



Family care for older
members: social
implications at personal
and community level
Psychoeducational
programs for informal
caregivers

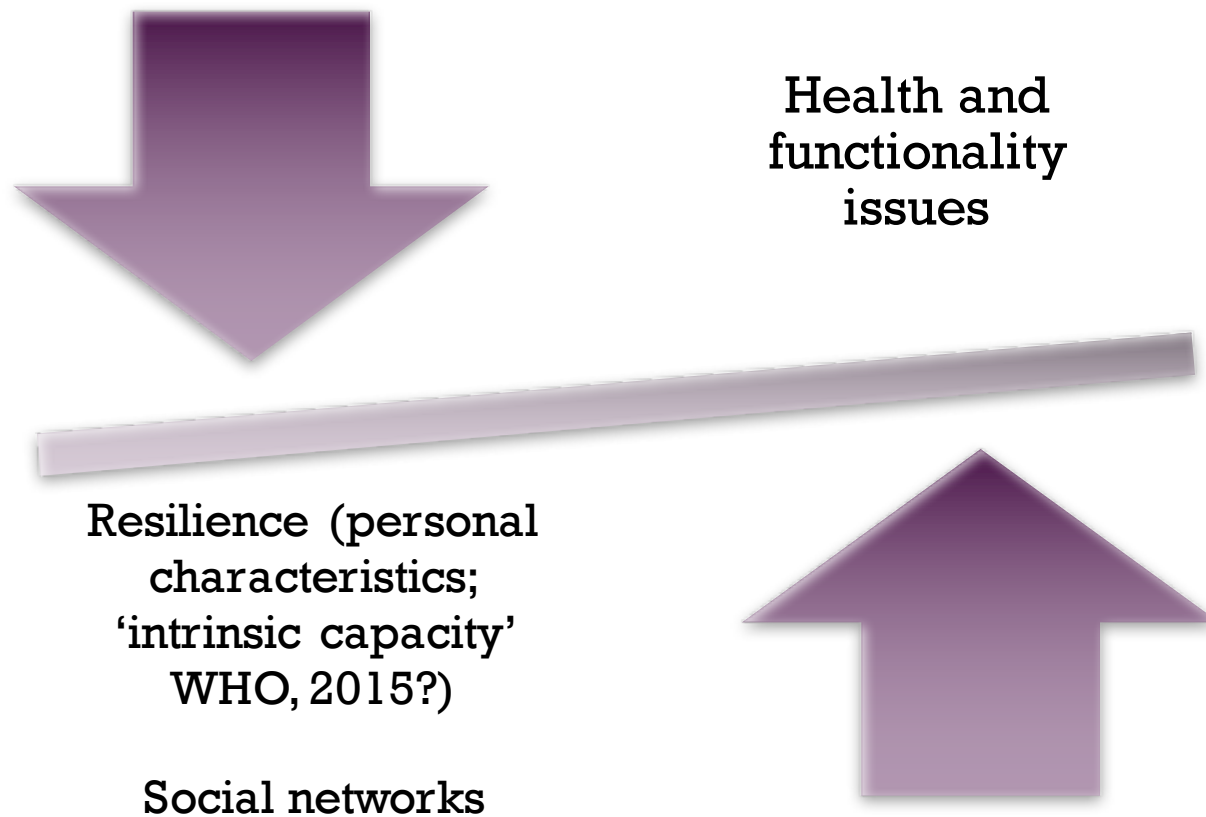


CONSTANÇA PAÚL



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UNIVERSIDADE DO PORTO

+ Well-being balance in old age

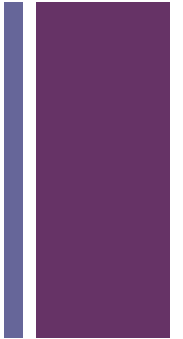


+ Caregiver and wellbeing in old age





Social networks (extend, accessibility, quality, history of the relationships , basic trust; intimacy...)



■ Family

■ Friends

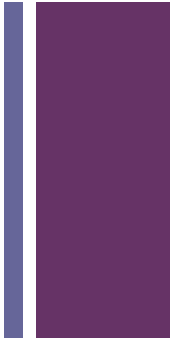
■ Neighbours

■ (Volunteers)



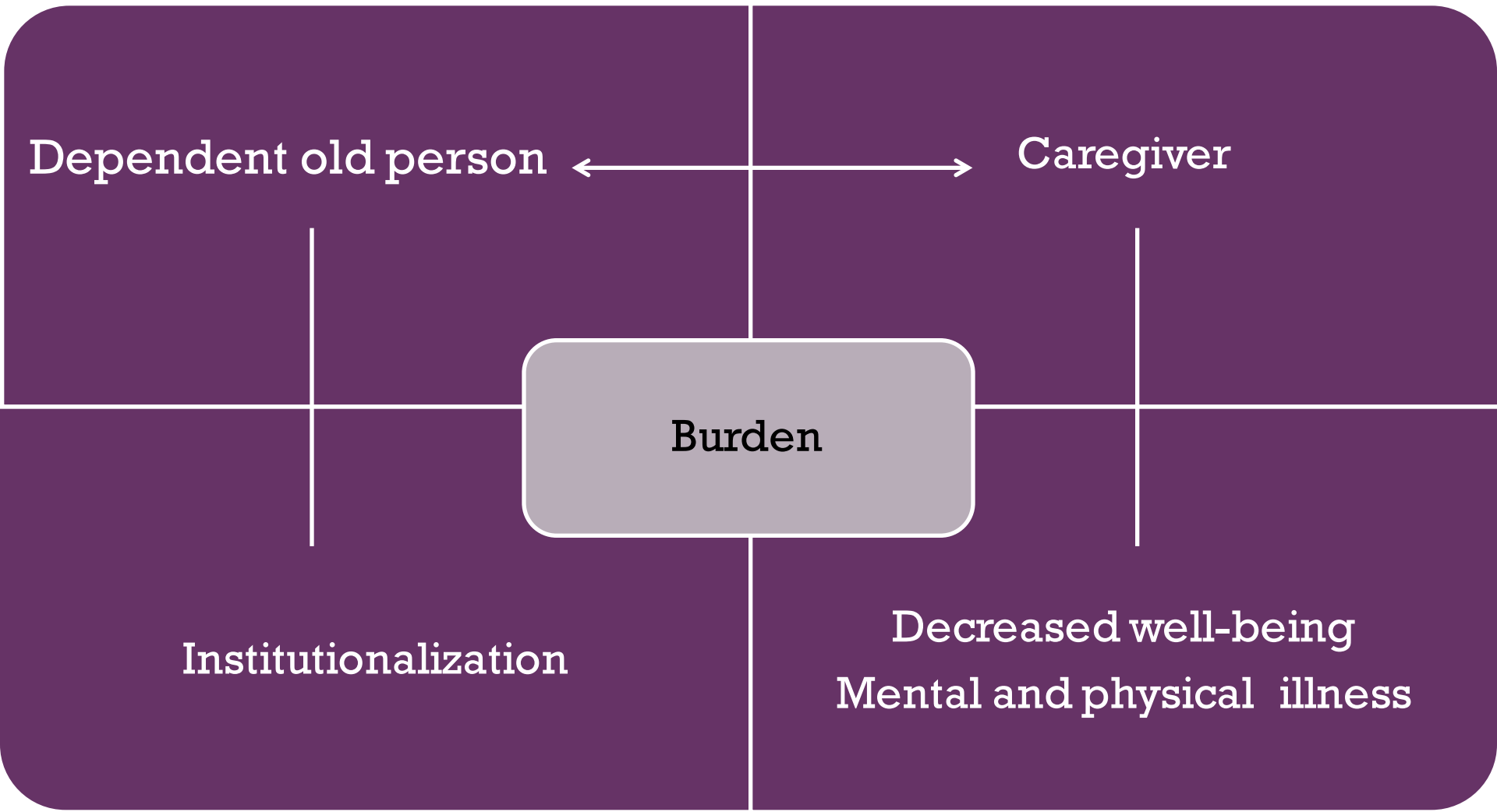
■ Primary caregiver (“it is not a choice!”)

+ Caregiver burden



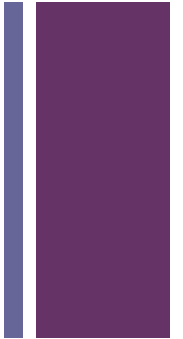
- Refers to the physical, psychological and social consequences of taking care of a patient
- Caregiver burden is used as synonyms of strain and stress of the caregiver. Considering that taking care of a dependent individual, be it a physical or mental patient will cause caregiving burden

+ Negative consequences of caregiving burden





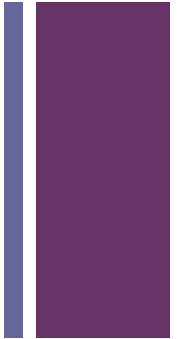
Other consequences of caregiver burden



- From the social and health policy perspective caregiving burden results in a long term grow of expenses with carer and care recipient



Some questions about Caregiving

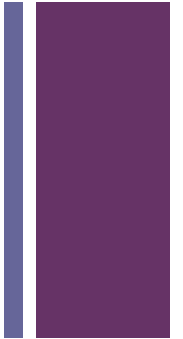


- **Who** are the carers?
 - Family, Neighbours, Friends (?)
- **Who pays** the care? and
- Who should pay the care?
 - Taxes, labour legislation

... if the NHS (or equivalent)
- What about training and follow-up of carers?
- The cases of changing residence from one child to another; foster family



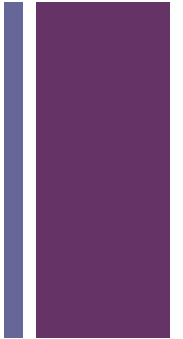
Care of old dependent people



- The families - as informal caregivers - remain the first, most reliable, and most acceptable source of assistance (Zarit, Pearlin and Schaie, 1993), in most of the European countries



Who gives care



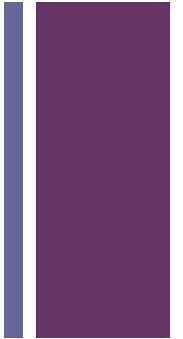
■ Primary caregiver

- Hierarchy substitution model: spouse/daughter/son (daughter in law) sisters, brothers, others
- Co-residence
- ...

■ Secondary caregiver



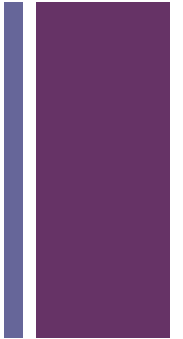
The aims of caregiving research are:



- the predictors
- the different kinds and levels of burden
- the positive aspects of caring
- the impact of physical versus cognitive impairment
- the gender differences and competing roles
- long term consequences of burden on caregivers and patients
- ...



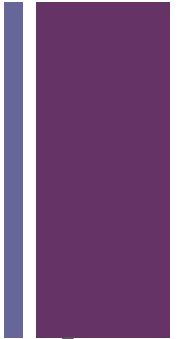
How to explain burden



- The conceptual framework is the stress model
- There is an overload of physical work derived from performing, or helping the dependent individual performing, the activities of daily living (ADLs) and the instrumental activities of daily living (IADLs)
- There are psychological and social costs of caregiving - more difficult to measure – that can lead to burden of caregiving



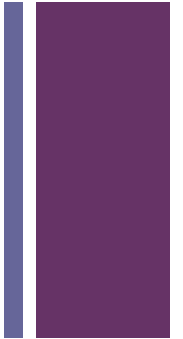
Caregiver stress (Pearlin et al,1990)



- The socio-economic characteristics and resources of caregivers
- Primary stressors - that are hardships and problems anchored directly in caregiving
- Secondary stressors
 - the strains experienced in roles and activities outside of caregiving
 - intrapsychic strains, involving the diminishment of self-concepts
- (Coping and social support can potentially intervene as buffers at multiple points along the stress process)



Physical / Cognitive impaired



- Most of the studies show higher depression rates and psychiatric symptomatology among caregivers comparing with controls
- It is well established that providing care to disabled relatives create emotional physical and financial strain and is generally believed that caring for a demented individual presents the greatest challenge of all



Hypothesis that explain the evolution of caregiving (Schulz and Williamson (1994)

- The wear-and-tear H: there will be a decrement in caregiver functioning as the illness progresses
- The adaptation hypothesis: caregivers will adapt to the demands of the situation, stabilising or even improving caregiver

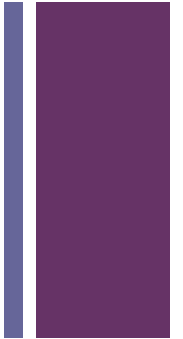


Hypothesis that explain the evolution of caregiving (Schulz and Williamson, 1994)

- The trait H: caregivers maintain a constant level of functioning depending on their resources of coping skills and social support
- The glucocorticoid cascade H: the effect of chronic stressors have persistent and severe consequences for immune function in older adults, including the acceleration of aging of the immune response



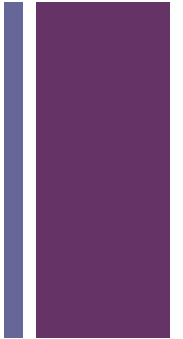
The objective and subjective burden is determined by (Gottlieb, 1989)



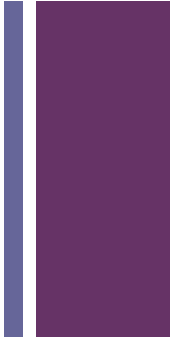
- The past and present quality of the relationship between caregiver and care recipient
- The role's reverberations on other life spheres
- The support available from the caregiver's social ecology and
- The psychosocial variables of the caregiver response to the demands of caregiving (communication skills, coping, perception of self-efficacy)



Risk factors for burden



- The worsening of the relationship between caregiver and patient
- Being a spouse
- Shorter length of caregiving
- Poor caregiver self-rated health
- Greater physical disability and
- Behaviour and mood disturbances in the patient



Context of Caregiving

- Household congruency between physical environment and patient capacities (architectonical barriers and aids)
- Income
- Available formal services



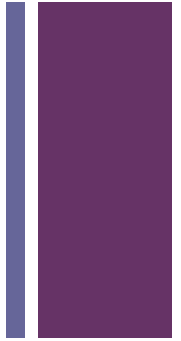
Risk factors

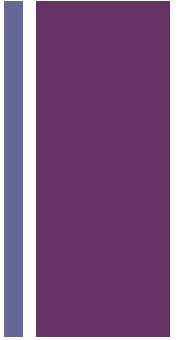
Caregiver

- Age, gender and SES;
- Baseline physical and mental health
- Coping capacities
- Development stage
- Beliefs and attitudes about caring
- Conflicts between caregiving and job
- Conflicts between caregiving role and family life

Care recipient

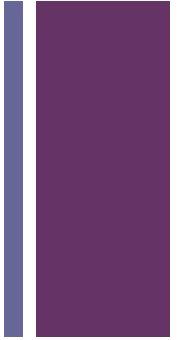
- Age, gender and SES;
- Type of impairment: physical, mental or both
- Level of disability
- The prognostic of illness (life expectancy, progressive or stable condition)





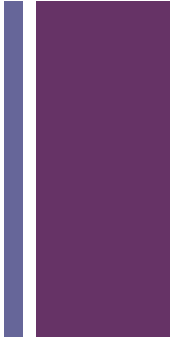
Relationship caregiver / care recipient

- Being a relative, friend, neighbour
- Quality of the actual and past relationship



Tasks: ADLs and IADLs

- The level of work and effort the caregiver must expend with care
- Time spent
- Tasks performed
- Information
- Competence



Caregiving outcomes

Physical Burden

- Immunological functioning
- Symptoms and complains
- Medicine consumption

Psychological burden

- Depression, anxiety, irritability, cognitive distress

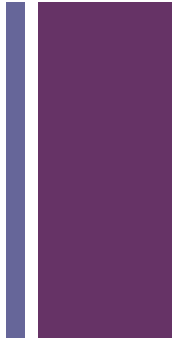
Social Burden

- Isolation
- Family disruption
- Career disruption

Satisfaction



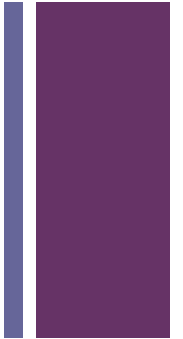
Gender differences, competing roles



- Caregiving is gender defined and largely assumed by women (wives and daughters). According to Dwyer e Coward (1991) women care 3.22 in ADL and 2.56 in IADLs times more than men
- **Hypothesis**
 - Finley, 1989: women have more time; were socialized to do so; are experts...
 - Lee e cols., 1993: The tendency that carer and recipient belong to the same gender because: there is a strong relation between mother and daughter; the incest taboo



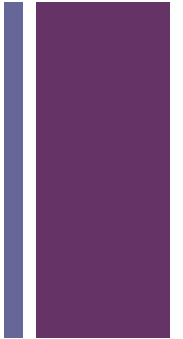
Profile of caregivers at risk



- Middle age or older women, living with the care recipient is the sole care provider, has personal health problems, is limited in personal social or financial resources, has other family social or job-related obligations that compete with the demands of caregiving, previously has had problems in personal relationship with the care recipient and perceives the caregiving experience to be a major personal life disruption (Davis, 1992)



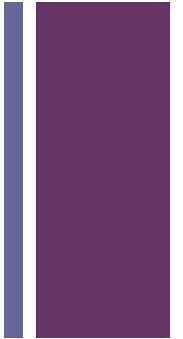
Measures of the impact of informal caregiving of elders



- Zarit et al. 1980 « Burden Interview » (BI) with one factor and that considered the impact as disruptions changes in social activities, physical and financial strain, emotional upset and elder-carer relationship
- Greene et al 1982 “Relatives Stress Scale” (RSS) with three factors one on personal distress other on domestic upset and the third on negative feelings



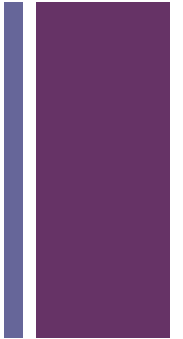
Measures of the impact of informal caregiving of elders



- Robinson, 1983 - *Caregiver Strain Index* (CSI) - with only one factor that conceptualise the impact as disruptions, changes in social activities. Physical and financial strain and emotional upset
- Poulshock and Deimling, 1984 - *Impact* - with two factors one including negative changes in the relationships between the elder, the caregiver and the family; and the second factor with restrictions in caregiver activities



Measures of the impact of informal caregiving of elders



- Montgomery 1985 – *Burden* - two factors referring to the objective burden including the restrictions to the social activities and subjective attitudes or emotional reactions to caregiving experience
- Novak and Guest 1989 - *Caregiver Burden* (CBI) - five factors: Time dependence burden; Developmental burden; Physical burden; Social burden and Emotional burden
- Lawton et al 1989 *Caregiving Appraisal* - three factors: Subjective burden; Caregiving satisfaction and Caregiving impact

+ Future Investigation

- Caregiving burden is not only an individual but a community problem and social policy should rethink services focusing on gender issues and diversity, to meet the needs of different caregivers and care recipients
- **Effectiveness of interventions with caregivers not only at caregivers but also at recipient of care level as well as the impact in health services use and institutionalization**
- Relation between informal and formal care: type and amount of formal services to support informal caregiving

Map 1: Share of single-person households, by NUTS level 3 region, 2011
(% of all households)

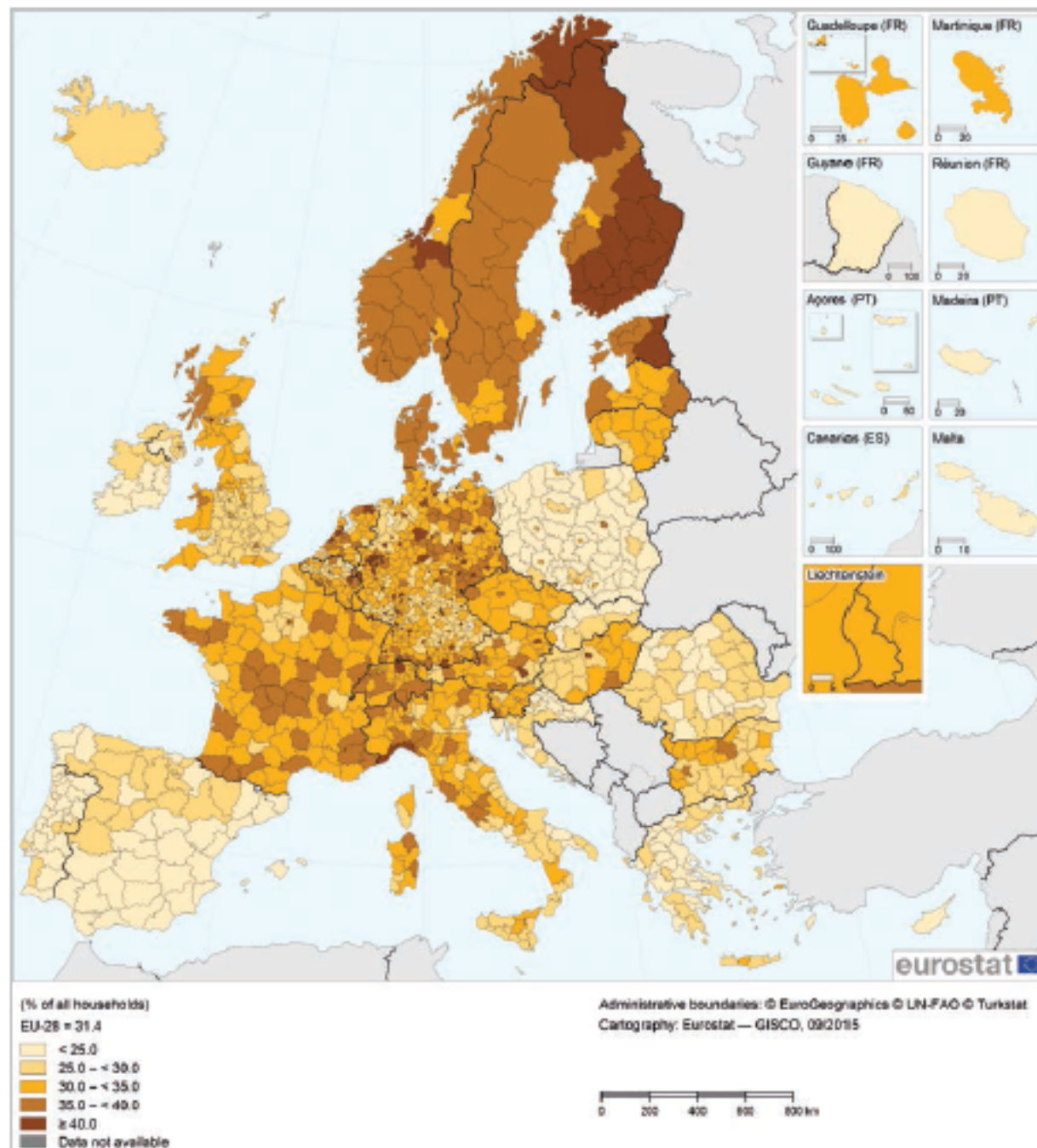
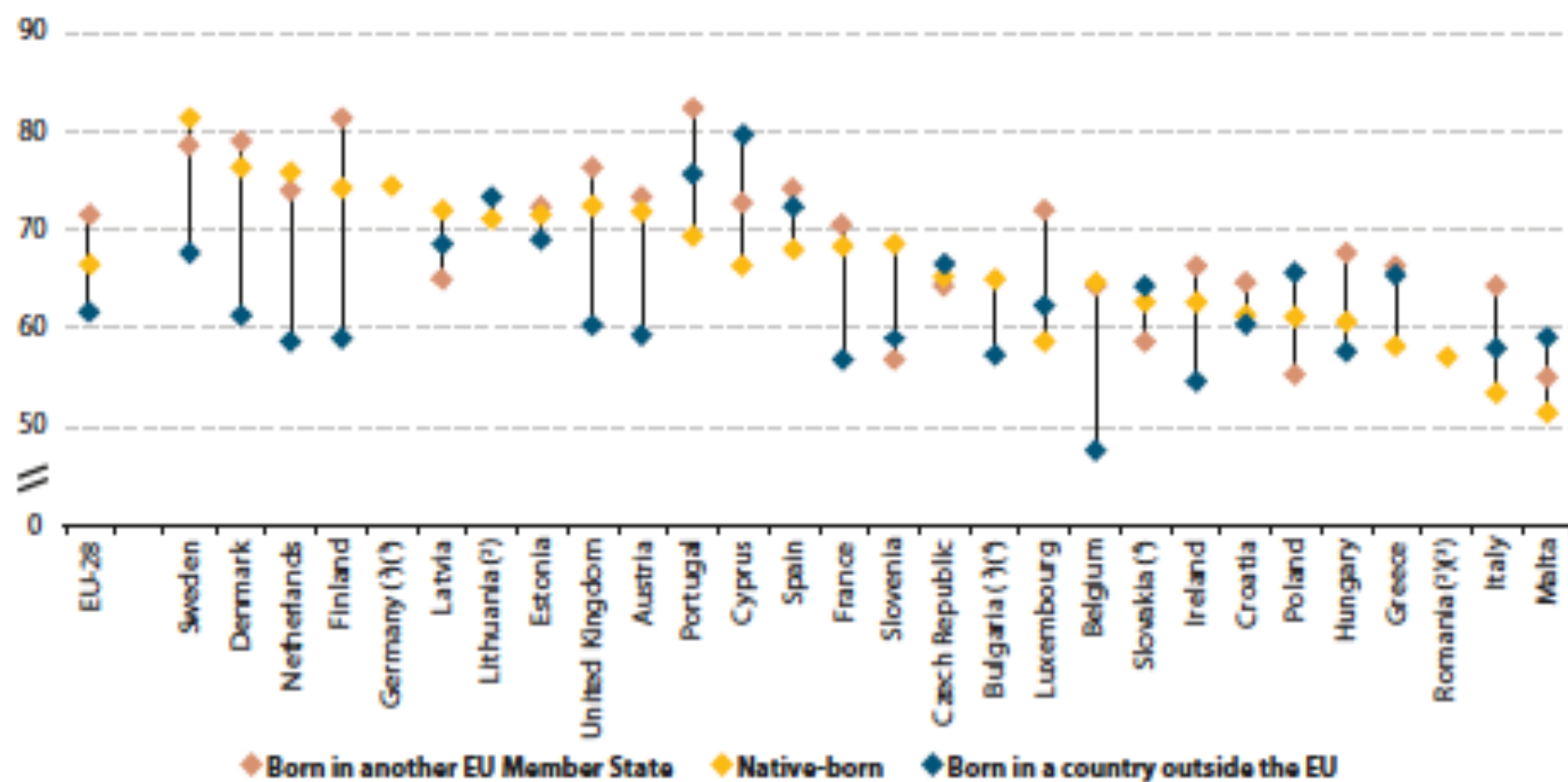


Figure 8: Female activity rates, persons aged 15–64, 2014 ⁽¹⁾

(%)



⁽¹⁾ Note the y-axis is cut. Ranked on the female activity rate for the whole population aged 15–64.

⁽²⁾ Born in another EU Member State: not available.

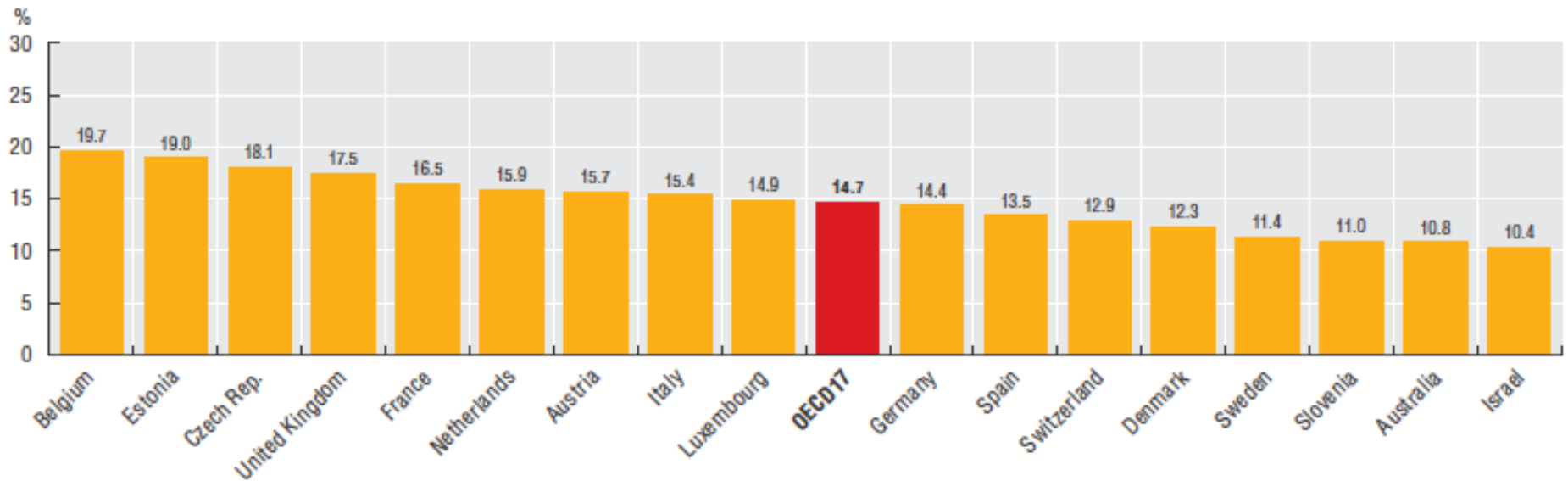
⁽³⁾ Born in a country outside the EU: not available.

⁽⁴⁾ Born in a country outside the EU: low reliability.


Source: Eurostat (online data code: [lfsa_argacob](#))



11.14. Population aged 50 and over reporting to be informal carers, 2013 (or nearest year)



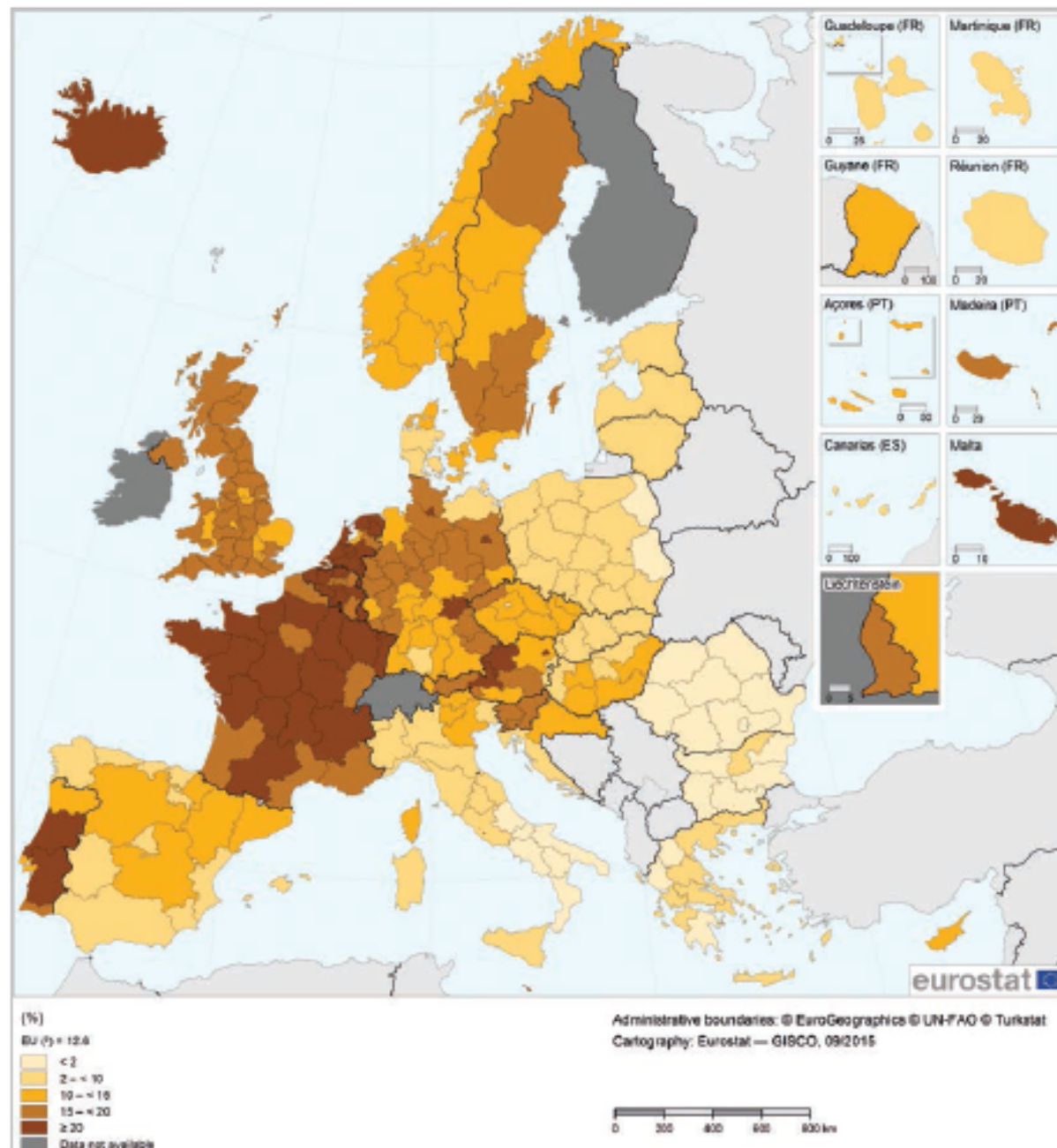
Source: OECD estimates based on 2013 HILDA survey for Australia, 2012-13 Understanding Society survey for the United Kingdom and 2013 SHARE survey for other European countries.

StatLink  <http://dx.doi.org/10.1787/888933281423>



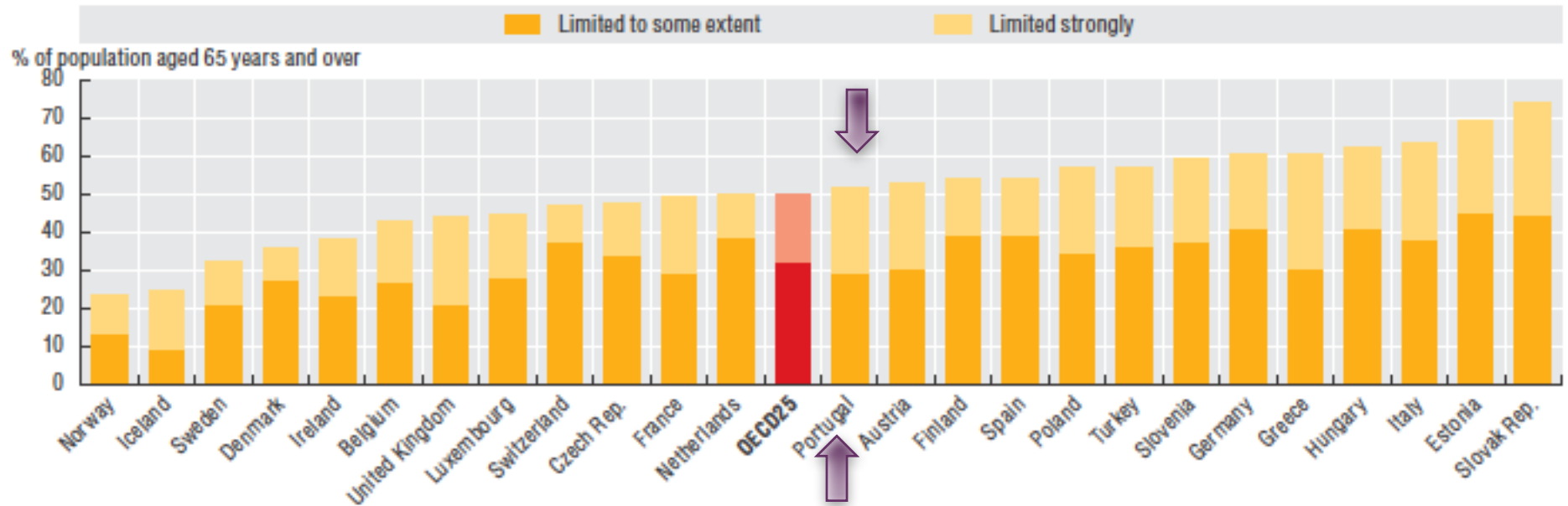
Almost half of all women
in the EU-28 aged 85 and
over were living alone in
2011

Map 2: Share of population aged 85 years and over living in an institutional household, by NUTS level 2 region, 2011 ⁽¹⁾
(%)






11.7. Limitations in daily activities in adults aged 65 years and over, European countries, 2013



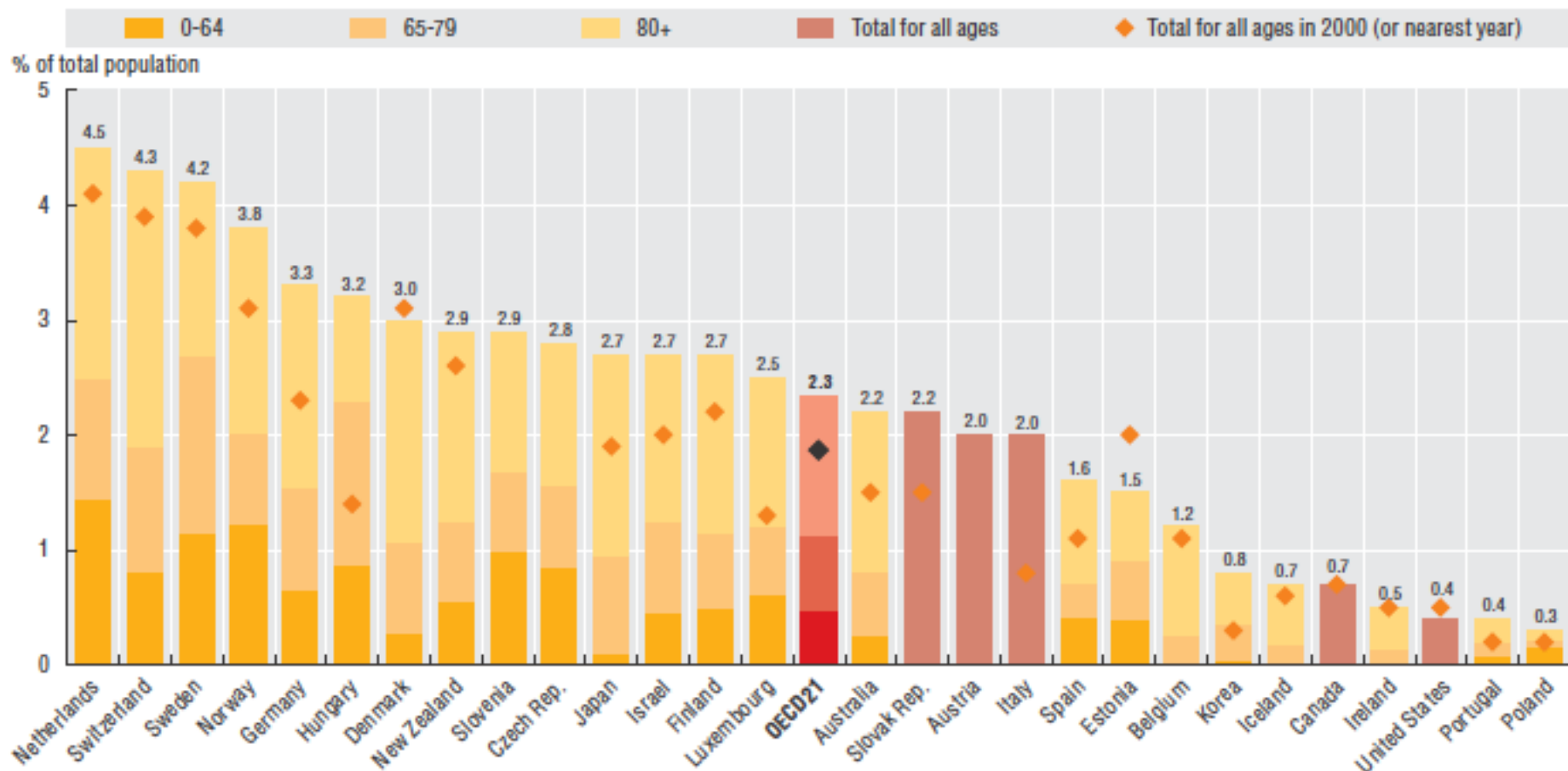
Source: Eurostat Database 2015.

StatLink  <http://dx.doi.org/10.1787/888933281398>

Map 1: Share of population aged 65 years and over living alone, by NUTS level 2 region, 2011 (%)



11.12. Proportion of population receiving long-term care, 2013 (or nearest year)



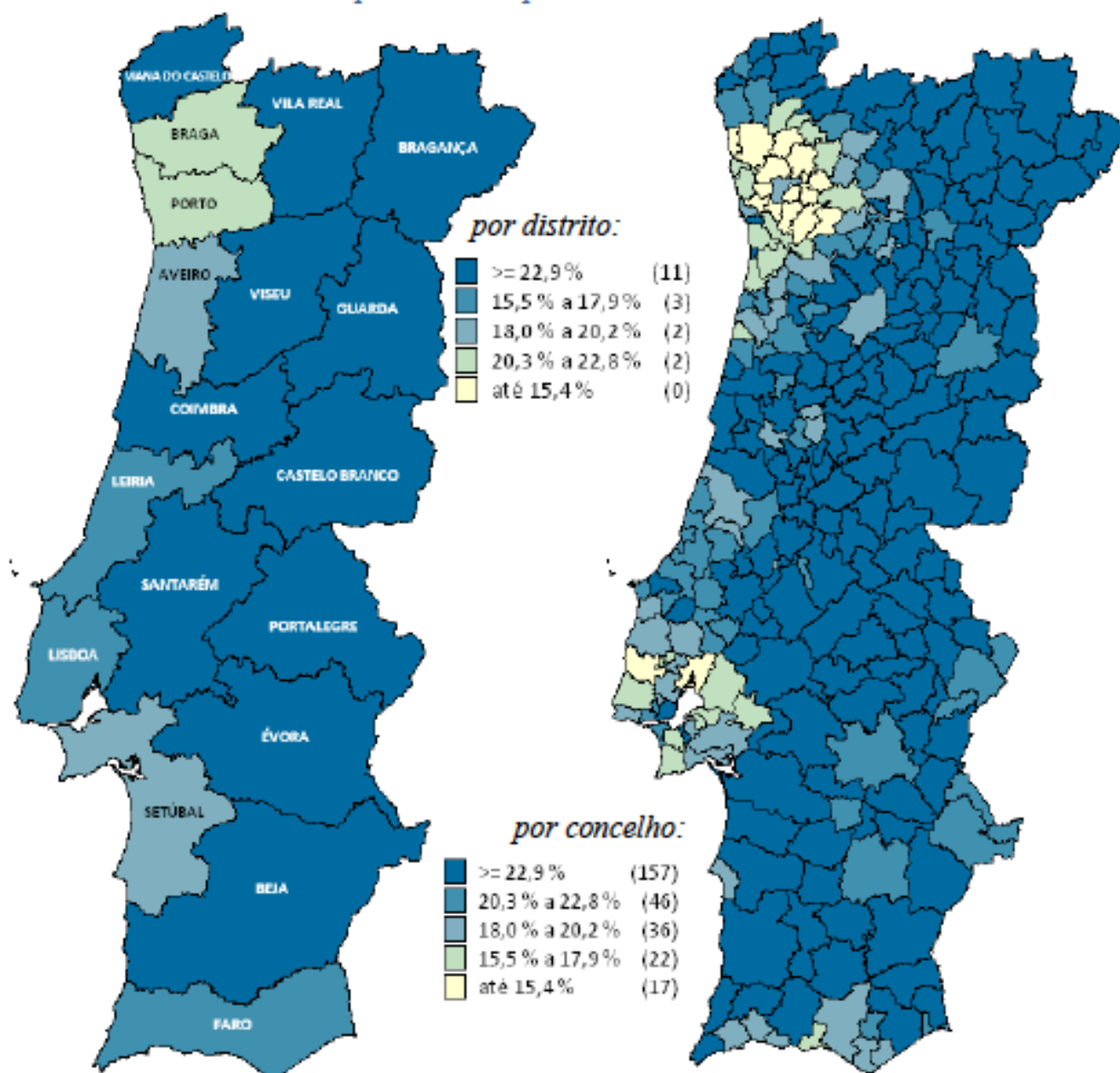
Source: OECD Health Statistics 2015, <http://dx.doi.org/10.1787/health-data-en>.

StatLink <http://dx.doi.org/10.1787/888933281419>



Source: Eurostat (Census hub HC48)

*Relação entre a População Idosa (≥ 65 anos) e a População Total,
por distrito e por concelho 2014*



Fonte: INE, Estimativas da População Residente 2014.

Effectiveness of a psychoeducational programme for informal caregivers of older adults

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Scand J Caring Sci; 2015

Effectiveness of a psychoeducational programme for informal caregivers of older adults

Purpose of the study: This study explored the effectiveness of psychoeducational programme for informal caregivers called 'Caring at home'.

Design and methods: The sample included 60 informal caregivers of elderly people (≥60 years) living in the community. Socio-demographic information of informal caregivers and care recipients was collected with the COPE Index. The assessment protocol comprised four scales: 12-item Short-Form Health Survey, General Health Questionnaire-12, Positive Aspects of Caregiving and Caregiver Strain Index Modified. There were five assessment moments: a pretest, a post-test and three follow-ups.

Results: Informal caregivers had an average age of 52.08 years (SD = 9.11) and were mainly women (90.0%), married/partnered (75.0%) and children of the

care recipients (61.7%). The median time spent in care was 12 hours/day (IQR = 18). Results showed a favourable evolution after the psychoeducational intervention, a significant improvement in caregivers' mental health ($p = 0.03$) from pretest to 1st follow-up (2/3 months after the psychoeducational intervention) and the maintenance of the other assessed dimensions of the caregivers' behaviour.

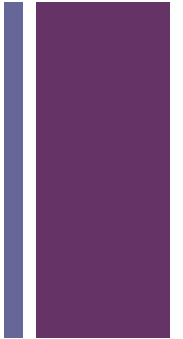
Implications: The psychoeducational intervention seems to promote improvements in mental health and the maintenance of other favourable conditions at baseline. These results may indicate that psychoeducational programme are beneficial to minimise or prevent adverse effects of caregiving.

Keywords: informal caregiving, old people, intervention, mental health, disabilities.

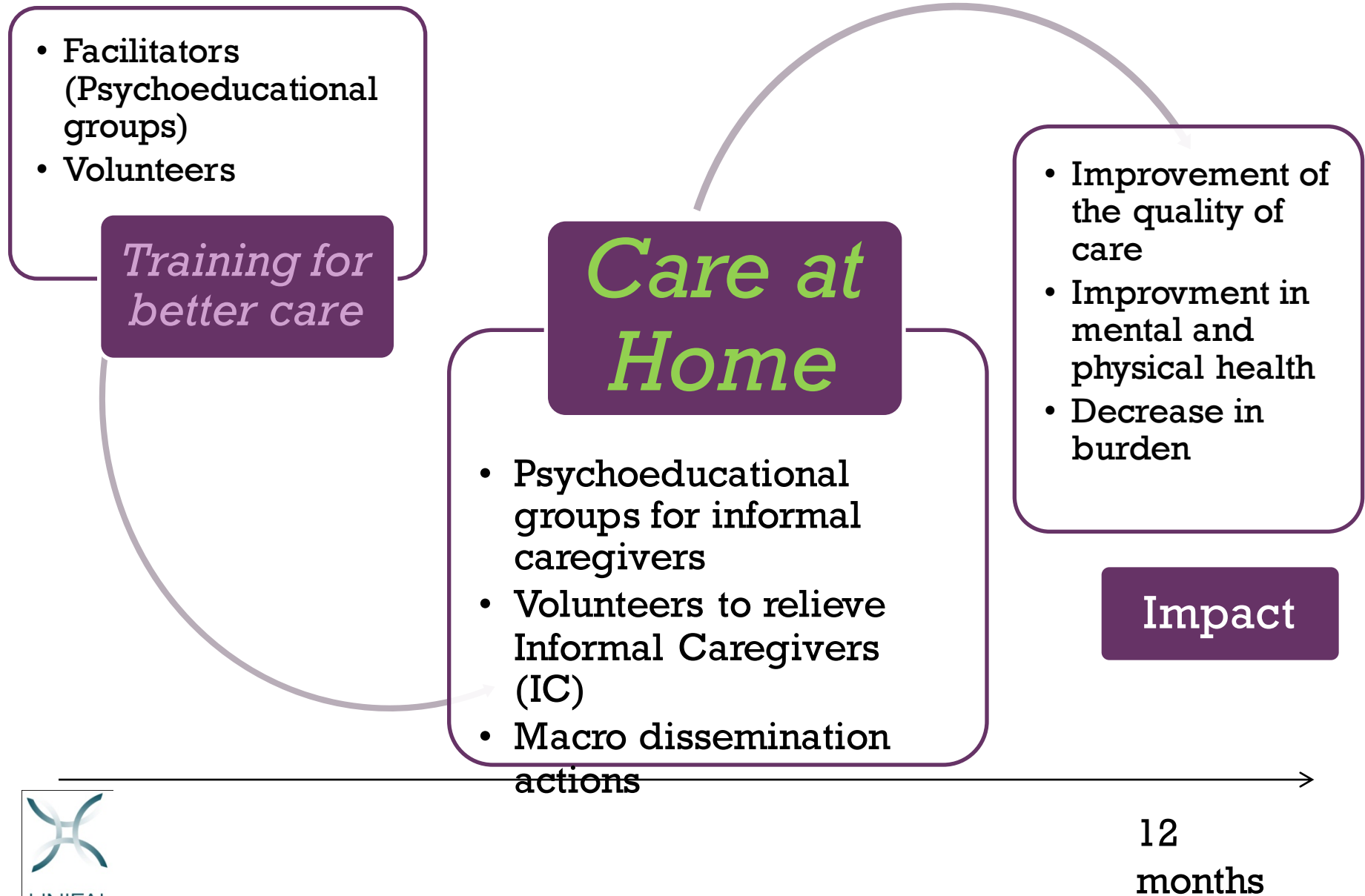
Submitted 26 September 2014, Accepted 30 January 2015



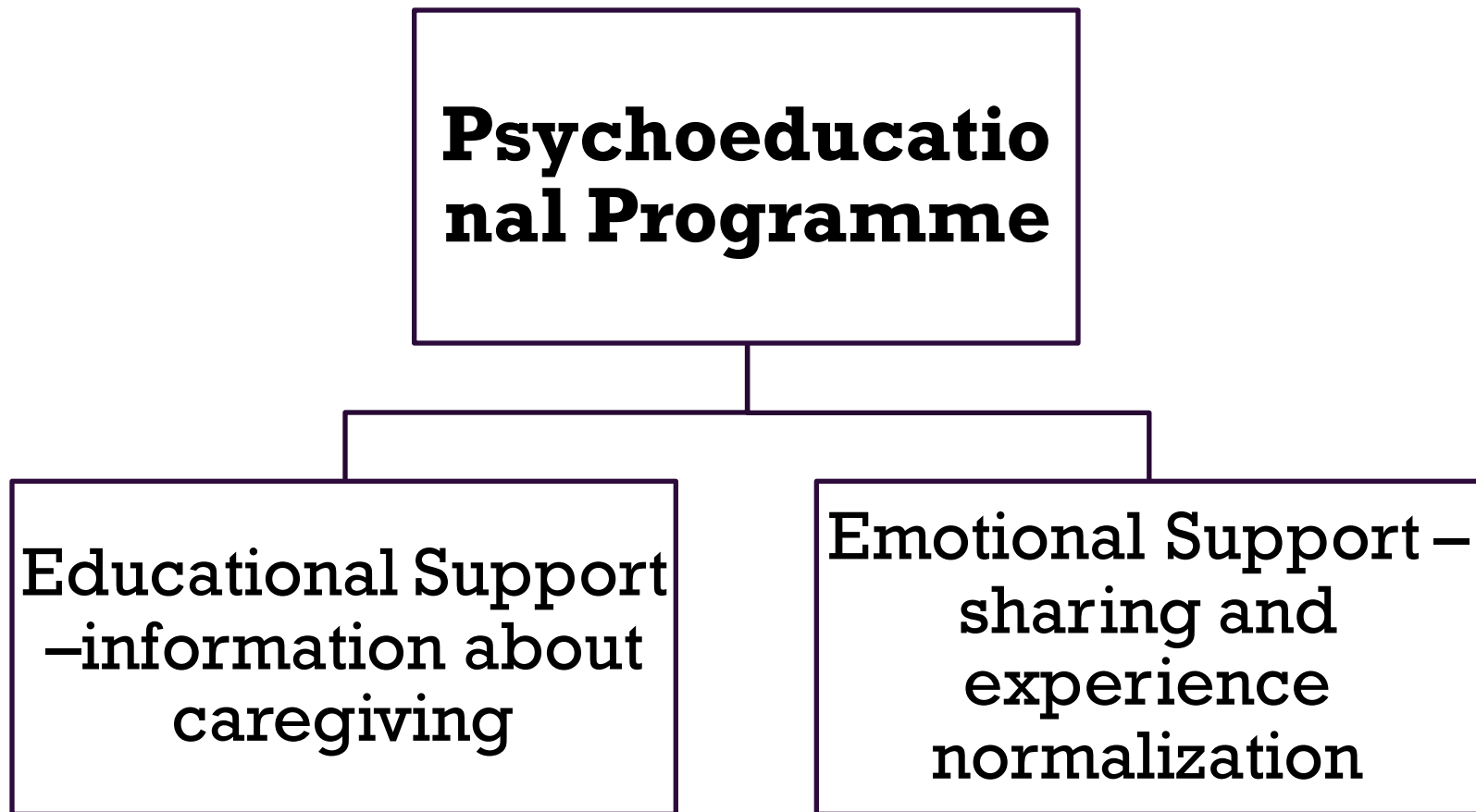
Objective

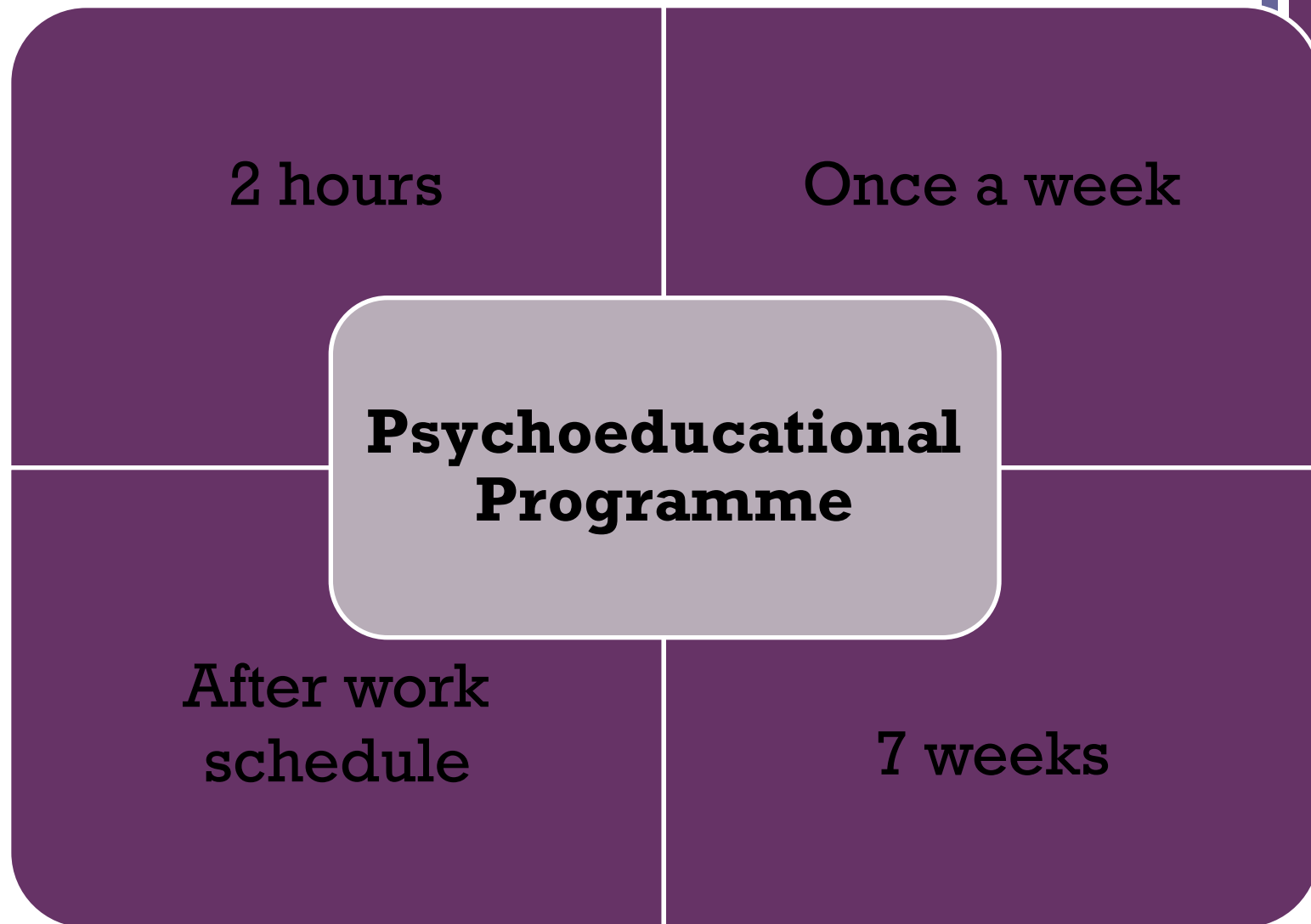


- To show and discuss results of 2 intervention programs on caregivers, carried out in the community by UNIFAI, in partnership with local authorities and NGOs:
 - ‘Care at home’ (municipality of Guimarães)
 - ‘Taking care of Carers’ (Municipalities “Entre Douro e Vouga”)



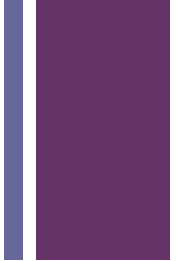
+ Program description







Sessions content



Session 1 – Understanding ageing

Session 2 – Caregiving tasks I

Session 3 – Caregiving tasks II

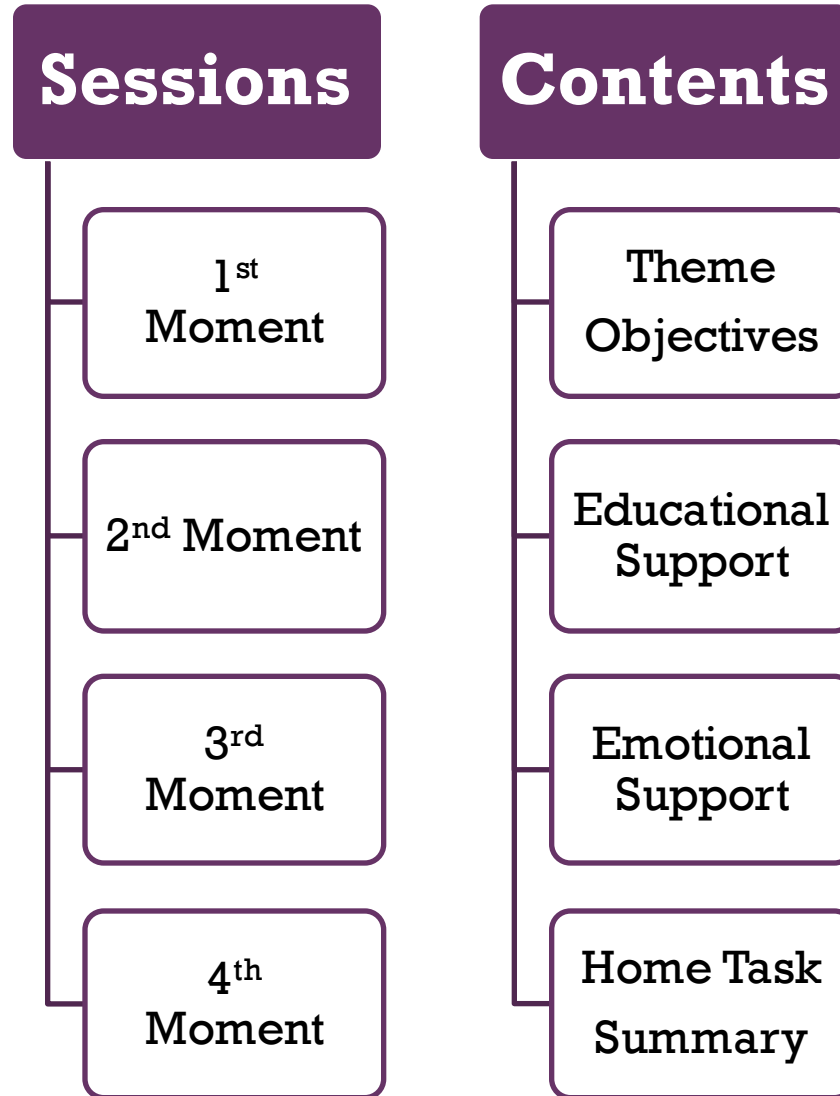
Session 4 – How to act in an emergency

Session 5 – Occupational Activities

Session 6 – Taking care of the caregiver

Session 7 – Support in the community

+ Session structure



+Example of a session plan

SESSION 2 – PERSONAL CARE I				
Phase		Contents	Facilitator	T'
Beginning		<p>Presentation of the structure and objectives of the session.</p> <p>Activity 4: Discussion of <i>Homework 1 what I learned...</i></p>	Coordinator	10min
Development	Educational	<p>Personal Care I</p> <ul style="list-style-type: none"> • Hygiene and comfort • Eating • Dressing and undressing • Elimination <p>Activity 5: Competencies training</p>	Nursing	60min
	Emotional	Activity 6: Emotions	Coordinator	40 min
Final		<ul style="list-style-type: none"> • <i>Homework 2 - Logbook</i> • Summary of session; • Presentation of the theme of session 3; • Closing remarks. 	Coordinator Nursing	10 min

- Recruitment of IC's through the media, brochures, raising awareness in the community
- Organization of the intervention groups according to care recipient (e.g stroke; dementia) and by geographic criteria
- Each group is coordinated by a psychologist and 1 or 2 specialist in the topic of each session (nurse, gerontologist)

+ Evaluation model

Pre - Test

- A week before the beginning of the programme
- Assessment: Profile of caregivers; self report of health; distress; positive aspects of caregiving, burden, and support services for caregiver

Post - Test

- At the end of the programme (last session)
- Assessment: self report of health; distress; positive aspects of caregiving, burden
- Satisfaction Assessment

1st Follow- up

- 8 / 12 weeks after the end of the programme
- Assessment: self report of health; distress; positive aspects of caregiving, burden
- Satisfaction and usefulness

2nd Follow- up

- 6 months after the end of the programme
- Pool of indicators
- Satisfaction and usefulness

3rd Follow- up

- 12 months after the end of the programme
- Pool of indicators
- Satisfaction and usefulness



Assessment protocol

- **Baseline**
 - COPE - pre-test only
 - a questionnaire about support services to the caregiver - pre-test only
- **Instruments:**
 - SF – 12v2
 - GHQ – 12
 - PAC
 - M-CSI
- **Follow-up (phone interview):** a questionnaire including the more relevant items from the instruments

+ Characteristics of the caregivers

		n	%
Age	(51,25; 8.95)		
Sex	Female	59	89.4
Marital Status	Married	50	75.8
	Divorced/ Separated	5	7.6
	Widow	6	9.1
	Single	5	7.6
Occupation	Full-time job	20	30.3
	Part-time job	1	1.5
	Retired	16	24.2
	Student	24	36.4
	Housewife	5	7.6

		n	%
Income	< 485 €	35	53.0
	485 € – 970 €	18	27.3
	970 € – 1455 €	3	4.5
	> 1455 €	2	3.0
Education	Illiterate	1	1.5
	4 years	29	43.9
	5/6 years	16	24.2
	7/8/9 years	14	21.2
	High school	3	4.5
	High education	2	3.0

Characteristics of the care recipient

		n	%
Age	(mean, sd)	81.28	
Sex	Female	44	66.7
Living arrangements	Alone	8	12.1
	Family house	41	62.1
	Own house, with family	16	24.2
	Residencial Care	-	-
	Other	1	1.5
Pathology	Physical	19	28.8
	Mental	18	27.3
	Both	29	43.9

+ Characteristics of care

		n	%
Duration of care	Mean/months	51.25	
Time of care/day	Mean/hours	14.26	
Periodicity	Permanently	49	74.2
	Weekly	8	12.1
	Weekends	1	1.5
	'Rotative Care'	4	6.1
	Evenning/night	2	3.0
	Hollidays	1	1.5



Characteristics of care

		n	%
kinship	Spouse	5	7.6
	Son/daughter	13	19.7
	Sister/brother	1	1.5
	Son/daughter in law	4	6.1
	Friend/neighbour	3	4.5
	Other	40	60.6
Distance	Same house	35	53.0
	Different houses, same building	6	9.1
	Walk Distance	17	25.8
	10 minuts by car/bus/train	4	6.1
	30 minuts by car/bus/train	2	3.0



Characteristics of care

		n	%
Type of care	Personal care	64	97.0
	Mobility	48	72.7
	House keeping	54	81.8
	Taking medicines	56	84.8
	Manage money	43	65.2
	Shopping	55	83.3
	Administrative issues	51	77.3
	Transportation	47	71.2
	Leisure activities	45	68.2
	Emotional support	53	80.3
	Financial support	23	34.8
	Regular supervision	53	80.3



Characteristics of care



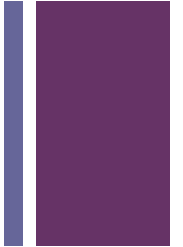
		n	%
Presence of formal social support	Home care	10	15.2
	Day centre	9	13.6
	Leisure Centre	1	1.5
	Other	16	24.2
Presence of formal health support	Ambulatory	5	7.6
	Home nursing	11	16.7
	Physiotherapy	11	16.7
	Occupation therapy	1	1.5
	Other	3	4.5

+ Characteristics of care

		n	%
Degree of dependency	Severe	38	57.6
	Moderate	22	33.3
	Minor	5	7.6
	Independent	-	-
Help from another caregiver		46	82.5
Caregiver of others		12	18.2



Impact



- mental health improvement from pre-test to follow-up
- subjective health and depressive symptoms improvement from pre-test to pos-test
- feeling depressed worsened between pos-test and follow-up 1
- positive aspects of caregiving worsened from post-test to follow-up 1



Discussion (1)

- Significant improvements found in subjective health and feeling depressed show gains with this intervention, but ending the program leads to some vulnerability – **sustainability of interventions**
- The program with 7 sessions may be short;
- The program is too general;

+ Discussion (2)

- Objective health (physical and mental) of the care recipient was not controlled in a regular base
- Participants' general good condition previous to the intervention may explain why we didn't found more improvement
- Discontinuing intervention contributed to feeling depressed from moment 2 to moment 3 (Informal caregivers perceived the opportunity to share their experience with each other as the best benefit of the program)
- Informal caregivers classify the program as positive

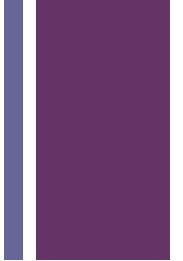


Conclusion (1)

- The program seems to have a good impact in some areas
- The program need to be tested in different health contexts
- Recruitment strategies to reach caregivers with higher needs at baseline



Conclusion (2)



- To have control groups
- Rethink the assessment measures
- To control for events that might interfere with the results (e.g. changes in health status of the care recipient or caregiver, unemployment)
- Psychoeducational programs are also useful as prevention tools



cuidar de quem cuida

entre douro e vouga



Entidade Promotora



Entidade Co-Promotora

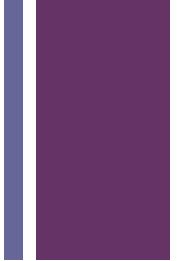


Entidade Co-Promotora e Financiadora



Entidades Financiadoras



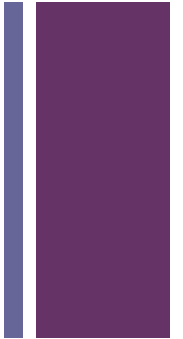


Five lines of intervention:

- **1. Psychoeducational Groups**
- **2. Training of Formal Carers**
- **3. Local Volunteers**
- **4. Respite Care**
- **5. Discussion Forums**



1. Psychoeducational Groups - Objectives



- Organize and implement intervention programs for caregivers of people i) with dementia (82%); ii) after a stroke.
- Help caregivers to understand disease, and have better care practices
- Promote strategies to diminish caregivers burden and promote caregivers self-care
- Support care recipients during caregivers training



| AROUCA | STA. M.ª DA FEIRA | VALE DE CAMBRA | S. JOÃO DA MADEIRA | OLIVEIRA DE AZEMÉIS |

DOENÇA DE ALZHEIMER
PROGRAMA PSICOEDUCATIVO
PARA CUIDADORES INFORMAIS
| MANUAL |



+ Procedure

Pre - intervention

- Referral of caregivers: questionnaire about caregiver, care recipient and the context of care
- Assessment with the Protocol of Caregivers Profile of the region “Entre Douro e Vouga” (including SF12-v2; GHQ12; positive aspects of caregiving_PAC; M-CSI)

Post - intervention

- Questionnaire about learning and satisfaction

1st Follow- up

- Follow-up face-to-face (2-3 month after): questionnaire about learning and its feasibility in daily living and satisfaction

2nd Follow- up

- Follow-up by phone (6 month after) questionnaire about learning and its feasibility in daily living and satisfaction

3rd Follow- up

- Follow-up by phone (12 month after) questionnaire about learning and its feasibility in daily living and satisfaction

■ Recruitment:

- Number of formal contacts **_1073**
- Number of spontaneous contacts **_40**
- Number of caregivers referred **_661**
- Number of caregivers that refuse participation **_373**

■ Implementation:

- Number of caregivers enrolled **_288**
- Number of psychoeducational groups **_37**
- Number of care recipients that participate in side sessions **_67**
- Number of dropouts **_47**

- Physical health and psychological distress - **improvement**
- Positive aspects of caregiving - **More**
- Caregiver burden - **Less**
- Learning knowledge and practical application – **improvement**
- High level of satisfaction of caregivers related with group participation

+ |Physical and mental health

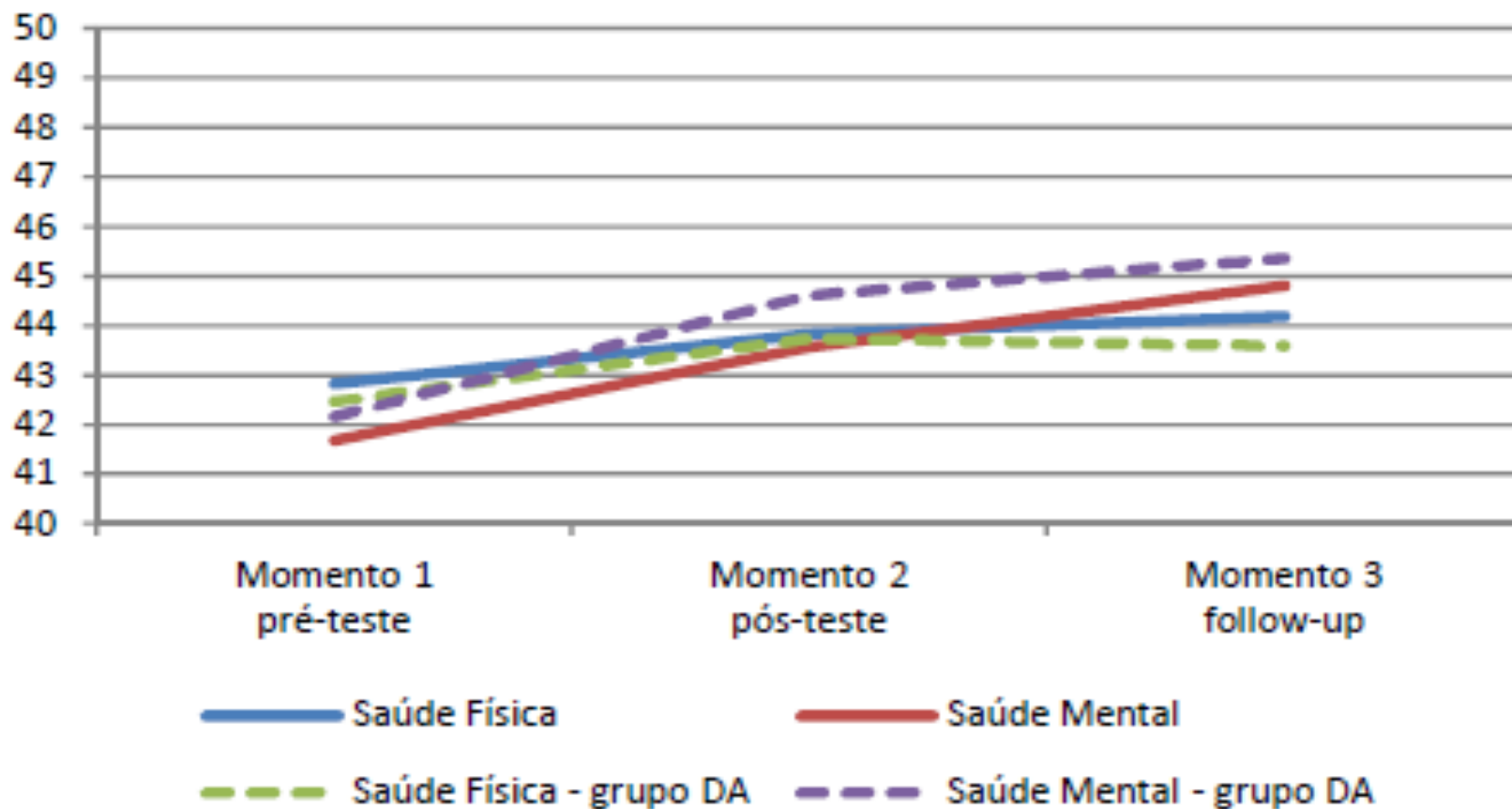


Gráfico 1: *Evolução dos resultados do SF-12 (saúde física e mental) nos momentos 1, 2 e 3*

+ |Psychological distress

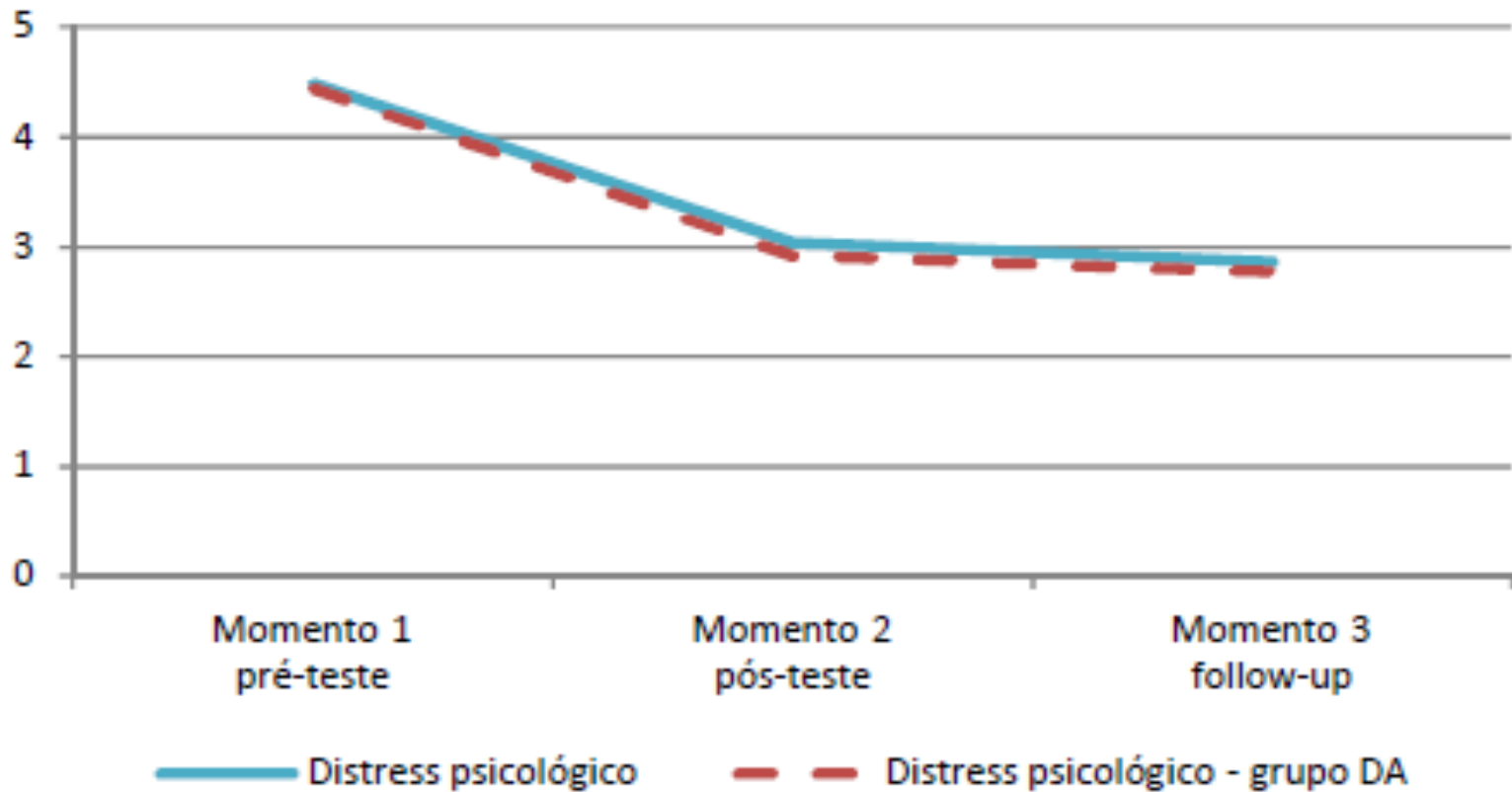


Gráfico 2. *Evolução da cotação da GHQ-12 para o distress psicológico nos momentos 1, 2 e 3*

+ |Positive aspects of caregiving

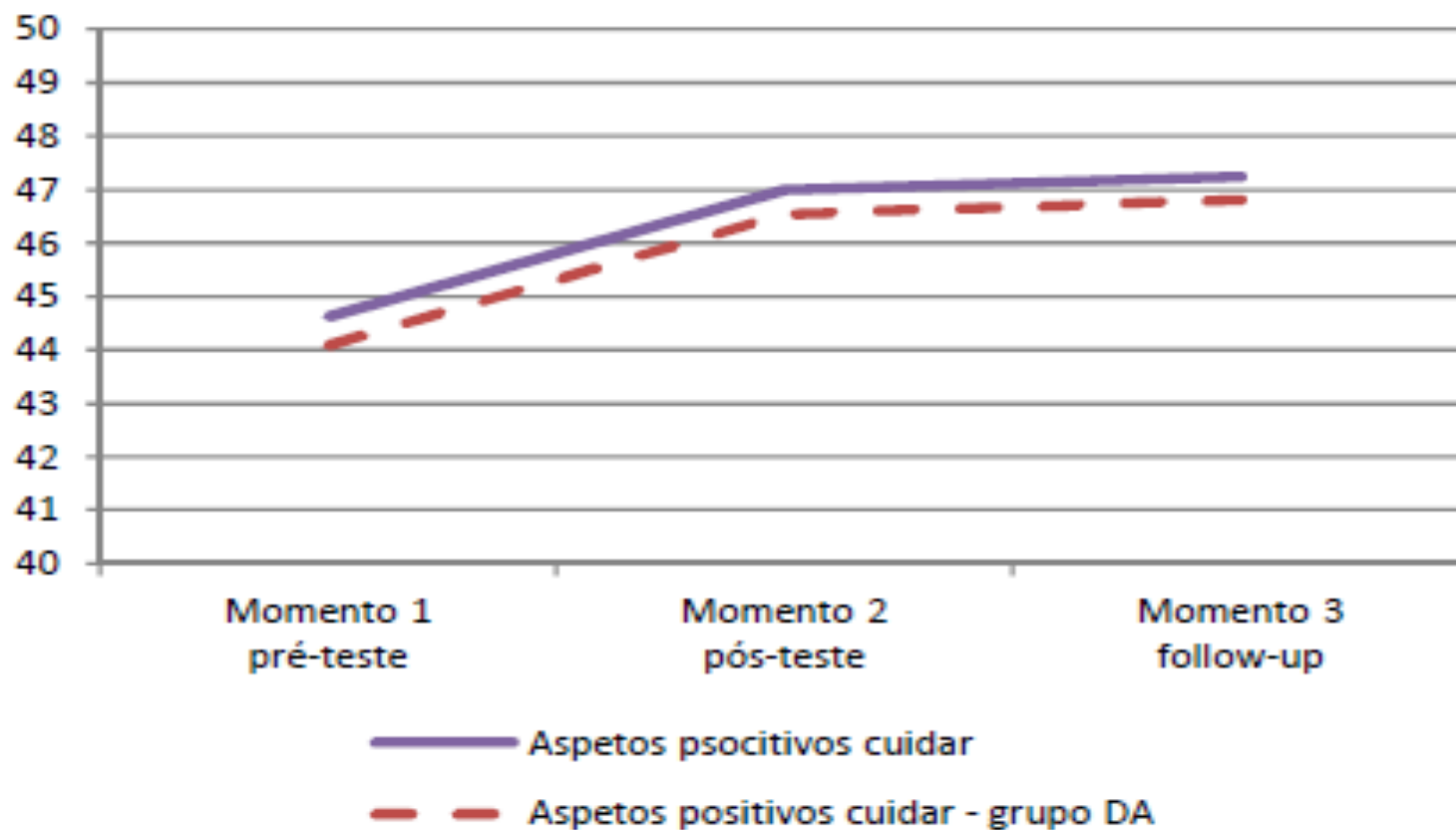


Gráfico 3. *Evolução da cotação da PAC na avaliação dos aspetos positivos do cuidar, nos momentos 1, 2 e 3*

+ |Burden

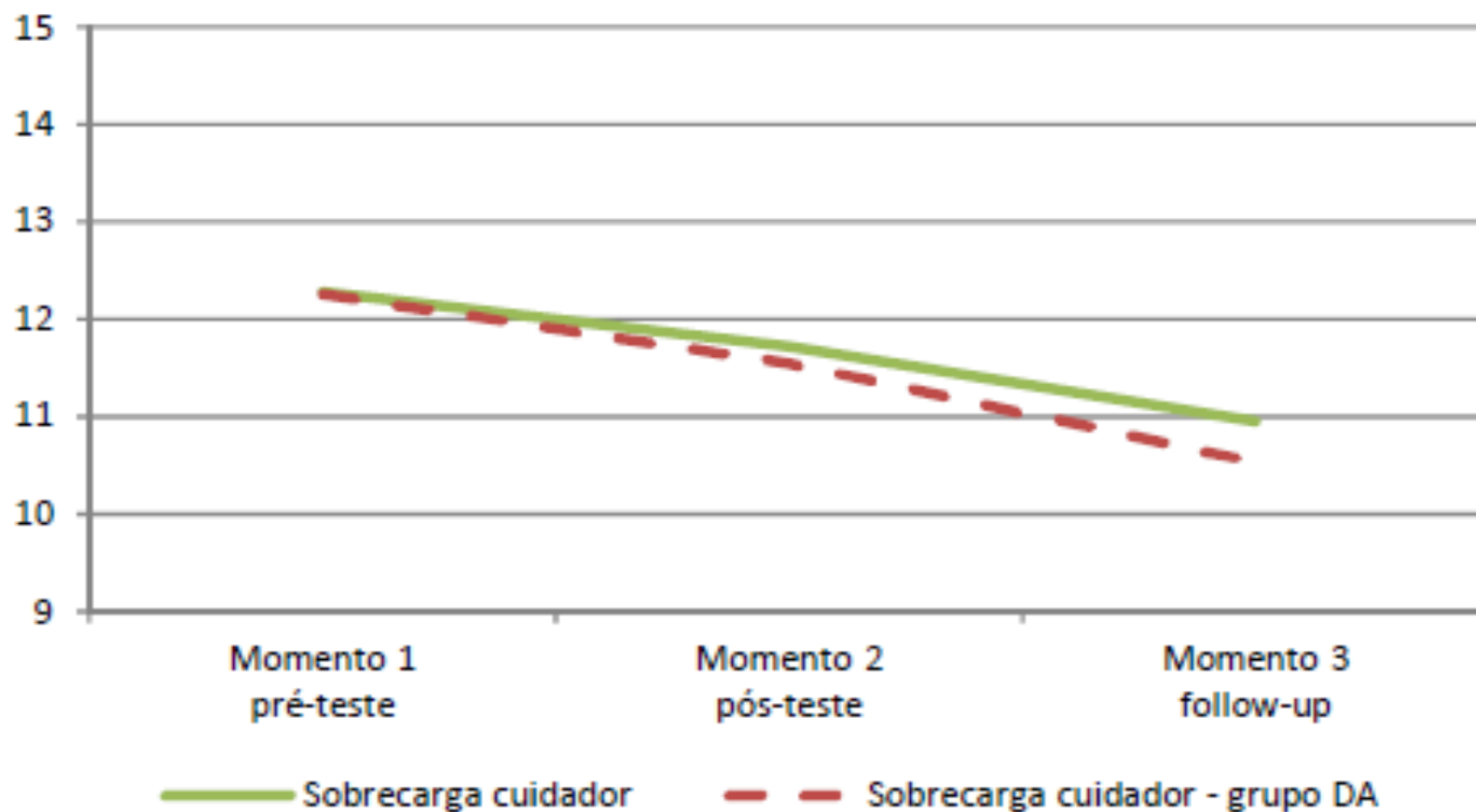


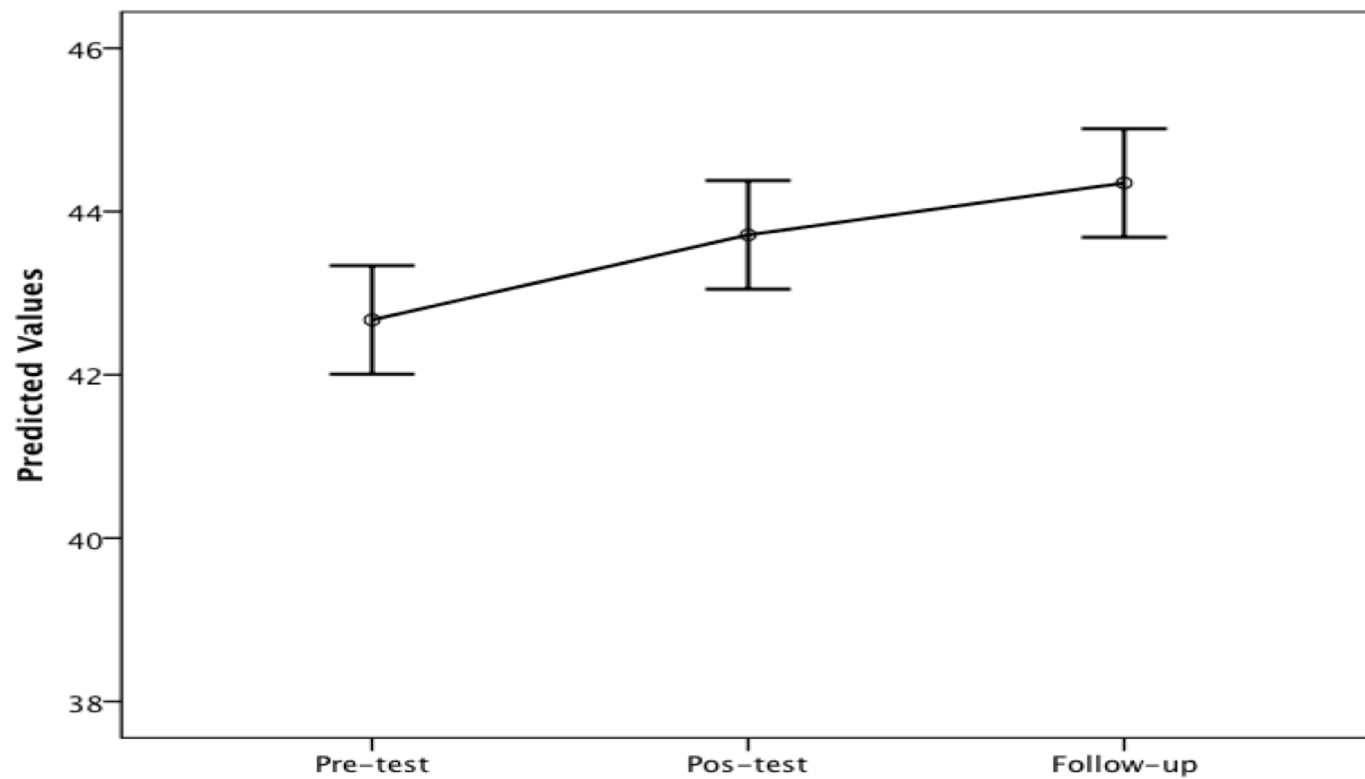
Gráfico 4. *Evolução da cotação da M-CSI sobre a sobrecarga do cuidador, nos momentos 1, 2 e 3*

Table 1: Characterization of the caregivers and care provision aspects.

	N	n	%
Age, mean (sd)	187	58.1 (13.4)	
Gender	187		
Male		37	19.8
Female		150	80.2
Marital Status	185		
Married		149	80.5
Divorced		10	5.4
Widowed		5	2.7
Single		21	11.4
Work situation	187		
Full-time		18	9.6
Part-time		8	4.3
Retired		76	40.6
Unemployed		39	20.9
Housewife		39	20.9
Other		7	3.7
Education level	187		
Illiterate		7	3.7
1-4 years		93	49.7
5-6 years		22	11.8
7-9 years		26	13.9
10-12 years		28	15.0
>12 years		11	5.9
Relation with the elderly	187		
Partner		61	32.6
Son/Daughter		85	45.5
Brother/sister		6	3.2
Son/Daughter in law		16	8.6
Friend/Neighbour		7	3.7
Other relative		12	6.4
Living with the elderly	186		
Yes		126	67.7
No		60	32.3
Number of hour of care/day	167		
<24 hours		80	47.9
24 hours		87	52.1
Presence of secondary caregiver	186		
Yes		132	71.0
No		54	29.0

Table 2: Estimates of fixed effects (coefficients, standard error, 95% confidence interval and p-value) for multivariable linear mixed model for each outcome.

Outcome	Time	Estimates		
		B (se)	95% CI	p
SF36 - Physical Health	Pre-test	-1.68 (1.20)	-4.05 – 0.69	0.165
	Pos-test	-0.64 (1.34)	-3.26 – 2.00	0.636
	Follow-up	0	-	-
SF36 - Mental Health	Pre-test	-5.25 (1.66)	-8.51 – -1.99	0.002
	Pos-test	-0.76 (1.85)	-4.39 – 2.87	0.680
	Follow-up	0	-	-
PAC modified score	Pre-test	0.42 (0.14)	0.15 – 0.70	0.003
	Pos-test	-0.02 (0.17)	-0.35 – 0.31	0.912
	Follow-up	0	-	-
M-CSI	Pre-test	2.10 (0.73)	0.66 – 3.54	0.004
	Pos-test	0.90 (0.81)	-0.70 – 2.50	0.271
	Follow-up	0	-	-



(a) SF 36 – Physical Health

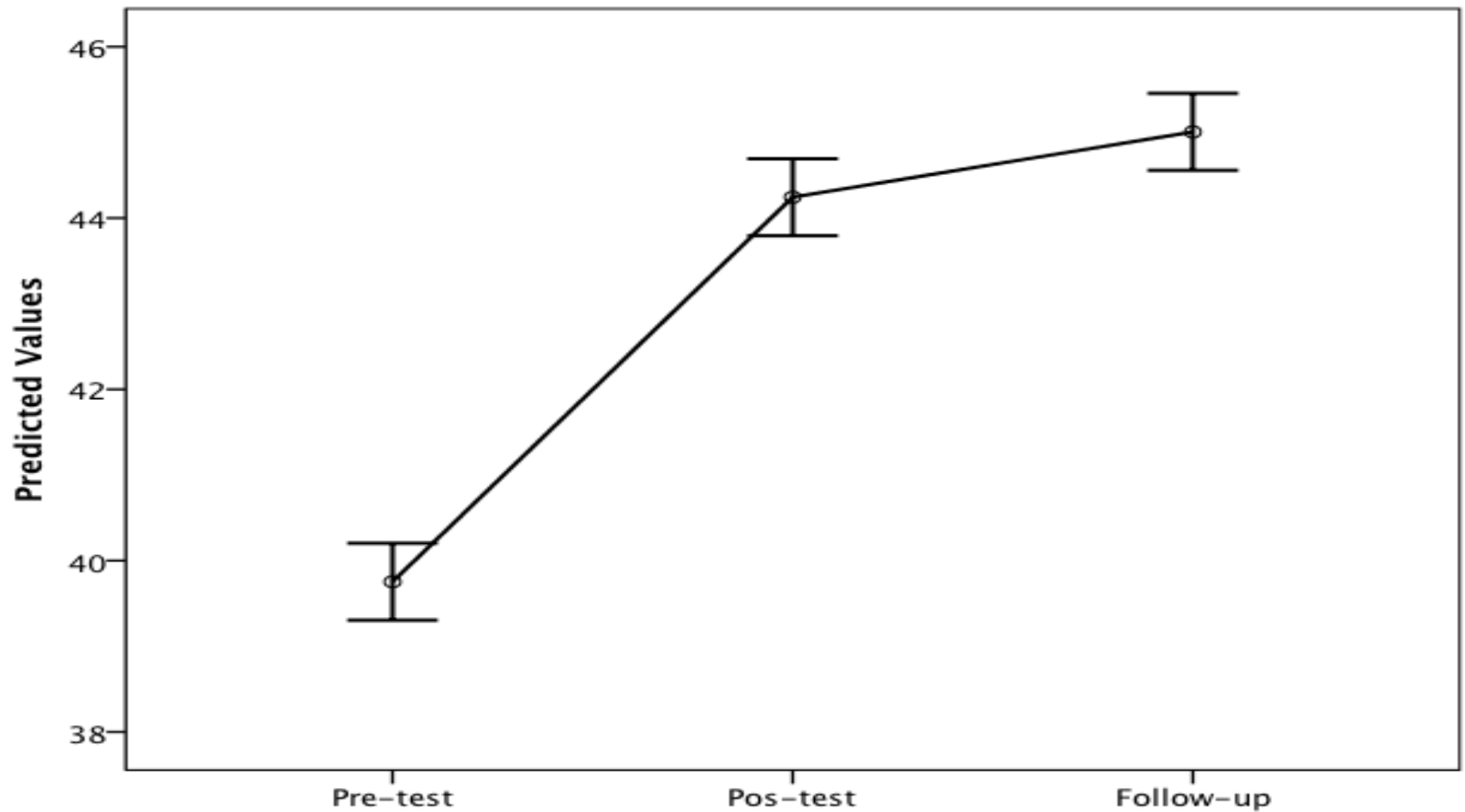


Figure 1. Predicted values of SF 36 (Physical and Mental domains) considering multivariable linear mixed model.

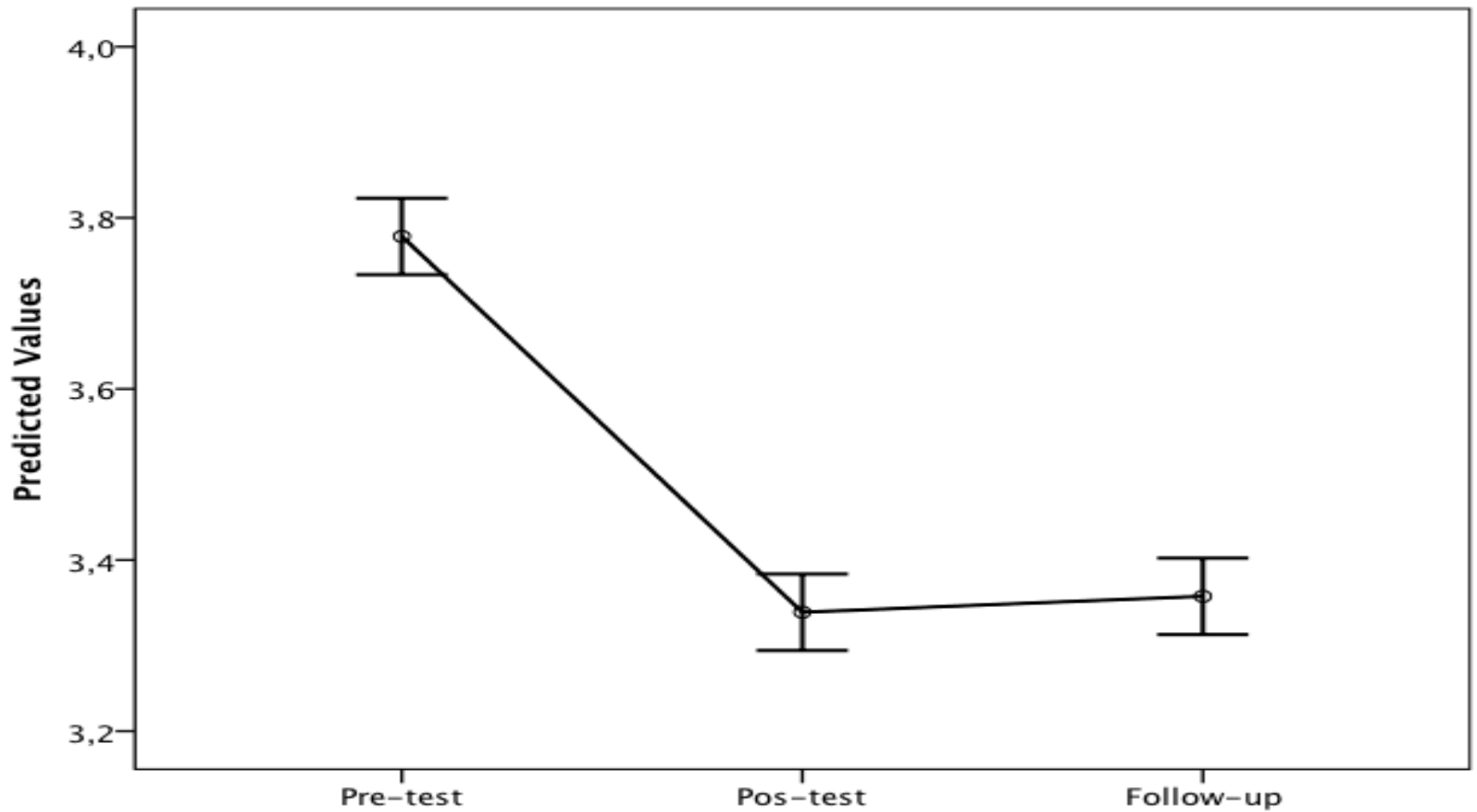


Figure 2. Predicted values of PAC modified score considering multivariable linear mixed model.

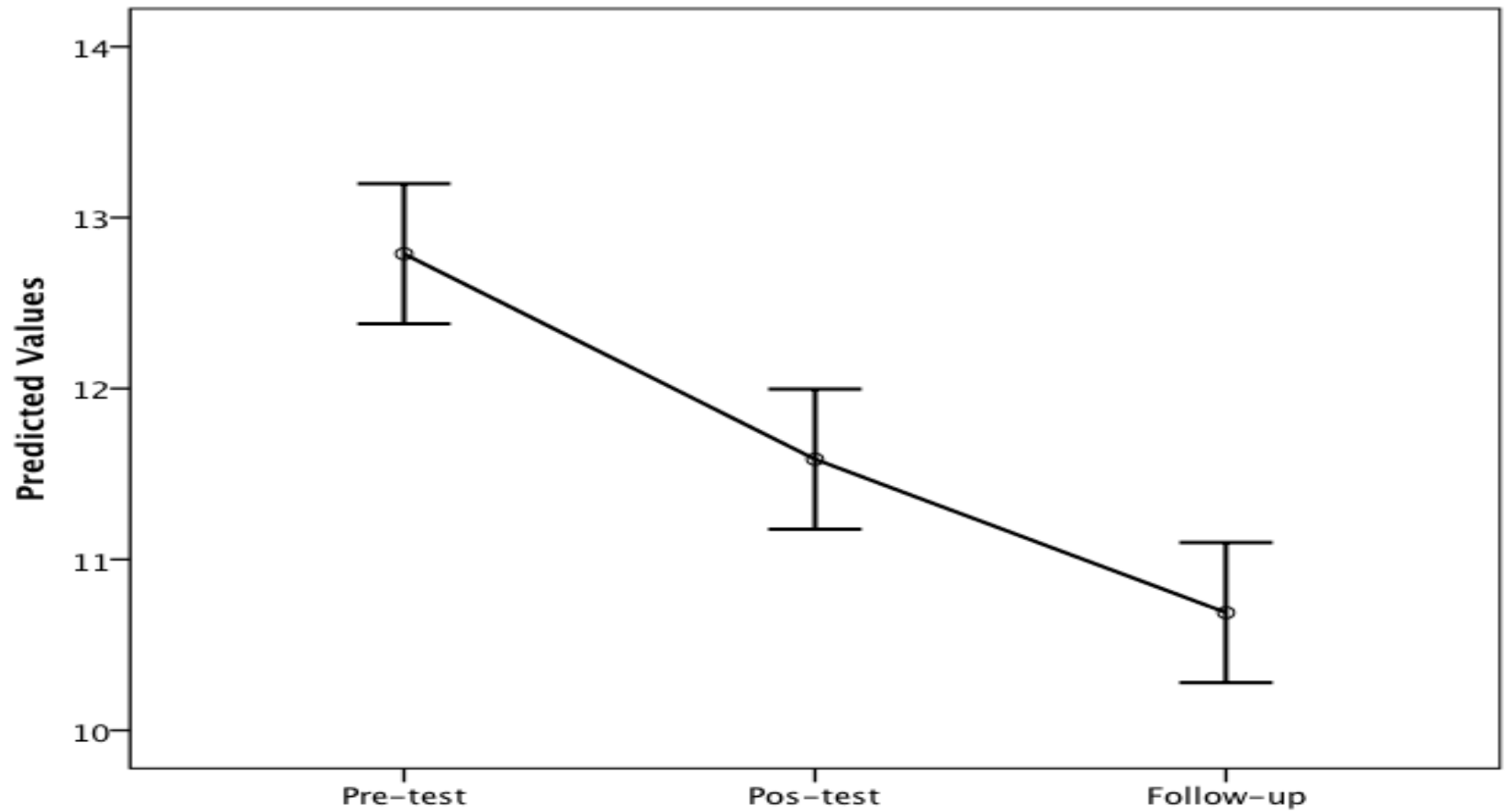
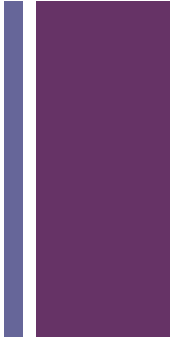


Figure 3. Predicted values of M-CSI considering multivariable linear mixed model.


+ Further development

- To know the cost-efficacy of psycho-educative programs in the:
- Amount/length of hospitalizations
- Amount of consultations with GP, nurses...
- Amount of medicine
- Delay of institutionalization
-
 - Of the care recipient as well as the caregiver



- Do the interventions impact the quality of care and/or the wellbeing of the care recipient?

Effectiveness of Caregiver Interventions on Patient Outcomes in Adults With Dementia or Alzheimer's Disease: A Systematic Review

Gerontology & Geriatric Medicine
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Roderick MacDonald, MS¹, Agnes Jensen, BS¹, Indulis Rutks, BS¹,
Maureen Carlyle, MPH¹, and Timothy J. Wilt, MD, MPH^{1,3,4}

Abstract

Objective: We conducted a systematic review to evaluate whether caregiver-involved interventions improve patient outcomes among adults with dementia or Alzheimer's disease. **Method:** We identified and summarized data from randomized controlled trials enrolling adults with dementia or Alzheimer's disease by searching MEDLINE, PsycINFO, and other sources. Patient outcomes included global quality of life, physical and cognitive functioning, depression/anxiety, symptom control and management, and health care utilization. **Results:** We identified 31 trials; 20 compared a caregiver intervention with usual care or usual care with promise of intervention at completion of study period. Fifteen compared one caregiver intervention with another individual or caregiver intervention (active control). Compared with usual care or active controls, caregiver-involved interventions had low to insufficient strength of evidence and did not consistently improve patient outcomes. **Discussion:** Evidence is insufficient to endorse use of most caregiver interventions to improve outcomes for patients with dementia or Alzheimer's disease.



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