



EUROFAMCARE

Family Caregivers of Older Dependent People in Europe

– Findings from a European Study –

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on behalf of the EUROFAMCARE-Group

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Content

- The EUROFAMCARE-project
- Sample-Description
- Reasons for caring
- Burdening factors and well-being
- Distress and coping
- Conclusions



**The 5th Framework Programme:
Quality of Life and Management of Living Resources**

**Services for Supporting Family Carers of
Elderly People in Europe:**

Characteristics, Coverage and Usage

EUR  FAM CARE

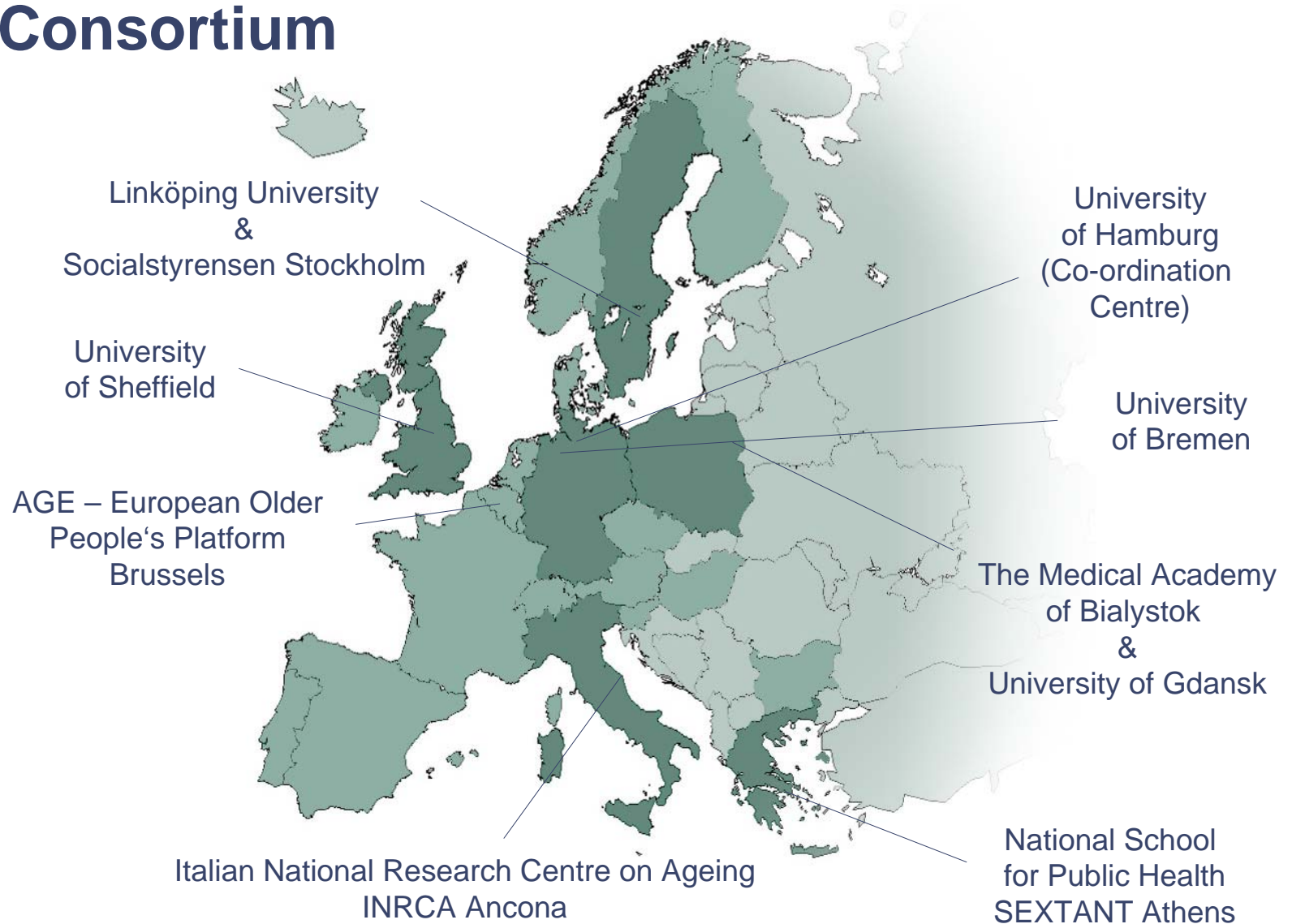
1.1.2003 – 31.12.2005

**Key Action 6: The Ageing Population and Disabilities
6.5: Health and Social Care Services to older People**

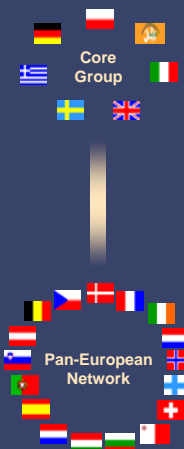


EUROFAMCARE

Consortium







Aims

- EUROFAMCARE provides a European review of the **situation of family carers of elderly people** in relation to the
 - existence,
 - familiarity,
 - availability,
 - use and acceptability of supporting services.
- EUROFAMCARE intends to promote social and health policies towards a **partnership approach** between family carers, professional providers and cared-for.



Six-Countries-Studie

In-depth studies in the 6 countries: Germany, Greece, Italy, Poland, Sweden and UK

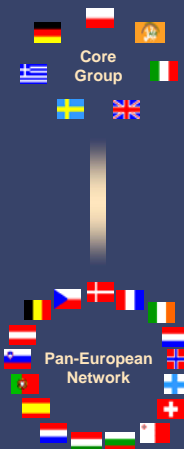
Face to face interviews with 1,000 carers per country providing 4 or more hours of personal care/support per week to an elderly relative (65+) in any need of support.





23 National Background Reports

- Same structure in all 23 reports following a Standardised Evaluation Protocol
- -> **Pan-European Background Report** (European Synopsis)











All Reports are available on the
EUROFAMCARE website:

www.uke.uni-hamburg.de/eurofamcare/









Sociodemographics (description of the samples)

							Σ
Number of Carers	1014	990	995	921	1000	1003	5923
ELDERS, women (%)	64,5	71,2	69,5	57,7	72,8	68,5	67,5%
CARERS, women (%)	80,9	77,1	75,4	72,0	76,0	76,1	76,3%
ELDERS' age (mean)	79,5	82,0	78,0	81,3	78,6	79,7	79,8 years
CARERS' age (mean)	51,7	53,4	54,5	65,4	51,0	53,8	54,8 years

25 years









Relationship to ELDER (% within country)

							Σ
spouse/partner	17,1	10,9	22,8	48,1	18,2	18,4	22,2
child	55,4	60,9	31,6	40,5	51,1	53,4	48,9
child-in-law	13,9	9,7	15,3	4,5	13,4	9,0	11,0
other	6,5	6,7	19,5	2,8	11,9	10,1	9,7
nephew/niece	4,2	8,3	4,6	1,3	3,0	2,8	4,1
sibling	1,8	2,4	3,6	1,8	0,9	3,0	2,3
uncle/aunt	1,0	0,6	1,5	0,9	0,6	2,7	1,2
cousin	0,1	0,5	1,1	0,1	0,9	0,7	0,6











Amount of and *main* reasons for caring

							all
Hours per week care/support (mean)	51	50	51	38	45	39	45,6 h
physical illness/disabilities	30,6	18,6	29,4	38,8	43,6	24,8	30,9
mobility problems	24,4	29,5	20,4	9,7	10,4	27,9	20,5
age-related decline, old age	15,9	15,0	10,7	23,9	28,0	12,1	17,5
memory problems / cognitive impairment	5,6	9,0	11,1	19,0	4,9	14,9	10,6
non self-caring	5,5	9,9	11,1	0,7	3,5	10,0	6,9
sensory problems	3,2	4,3	4,9	3,9	2,6	3,8	3,8
social reasons, loneliness, need for company	5,7	2,3	5,4	0,4	4,3	2,2	3,5
safety/feeling of insecurity	6,4	7,8	2,3	0,5	0,3	1,7	3,2
psychological / psychiatric illness / problems	1,9	1,7	2,5	2,2	1,0	1,5	1,8
other reason	0,7	1,8	2,2	0,9	1,3	1,1	1,3



Number of Caring Needs (0-8) and Degree of Dependency (0-100)

							all
Number of Needs (Mean, N=5811)	6,08	6,77	5,52	5,78	5,71	6,20	6,01
Number of Needs (SD)	1,84	1,33	2,06	1,58	1,78	1,75	1,79
Barthel-Index (Mean, N=5684)	70	63	74	71	79	62	69,7
Barthel-Index (SD)	31	33	27	26	26	31	29,75



Core
Group



Pan-European
Network

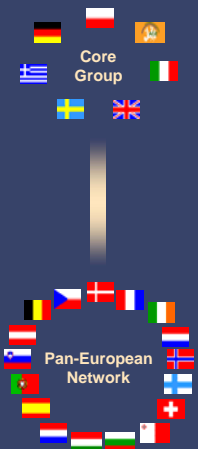
How do family carers cope with their caring role?





COPE-Index

- The COPE-Index is a Family Care Assessment Instrument
- 2 Dimensions:
 - Burden (negative impact)
 - Positive Value
- Questions about support
- Available in several languages, psychometrically tested



McKee KJ, Philp I, Lamura G, Prouskas C, Oberg B, Krevers B, Spazzafumo L, Bien B, Parker C, Nolan MR, Szczerbinska K; COPE Partnership. (2003) The COPE index - a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging Ment Health*. 2003 Jan;7(1):39-52.



		Always	Often	Sometimes	Never	N / A
82 C82COP1	Do you feel you cope well as a caregiver?	④	③	②	①	
83 C83COP2	Do you find caregiving too demanding?	①	②	③	④	
84 C84COP3	Does caregiving cause difficulties in your relationships with friends?	①	②	③	④	⑧
85 C85COP4	Does caregiving have a negative effect on your physical health?	①	②	③	④	
86 C86COP5	Does caregiving cause difficulties in your relationship with your family?	①	②	③	④	⑧
87 C87COP6	Does caregiving cause you financial difficulties?	①	②	③	④	
88 C88COP7	Do you feel trapped in your role as a caregiver?	①	②	③	④	
89 C89COP8	Do you feel well supported by your friends and / or neighbours?	④	③	②	①	⑧
90 C90COP9	Do you find caregiving worthwhile?	④	③	②	①	
91 C91COP10	Do you feel well supported by your family?	④	③	②	①	⑧
92 C92COP11	Do you have a good relationship with the person you care for?	④	③	②	①	
93 C93COP12	Do you feel well supported by health and social services? (for example, public, private, voluntary)	④	③	②	①	⑧
94 C94COP13	Do you feel that anyone appreciates you as a caregiver?	④	③	②	①	
95 C95COP14	Does caregiving have a negative effect on your emotional well-being?	①	②	③	④	
96 C96COP15	Overall, do you feel well supported in your role of caregiver?	④	③	②	①	

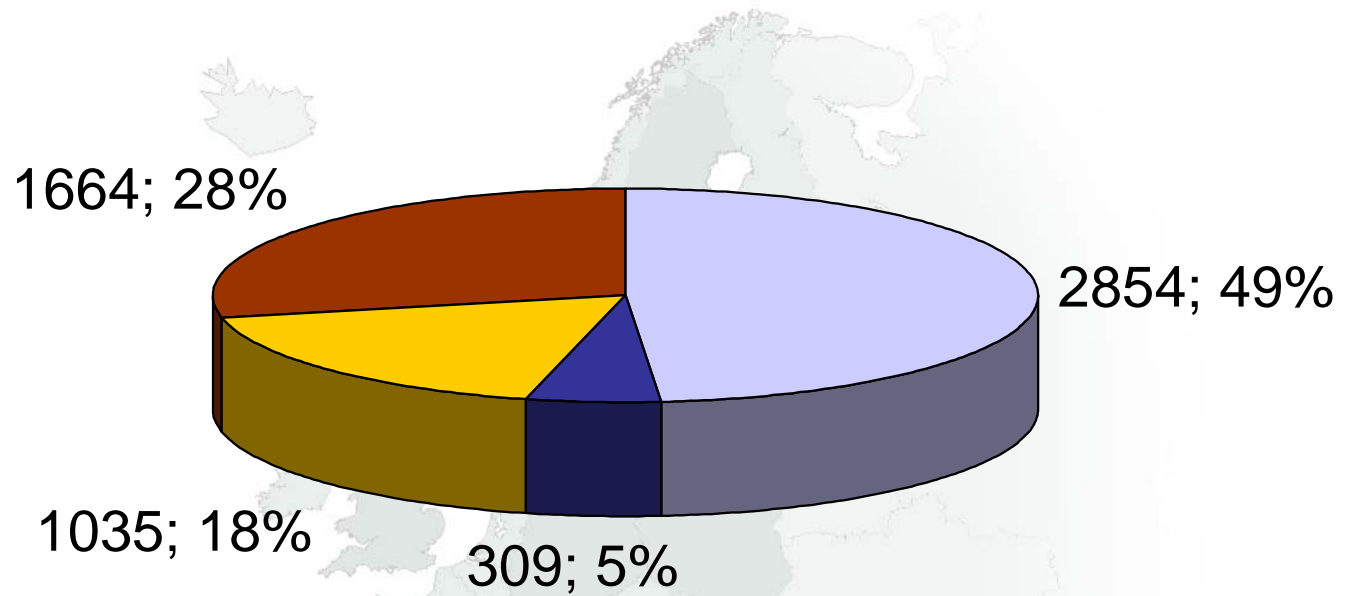


Correlations between specific Caring aspects and Carer's Quality of Life (N = 5551 – 5865)

Spearman-Correlations / Phi	COPE-Index Negative Impact	COPE-Index Positive Value	WHO5-QoL Bref	SF36 – General Health
Memory Problems	0,285	-0,148	-0,165	0,126
Behavioural Problems	0,406	-0,245	-0,216	0,130
Barthel Index	-0,421	0,111	0,237	
Number of Caring Hours	0,348	-0,023	-0,282	
Carer's Age		0,011	-0,130	
Carer's Sex				



Memory and behavioural problems, N = 5862



- no memory and no behavioural problems
- no memory problems, but behavioural problems
- memory problems, but no behavioural problems
- memory and behavioural problems



Correlations between specific Caring aspects and Carer's Quality of Life (N = 5551 – 5865)

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Behavioural Problems	0,406	-0,245	-0,216	0,130
Barthel Index	-0,421	0,111	0,237	-0,150
Number of Caring Hours	0,348	-0,023	-0,282	0,230
Carer's Age	0,171	0,011	-0,130	0,307
Carer's Sex	0,097	-0,039	-0,137	0,089

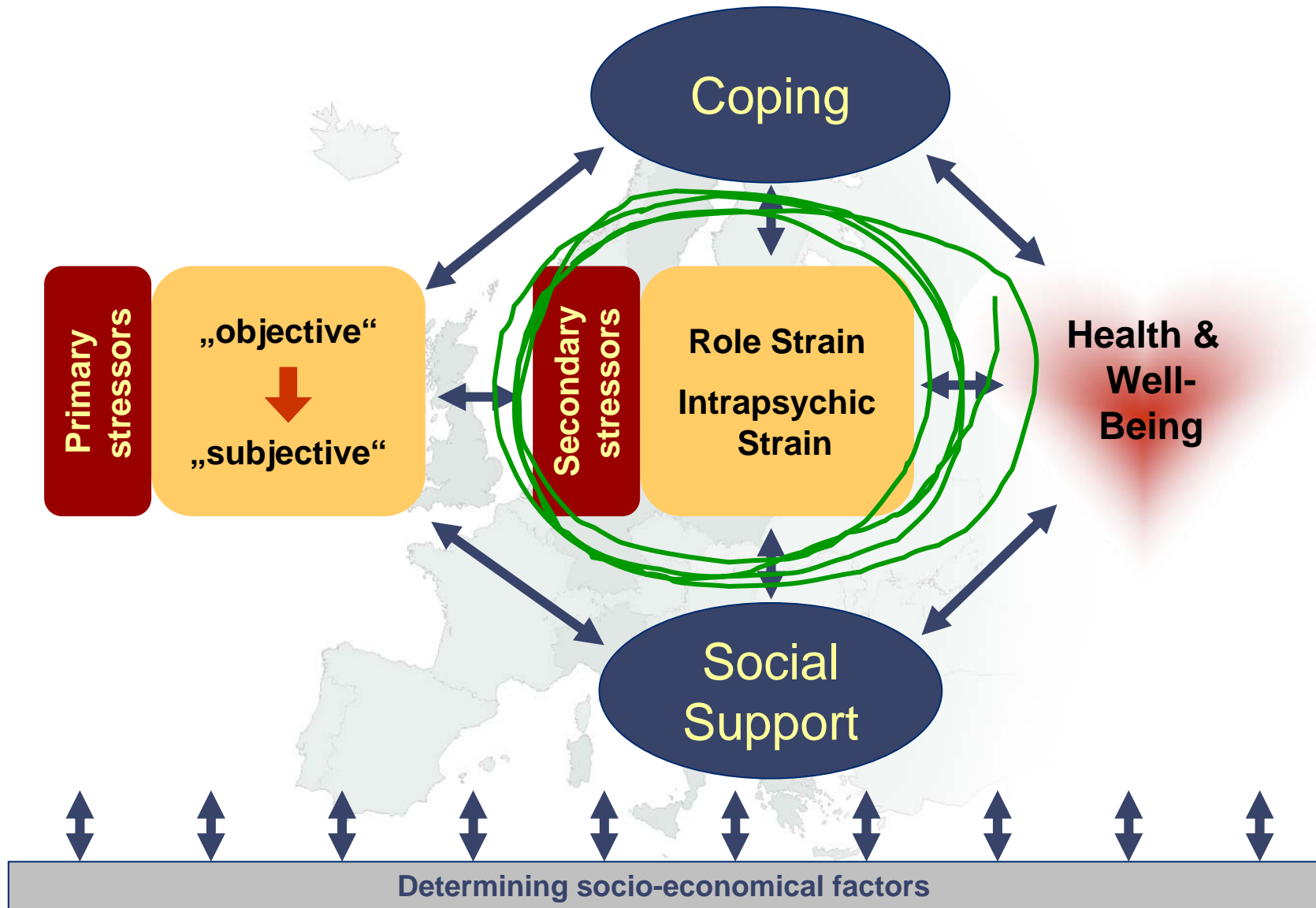


Family Care = Burden?



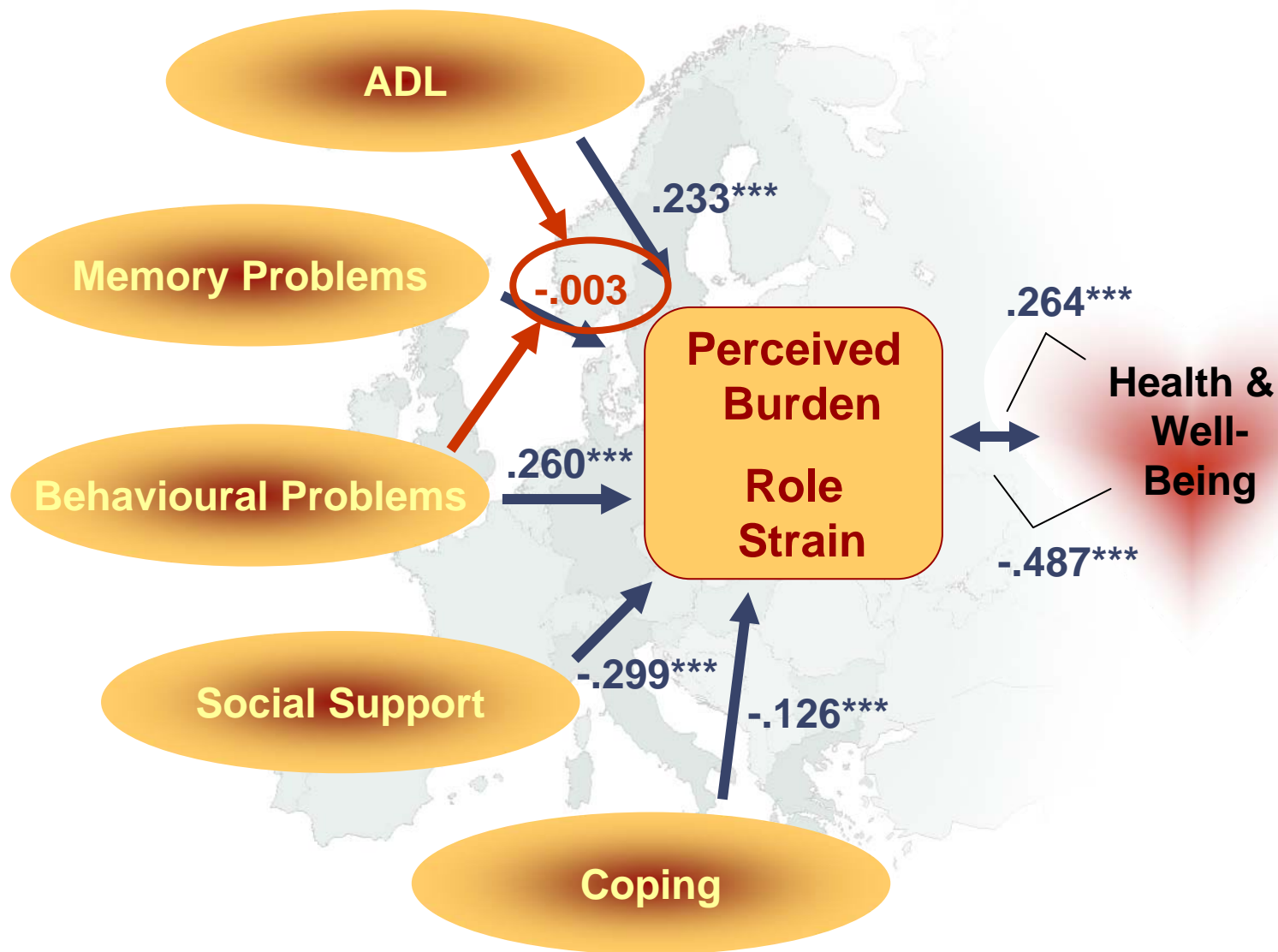


Stress-Coping Model of Care-giving





Impact on carers' perceived burden – linear regression, standardised beta-coefficients





Conclusions

- The results on carers' burden reinforce the results from other studies with regard to the importance of behavioural problems.
- The most burdening factors are limited ADL-capabilities, behavioural problems (respectively inner family conflicts) and lack of social support.
- Memory problems alone are not necessarily decreasing carers' well-being.
- Despite perceived burden, positive value of caring is high in our sample, and the will to care for elderly relatives remains high for the vast majority of family carers.
- Correlations are only moderate, with most variance remaining unexplained.
- This is probably grounded in different coping capabilities and care arrangements .

