.05$;
**$p < 0.01$.

Table 5 Logistic regression of PCI-S and dimensions 25th percentile with caregivers and persons with dementia health variables

	Model 1			Model 2			Model 3		
	Total PCI-S	PCI-S ability to manage	PCI-S somatic well-being and affects	Total PCI-S	PCI-S ability to manage	PCI-S somatic well-being and affects	Total PCI-S	PCI-S ability to manage	PCI-S somatic well-being and affects
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Caregiver sociodemographic characteristics (n = 86)									
Age	0.99 [9.94–1.05]	1.01 [0.97–1.06]	1.00 [0.95–1.06]	0.95 [0.89–1.02]	0.99 [0.95–1.05]	0.97 [0.90–1.04]	0.93 [0.84–1.05]	1.00 [0.95–1.06]	0.97 [0.89–1.05]
Female sex	0.78 [0.13–4.84]	1.41 [0.3–6.8]	0.86 [0.14–5.19]	0.32 [0.04–2.83]	0.31 [0.05–1.93]	0.31 [0.04–2.60]	0.33 [0.03–3.73]	0.35 [0.05–2.11]	0.28 [0.03–2.99]
Years caregiving	1.04 [0.84–1.3]	1.04 [0.84–1.3]	0.95 [0.75–1.20]	1.11 [0.83–1.50]	1.04 [0.81–1.32]	0.98 [0.71–1.36]	1.17 [0.87–1.58]	1.05 [0.82–1.33]	1.05 [0.75–1.45]
Education years	0.97 [0.8–1.16]	1.09 [0.9–1.31]	0.96 [0.80–1.16]	0.87 [0.67–1.12]	1.11 [0.90–1.37]	0.86 [0.66–1.11]	0.82 [0.60–1.11]	1.11 [0.89–1.38]	0.79 [0.58–1.09]
Approximate monthly income (CLP)									
≤$80.000	0.42 [0.08–2.34]	0.41 [0.07–2.26]	0.49 [0.09–2.69]	0.15 [0.01–1.61]	0.31 [0.05–2.04]	0.17 [0.02–1.86]	0.20 [0.02–2.84]	0.35 [0.05–2.40]	0.32 [0.02–4.83]
$80.000–$300.000	1.02 [0.27–4.51]	1.8 [0.43–7.47]	0.58 [0.12–2.79]	2.39 [0.34–16.99]	2.47 [0.49–12.27]	1.13 [0.16–8.13]	3.28 [0.38–28.07]	2.59 [0.50–13.39]	1.88 [0.19–17.99]
Health variables of the persons with dementia (n = 86)									
Functionality (ADCS-ADL)	0.95* [0.91–0.99]	0.98 [0.94–1.03]	0.95* [0.91–0.99]				0.98 [0.92–1.05]	0.99 [0.95–1.05]	0.99 [0.93–1.05]
BPSD (NPI-Q)	1.07** [1.03–1.15]	1.07** [1.03–1.12]	1.07** [1.03–1.13]				1.09 [0.99–1.19]	1.03 [0.97–1.09]	1.11* [1.01–1.23]
Health variables of the caregivers (n = 86)									
Health perception (EQ-5D-VAS)				0.99 [0.96–1.03]	1.00 [0.98–1.03]	1.00 [0.97–1.04]	0.99 [0.96–1.05]	1.00 [0.97–1.03]	0.99 [0.96–1.04]
Distress related to BPSD (NPI-Q)				1.07 [0.99–1.16]	1.11** [1.04–1.19]	1.08 [0.99–1.17]	0.92 [0.84–1.10]	1.08 [0.98–1.19]	0.93 [0.79–1.09]
Burden sensation (Zarit-6)				1.39** [1.17–1.65]	1.13* [1.02–1.24]	1.41** [1.18–1.69]	1.48** [1.18–1.86]	1.13* [1.02–1.25]	1.55** [1.19–2.01]

Reference categories: Male sex, Income higher or equal to CLP$300.000.

n, number of persons; OR, Odds ratio; CI, Confidence interval; PCI-S, Perceived Change Index Spanish Version; BPDS, Behavioral and Psychological Symptoms of Dementia; The Odds ratios showing association between PCI-S and convergent and divergent variables. The Hosmer–Lemeshow test represent a satisfactory goodness of fit in all models [Model 1 Total PCI-S p = 0.283] [Model 2 Total PCI-S p = 0.764; PCI-S Ability to manage p = 0.924; PCI-S Somatic well-being and affects p = 0.469; PCI-S Somatic well-being and affects p = 0.686; PCI-S Ability to manage p = 0.764; PCI-S Somatic well-being and affects p = 0.874] [Model 3 Total PCI-S p = 0.731; PCI-S Ability to manage p = 0.923; PCI-S Somatic well-being and affects p = 0.970].

*p < 0.05.
**p < 0.01.

As to divergent validity, there were no large or statistically significant PCI-S, and its subscales were not statistically associated with caregiver background characteristics.

Discussion

This study examined the psychometric properties of PCI-S for caregivers of persons with dementia in Chile. The scale and its dimensions demonstrated very good internal consistency, semantic, content, convergent, and divergent validity and internal consistency and test–retest reliability.

Specifically, we found that PCI-S presents high inter-observer agreement (intra-class correlation = 0.99), and internal consistency (α = 0.94). We identified two dimensions ('ability to manage' and 'somatic well-being and affects'), with items showing >0.5 factor loadings. Whereas the psychometric study of the original scale identified three distinct dimensions (management, somatic well-being and affective well-being), the better solution for the PCI-S was two dimensions. The 'Somatic well-being' and 'Affects' appeared to form a single factor, whereas 'Ability to manage' factor remained as in the original. Our two-factor solution had the same percentage of explained variance (63%) as with the three-factor model of the original scale (Gitlin et al., 2006b).

Although the item 'things have been going your way,' presented a similar factor loading along two dimensions, we included it in the 'somatic well-being and affects' factor. Conceptually, one's expectation about how things are going corresponds more to an affective and emotional evaluation of a situation (Suh et al., 1996; Diener et al., 1999).

Moreover, we found that items were understood by caregivers and they responded appropriately. We also found that items had a mean score close to 2 points indicating that most caregivers perceived that things had 'worsened a little' in the past month. The 'somatic well-being and affects' subscale had the lowest scores reflecting the personal toll of caregiving on their well-being (Moreno-Villanueva and Bürkle, 2015; Allen et al., 2016).

As to convergent validity, we show that PCI-S was associated in expected directions with caregiver measures of their overall health, burden and distress, and factors related to persons with dementia including BPSD, physical function and dementia severity. Greater burden, distress with BPSD, and poor perceived caregiver health, and of the person with dementia, poor physical functioning and dementia severity were each associated with perceived worsening in the past month.

One subscale, 'somatic well-being and affects' was positively related to dementia functionality suggesting that greater independence was associated with perceived improvement over the past month. Caregivers providing care to persons with dementia with more independence in daily activities may have lower care demands, resulting in caregiver appraisal that things are improving or going well (Given et al., 1999). Similarly, we found a negative, albeit low, association between 'ability to manage' subscale and dementia severity suggesting that with disease progression, everyday care becomes more challenging to manage, with caregivers perceiving a worsening in their situation (Hodgson et al., 2014).

As expected, caregiver burden was associated with PCI-S and subscale scores suggesting that caregivers perceiving things as worsening also reported greater burden. Other studies show that dementia caregivers have higher burden than caregivers of individuals without dementia (Di Mattei et al., 2008), and that burden is linked to poor quality of life (Adelman et al., 2014; Reviews and Wu, 2015).

Also as expected, statistically significant associations were found between PCI-S and its subscale scores and overall health perception, and anxiety and depression (EQ-5D item). There were no statistically significant correlations between PCI-S and other EQ-5D items (mobility, personal care, daily activities and pain) which we expected. This suggests that caregiver health in these areas is not directly associated with everyday care challenges as is mental health (Diener et al., 1999; Gitlin et al., 2010a). Similarly, caring for persons with dementia, although physically challenging, does not immediately impact mobility, or the ability for the caregiver to carry out self-care or necessarily cause physical pain.

Associations between PCI-S and BPSD were also observed along with caregiver distress with behaviours. Previous research shows that BPSD trigger need for more caregiving and are associated with caregiver distress (Feast et al., 2016; Jutkowitz et al., 2017). Similarly, if caregivers perceive that they are unable to manage day-to-day, they may experience anxiety and loss of control (Gitlin and Rose, 2014).

The study sample reflects the socio-demographic characteristics of Chilean caregivers, most of whom are women with low education and low income (Slachevsky et al., 2013). There were no associations between background characteristics including caregiver age, gender and income, and PCI-S or its subscales, supporting our divergent validity

assumptions. This suggests that perceived well-being is linked to daily care challenges and not necessarily basic characteristics. However, in the original English study, PCI scores were found to significantly differ by gender. Also, in the original English validation, there were differences by race (white versus nonwhite) but that distinction was not relevant to this study sample, and hence not examined. As to gender, in Chile, culturally-speaking, caregiving is considered a woman's role, and male caregivers tend to be stigmatised. The proportion between men and women in the Chilean study versus the English validation study was high (28.3% of sample were men in PCI-English version vs. 14.9% in this PCI-Spanish version study). One reason why we may not have found a gender difference in this study was that the small number of male participants.

One study limitation is that the Spanish translation reflects Chilean language preferences. Additional adjustments to its translation may be necessary for other Spanish-speaking countries. Moreover, as caregivers were recruited from an adult day service, they may have been more aware of their situation than caregivers not using these services and rated items differently. There is a need for this version to be tested with other populations.

Noteworthy is that the response format of PCI-S asks caregivers to appraise change in aspects of well-being over the past month. Thus, PCI-S can be used to establish a baseline of whether things are improving, worsening or staying the same or re-administered following implementation of a dementia caregiver support programme to evaluate impact. Although this study evaluated psychometric properties at one time point, other studies using the original English version have shown its sensitivity to intervention (Gitlin et al., 2010b).

Conclusion

Spanish version of the 13-item Perceived Change Index is a valid and reliable scale for use with Spanish-speaking caregivers of persons with dementia that family caregivers with literacy can self-administer. The scale can be used in its entirety and its two subscales provide insight as to which areas are of most concern or for which caregivers are at risk. As PCI-S measures worsening and improvement, it captures perceived change over a 1-month period. Others have also shown its utility for evaluating programme impact from one point in time to another. As PCI-S items are proximal to daily caregiver concerns and experiences, it can be used in conjunction with other scales assessing global experiences such as burden or mastery.

> ### Key points
> - There is a need for valid and reliable scales to evaluate caregiver well-being and change over time that are culturally sensible, and which have clinical utility in dementia care.
> - Perceived Change Index (PCI) is a brief 13-item scale that evaluates changes in well-being (improvement or worsening) in caregivers along a number of dimensions that can be used to evaluate the effectiveness of dementia care interventions.
> - Originally validated in English in the USA, we demonstrate that its Spanish version (PCI-S) has very good internal consistency, semantic and content validity and convergent and divergent validity. It is associated with caregiver burden, health perception, depressive symptoms, and distress, and behavioural symptoms and functionality in persons with dementia in expected directions but not associated with socio-demographic characteristics as anticipated.
> - Our results extend the utility of the original scale by showing that PCI-S can be used with Spanish speaking caregivers of persons with dementia to evaluate their well-being and the effects of care and services.

Disclosure

None declared.

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Supporting Information

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