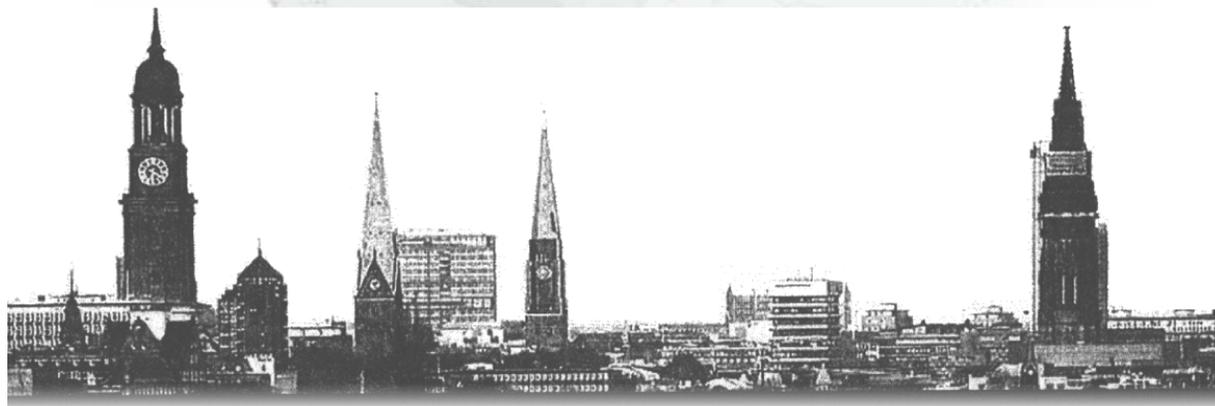


Welcome to Hamburg!

EUROFAMCARE Final Conference
Hamburg 18th of November 2005

Family Care of Older People in Europe





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

E U R  F A M C A R E

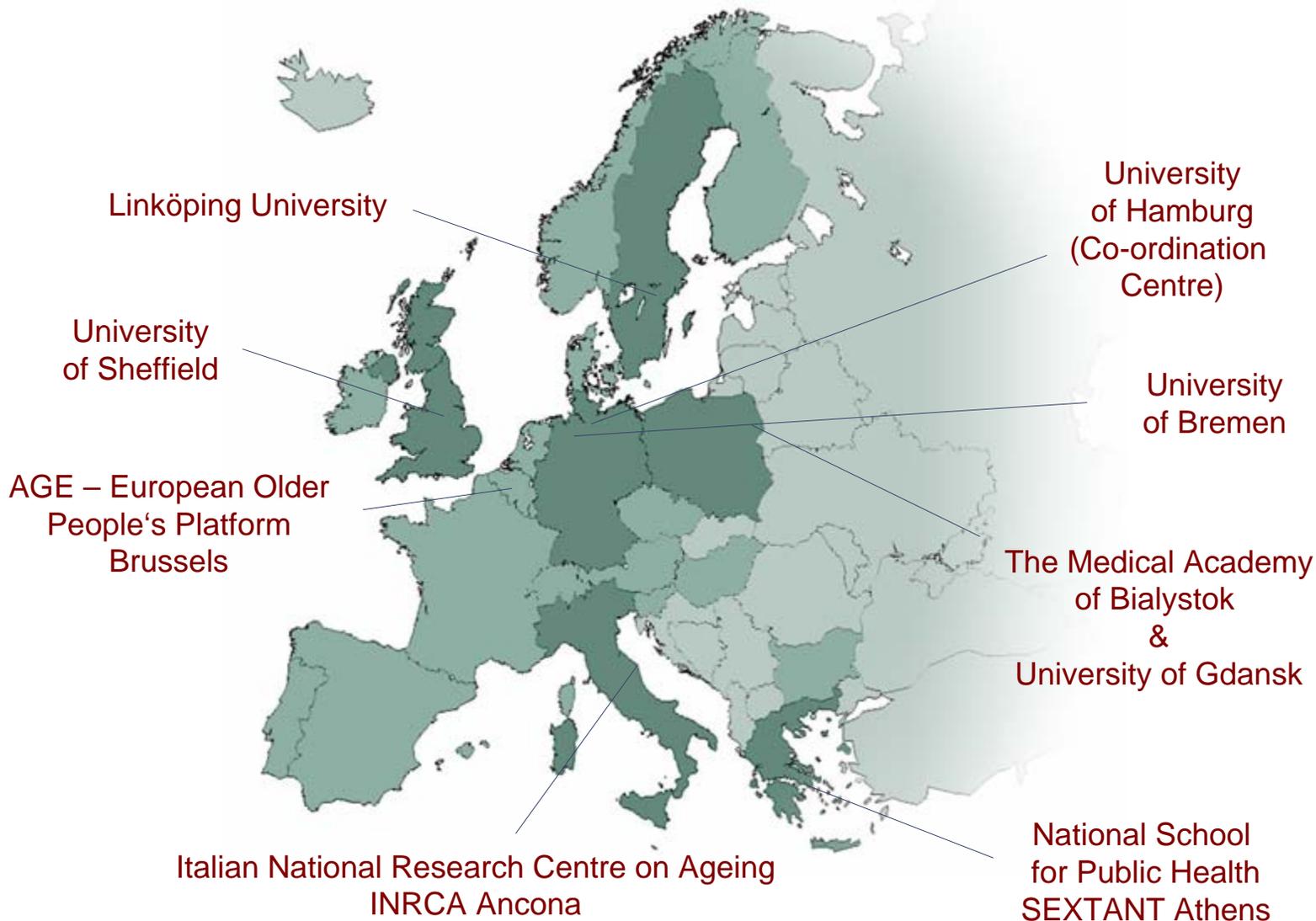
**Key Action 6: The Ageing Population and Disabilities
6.5: Health and Social Care Services to older People**

This project (Contract: QLK6-CT-2002-02647) is supported by the European Union in the Vth Framework Programme:
Quality of Life and Management of Living Resources - Key action 6: The Ageing Population and Disabilities
6.5: Health and Social Care Services to Older People



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Needs for care - the impact on family carers' burden and well-being

Christopher Kofahl and Kevin McKee



Content

- Reasons for caring
- Burdening factors and well-being
- Distress and coping
- Conclusions





Amount of and *main* reasons for caring

							all
			51	36			
physical illness/disabilities	30,6	18,6	29,4	38,8	43,6	24,8	30,9
		29,5	20,4	9,7	10,4		
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
	5,5	9,9	11,1	0,7	3,5		
sensory problems	3,2	4,3	4,9	3,9	2,6	3,8	3,8
	5,7	2,1	5,4	0,4	4,3		
safety/feeling of insecurity	6,4	7,8	2,3	0,5	0,3	1,7	3,2
		7,7		2,2			
other reason	0,7	1,8	2,2	0,9	1,3	1,1	1,3

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
		29,5	20,4	9,7	10,4		
age-related decline, old age	15,9	15,0	10,7	23,9	28,0	12,1	17,5
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	5,7	2,1	5,4	0,4	4,3		
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Hours per week care/support (mean)	51	50	51	38	45	39	45,6 h
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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
	5,5	9,9	11,1	0,7	3,5		
sensory problems	3,2	4,3	4,9	3,9	2,6	3,8	3,8
	5,7	2,1	5,4	0,4	4,3		
safety/feeling of insecurity	6,4	7,8	2,3	0,5	0,3	1,7	3,2
other reason	0,7	1,8	2,2	0,9	1,3	1,1	1,3

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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
	5,5	9,9	11,1	0,7	3,5		
sensory problems	3,2	4,3	4,9	3,9	2,6	3,8	3,8
	5,7	2,1	5,4	0,4	4,3		
safety/feeling of insecurity	6,4	7,8	2,3	0,5	0,3	1,7	3,2
other reason	0,7	1,8	2,2	0,9	1,3	1,1	1,3



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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



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.



Core
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Network

		Always	Often	Some- times	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		0,148	-0,165	
Behavioural Problems	0,406	-0,245	-0,216	
Barthel Index	-0,421	0,111	0,237	
Number of Caring Hours	0,348	-0,023	-0,282	
Carer's Age		0,011	-0,131	
Carer's Sex		0,039		



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	
Barthel Index	-0,421	0,111	0,237	
Number of Caring Hours	0,348	-0,023	-0,282	
Carer's Age	0,031	0,011	-0,131	
Carer's Sex		0,039		



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				



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	-0,150
Number of Caring Hours	0,348	-0,023	-0,282	
Carer's Age		0,011	-0,130	
Carer's Sex				



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	-0,150
Number of Caring Hours	0,348	-0,023	-0,282	0,230
Carer's Age		0,011	-0,100	
Carer's Sex				



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	-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				



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	-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

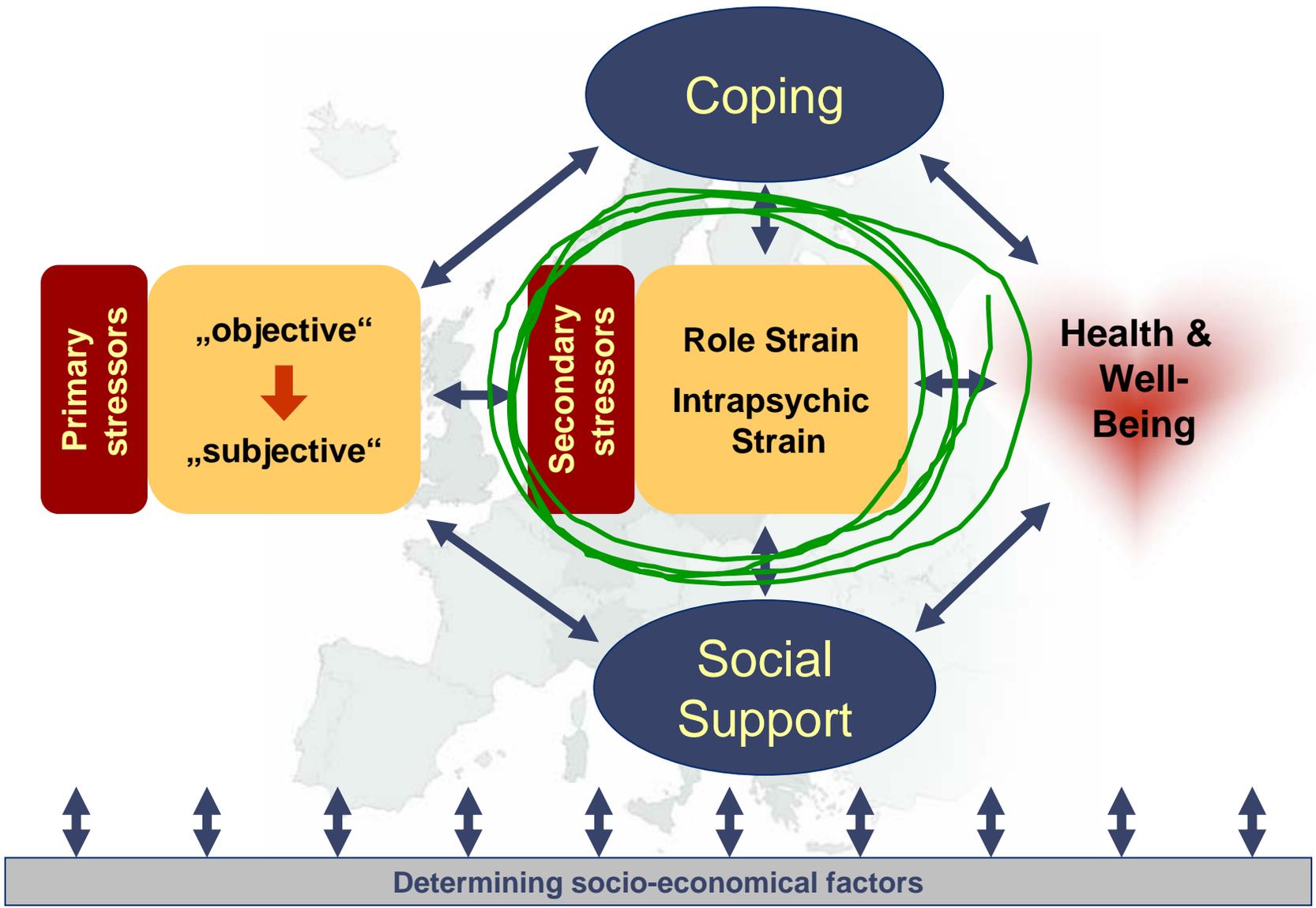


Family Care = Burden?



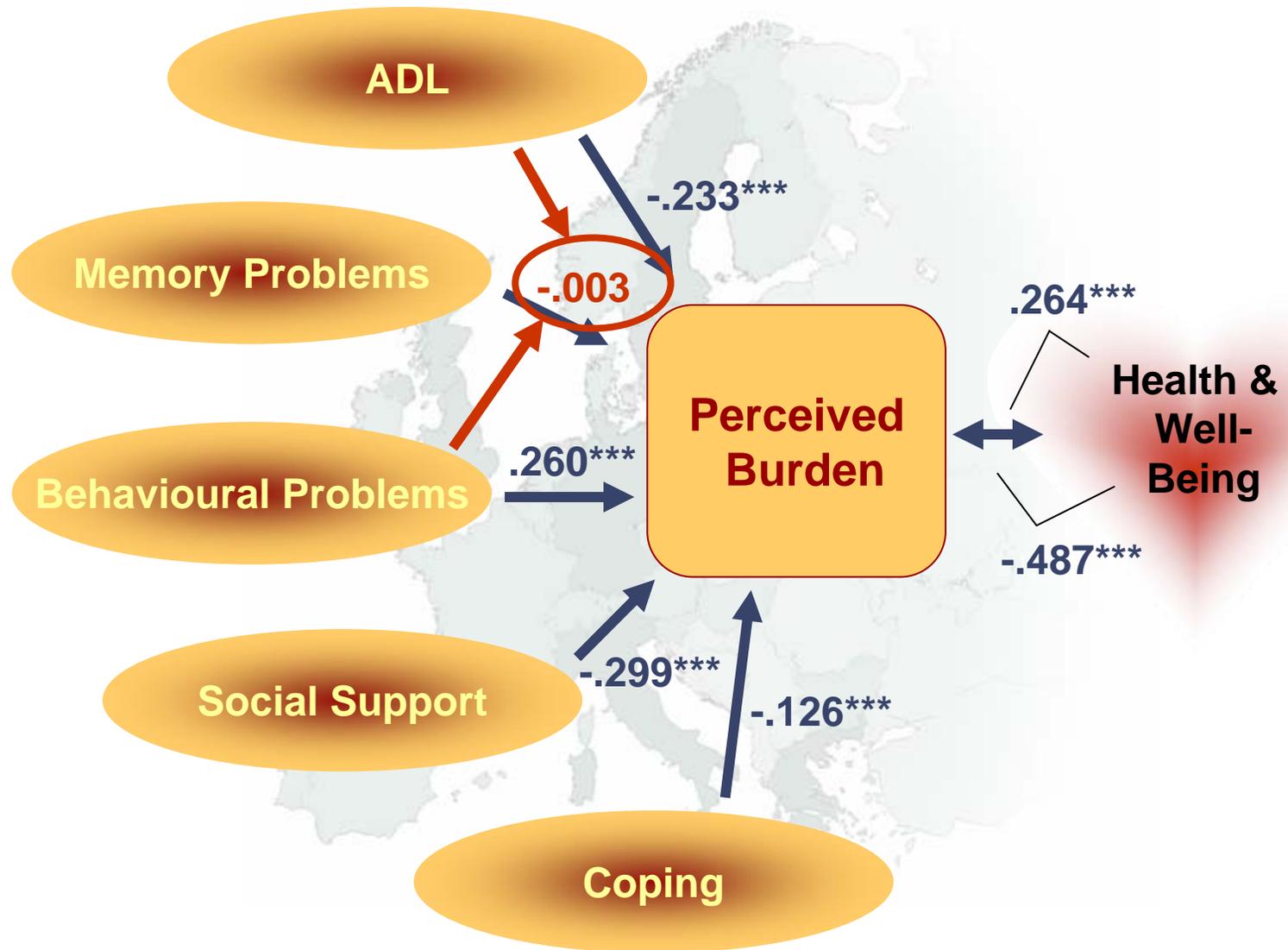


Stress-Coping Model of Care-giving





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





Memory and behavioural problems as potentially burdening factors

Subgroups on cognitive and behavioural variables



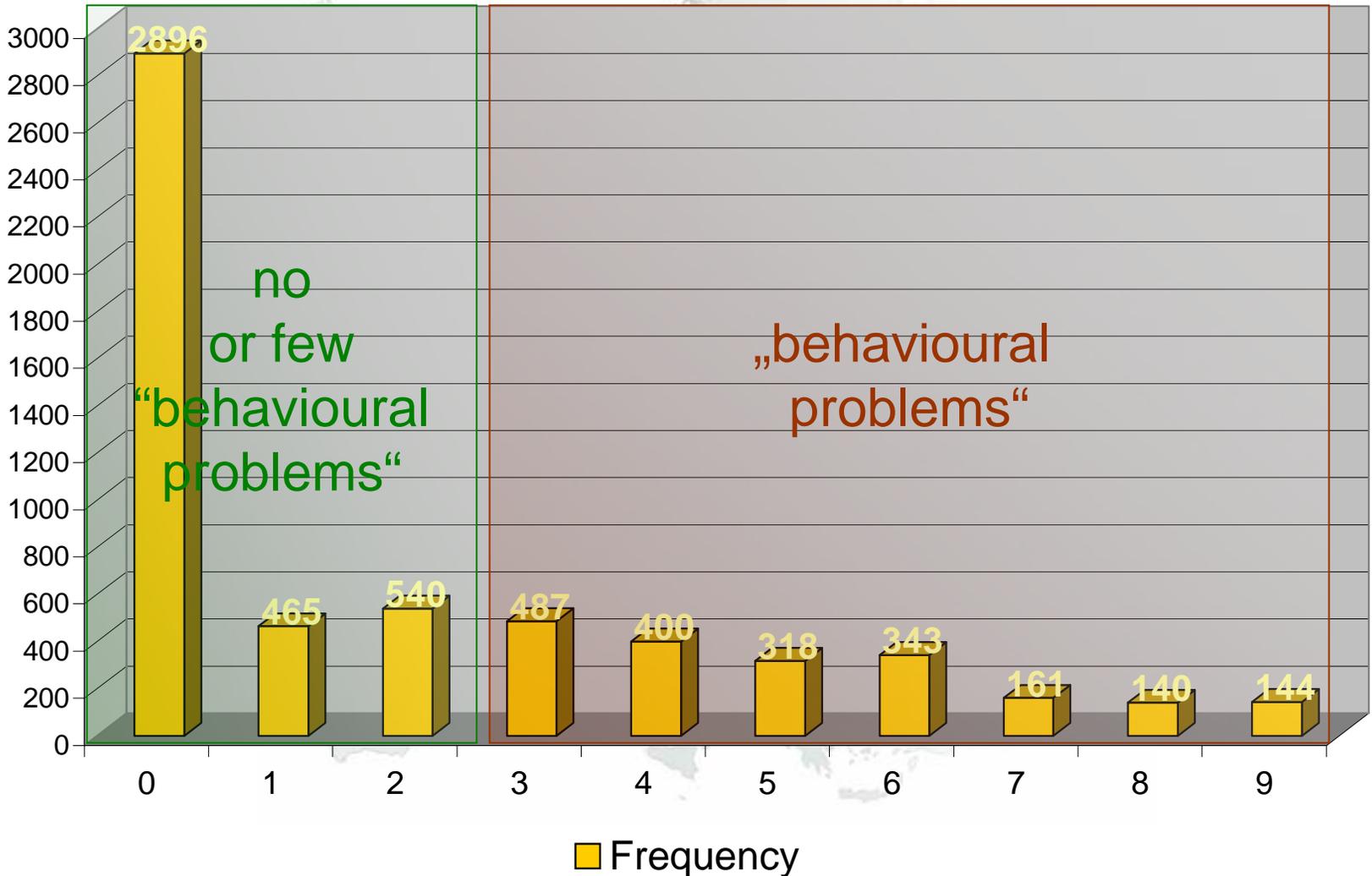
“Behavioural Problems”

	How frequently, if at all, does ELDER demonstrate any of these behaviours?	Most of the time	Sometimes	Rarely	Never
39 E39BEHP1	Wander in or outside the home environment or behaving in a way that endangers their safety?	③	②	①	①
40 E40BEHP2	Have difficulty holding normal conversation, have no insight into their problems, or become uncooperative with your requests?	③	②	①	①
41 E41BEHP3	Do they behave in ways that you find upsetting? (For example constantly asking questions, following you around, repeat what has been said shout and scream for no particular reason or inappropriately dress or undress)	③	②	①	①

Behavioural component of BISID (Behavioural and Instrumental Stressors in Dementia; Keady & Nolan, 1996)

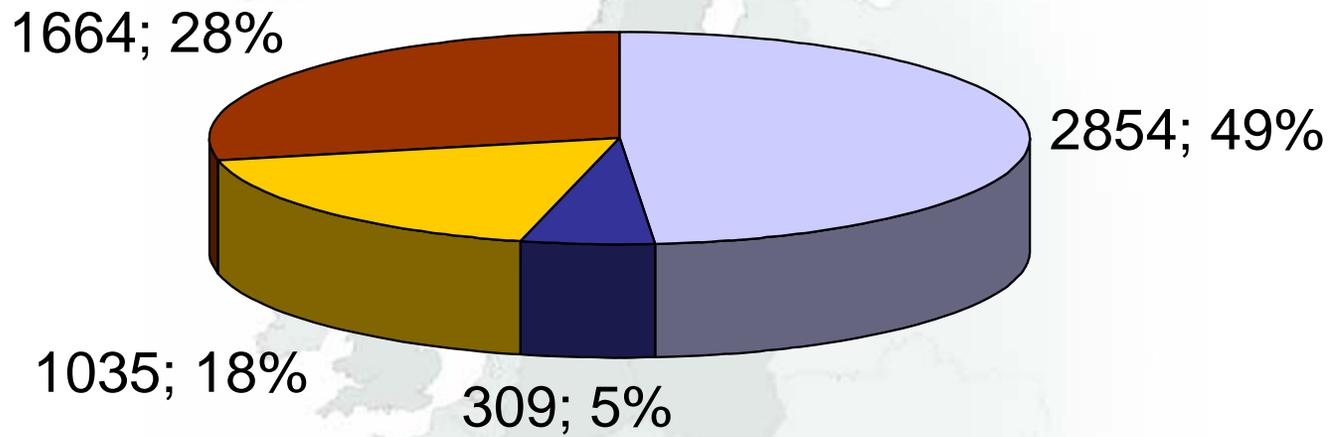


Dichotomising „behavioural problems“

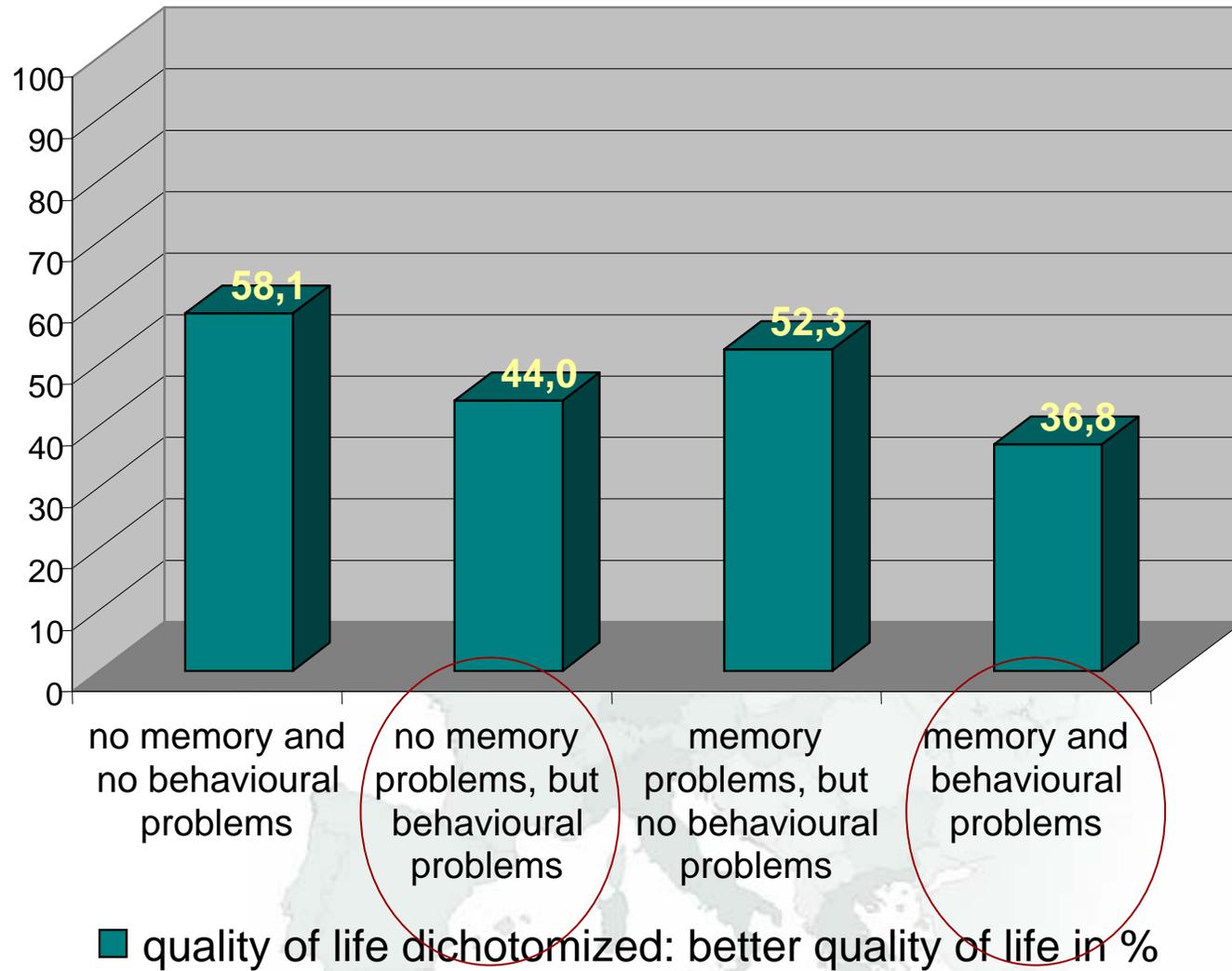


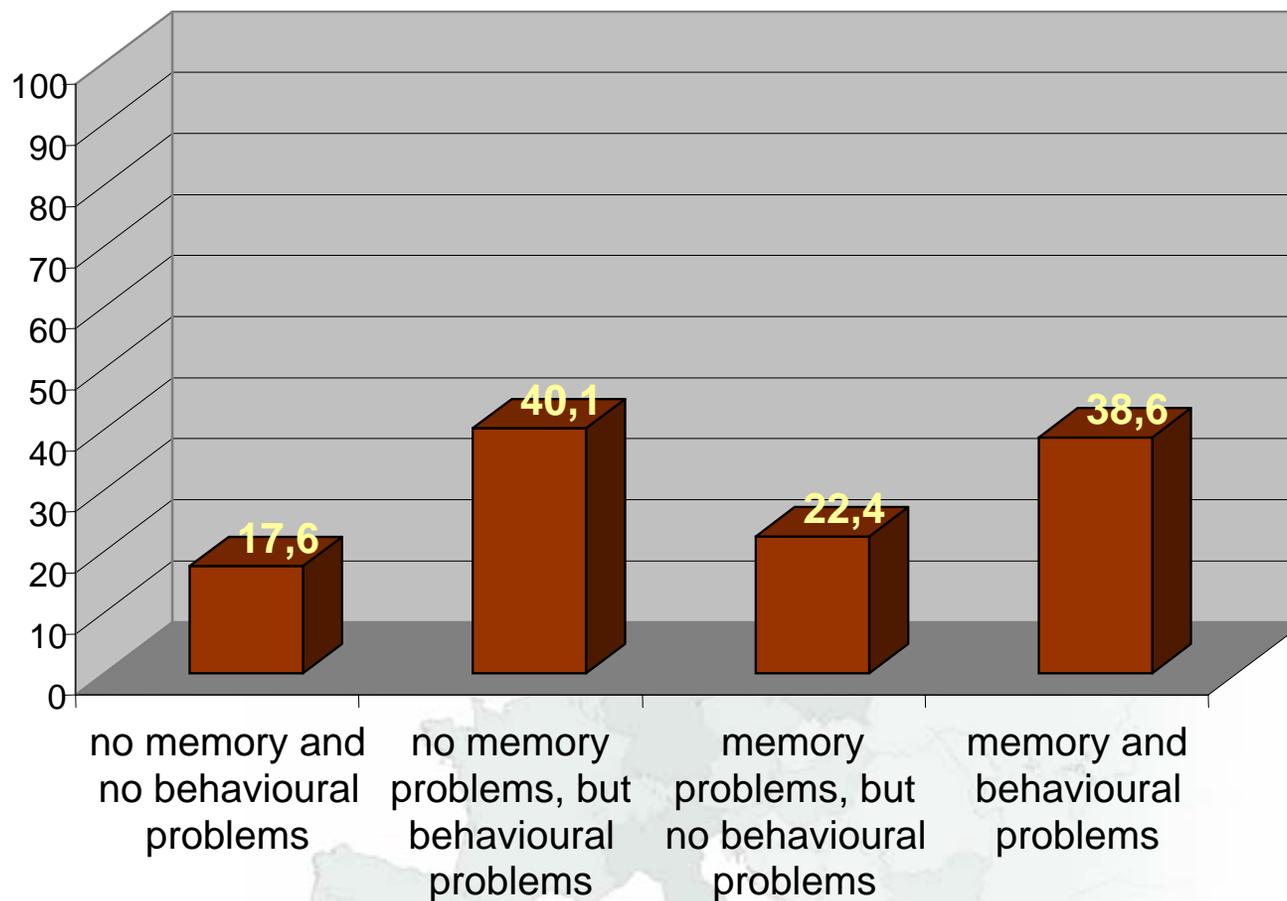


Memory and behavioural problems, N = 5862

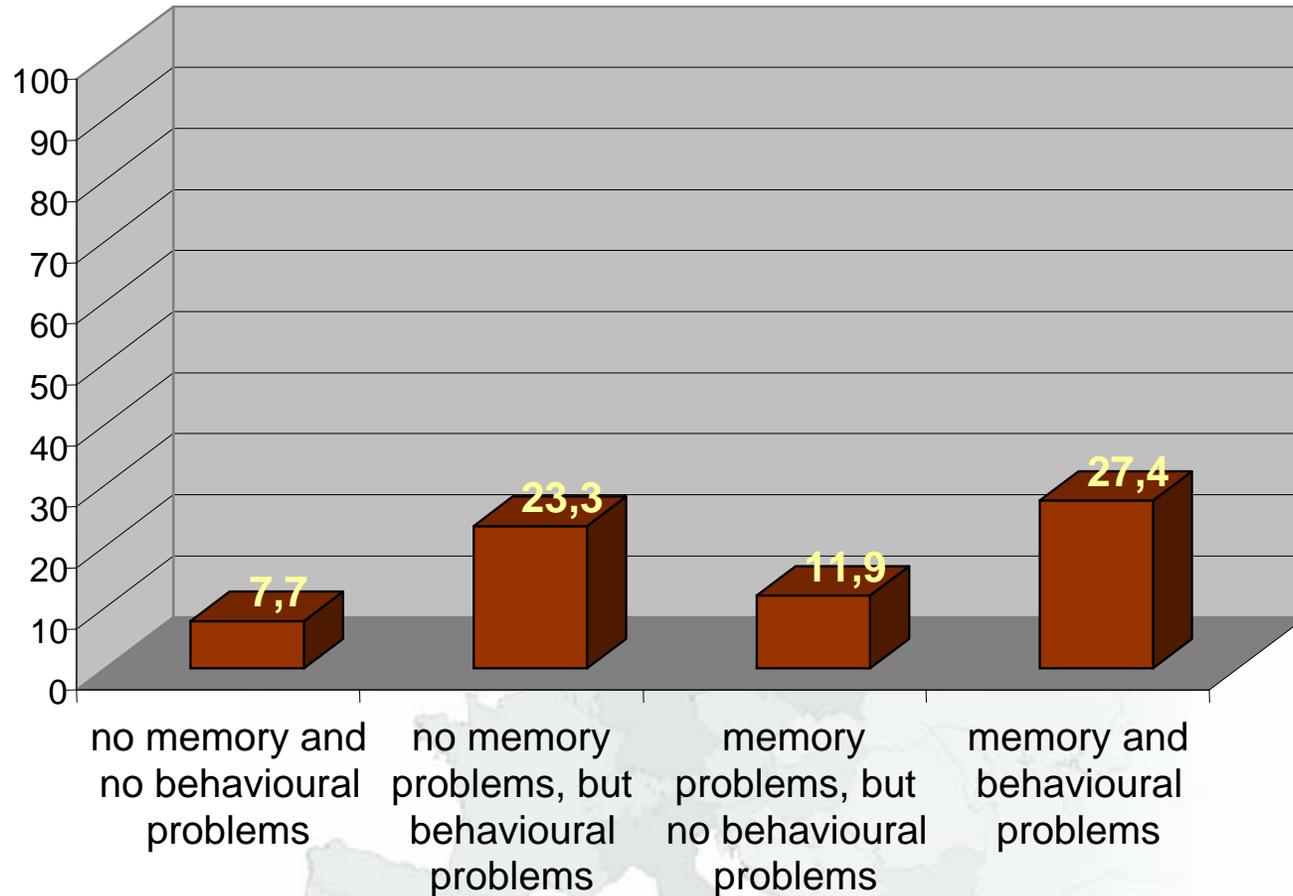


- no memory and no behavioural problems
- no memory problems, but behavioural problems
- memory problems, but no behavioural problems
- memory and behavioural problems

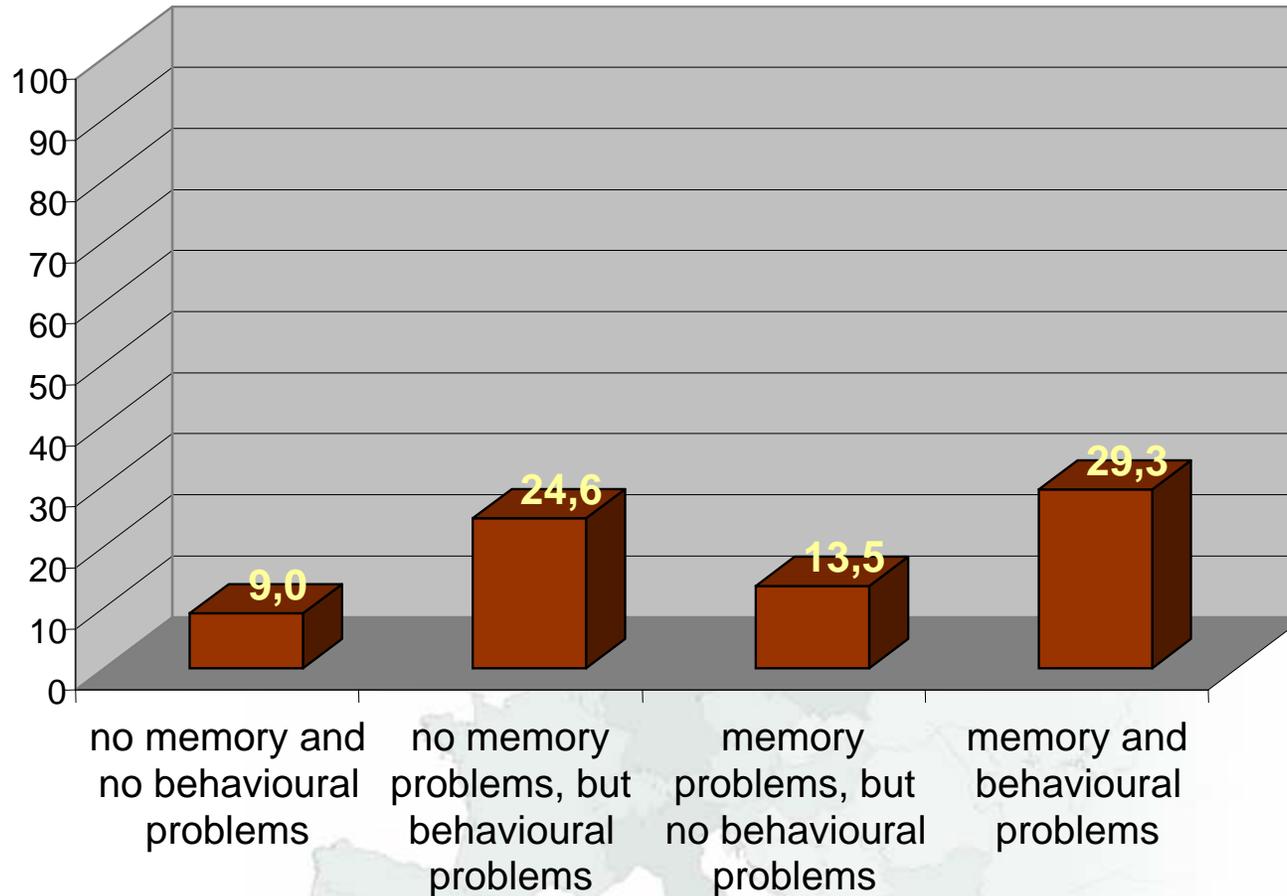




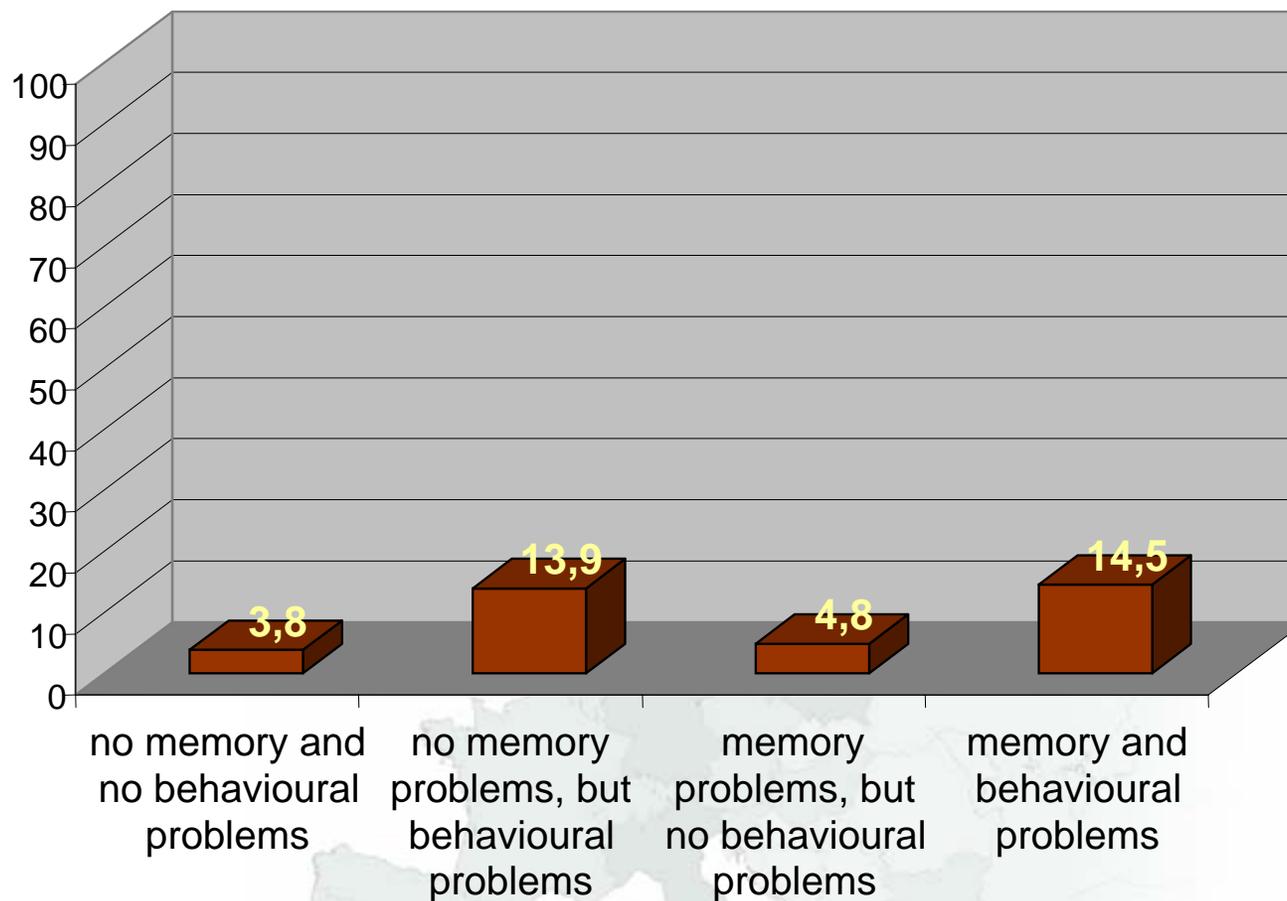
■ Do you find caregiving too **demanding**?
(always/often in %)



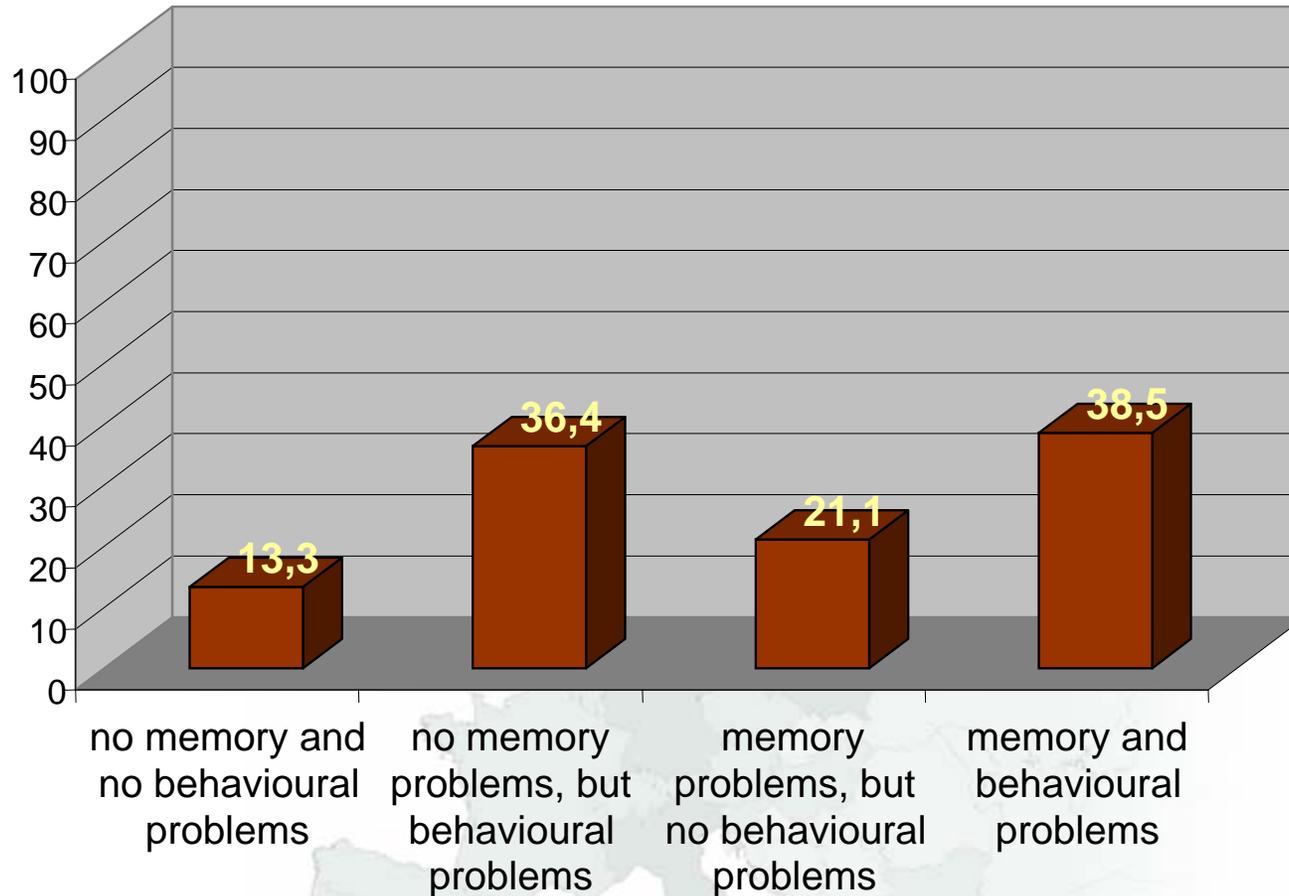
- Does caregiving cause difficulties in your **relationships with friends**? (always/often in %)



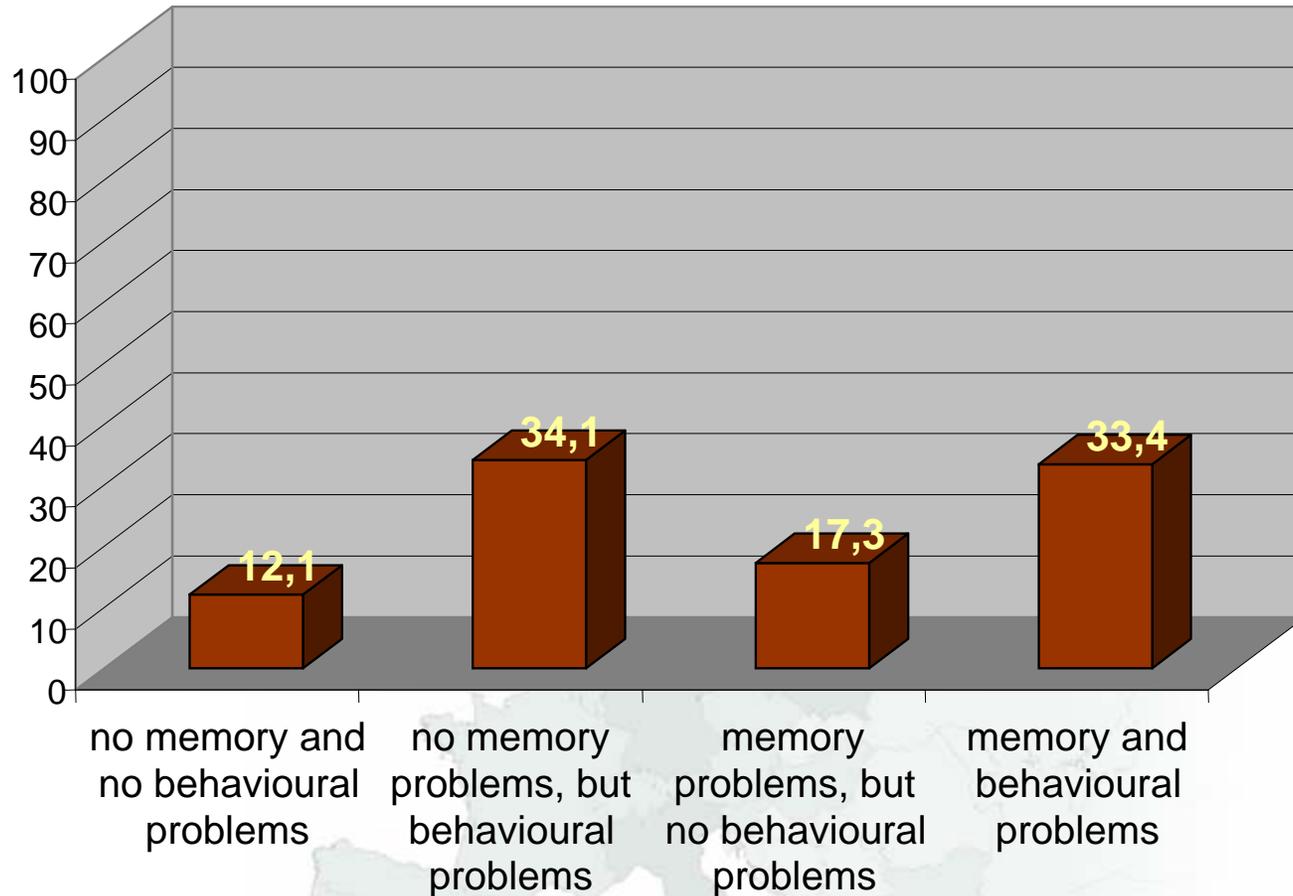
- Does caregiving have a negative effect on your **physical health**? (always/often in %)



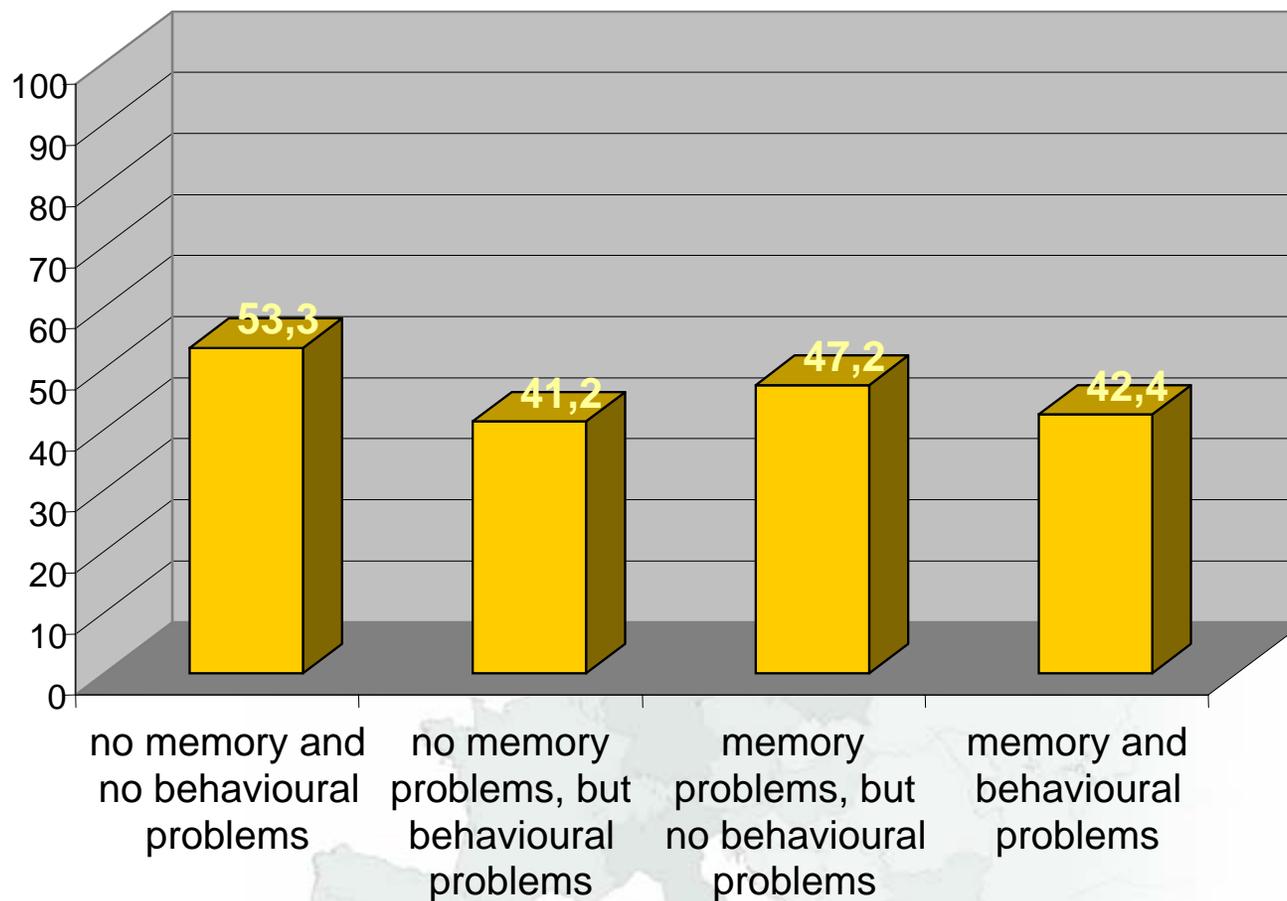
- Does caregiving cause difficulties in your **relationship with your family?** (always/often in %)



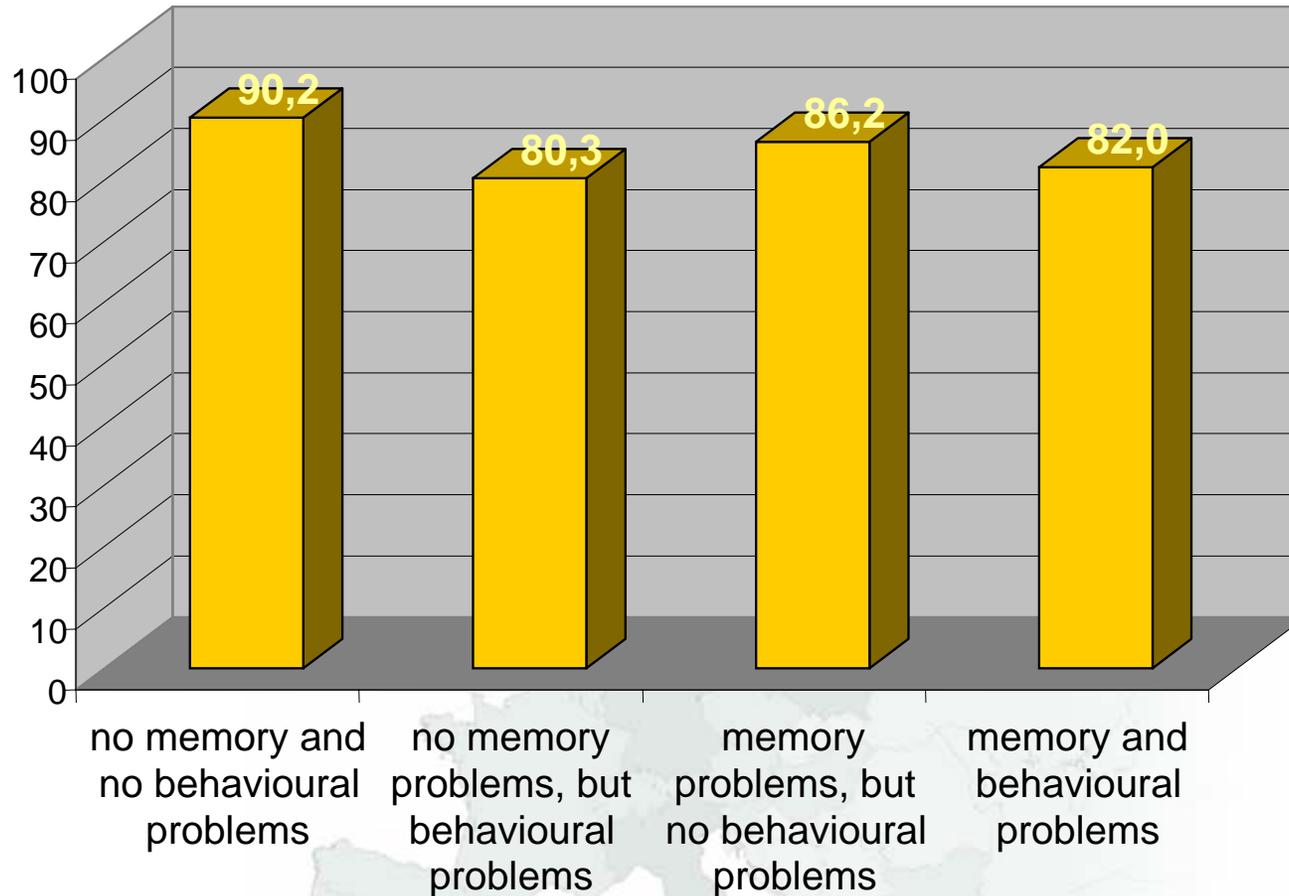
■ Do you feel **trapped** in your role as caregiver?
(always/often in %)



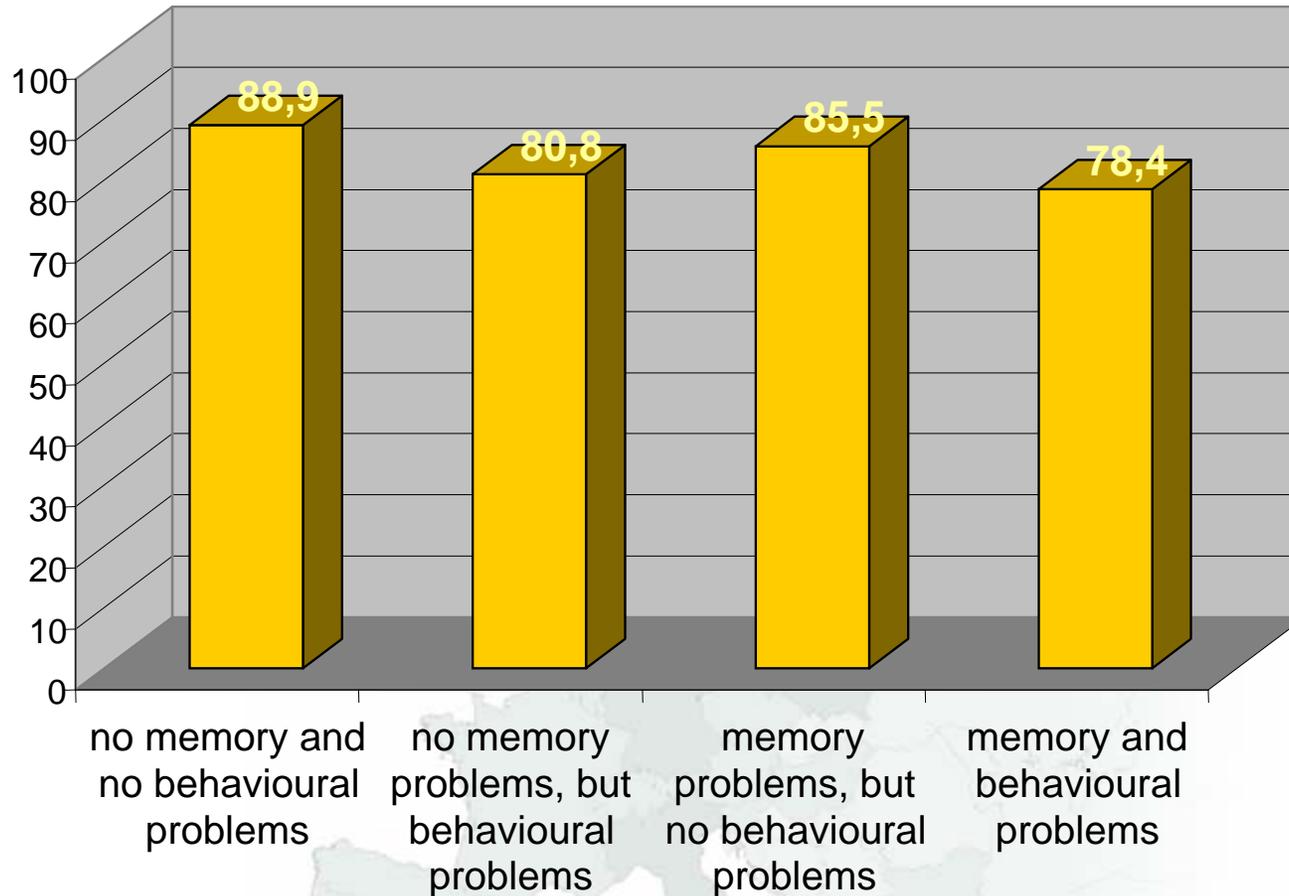
- Does caregiving have a negative effect on your **emotional well-being**? (always/often in %)



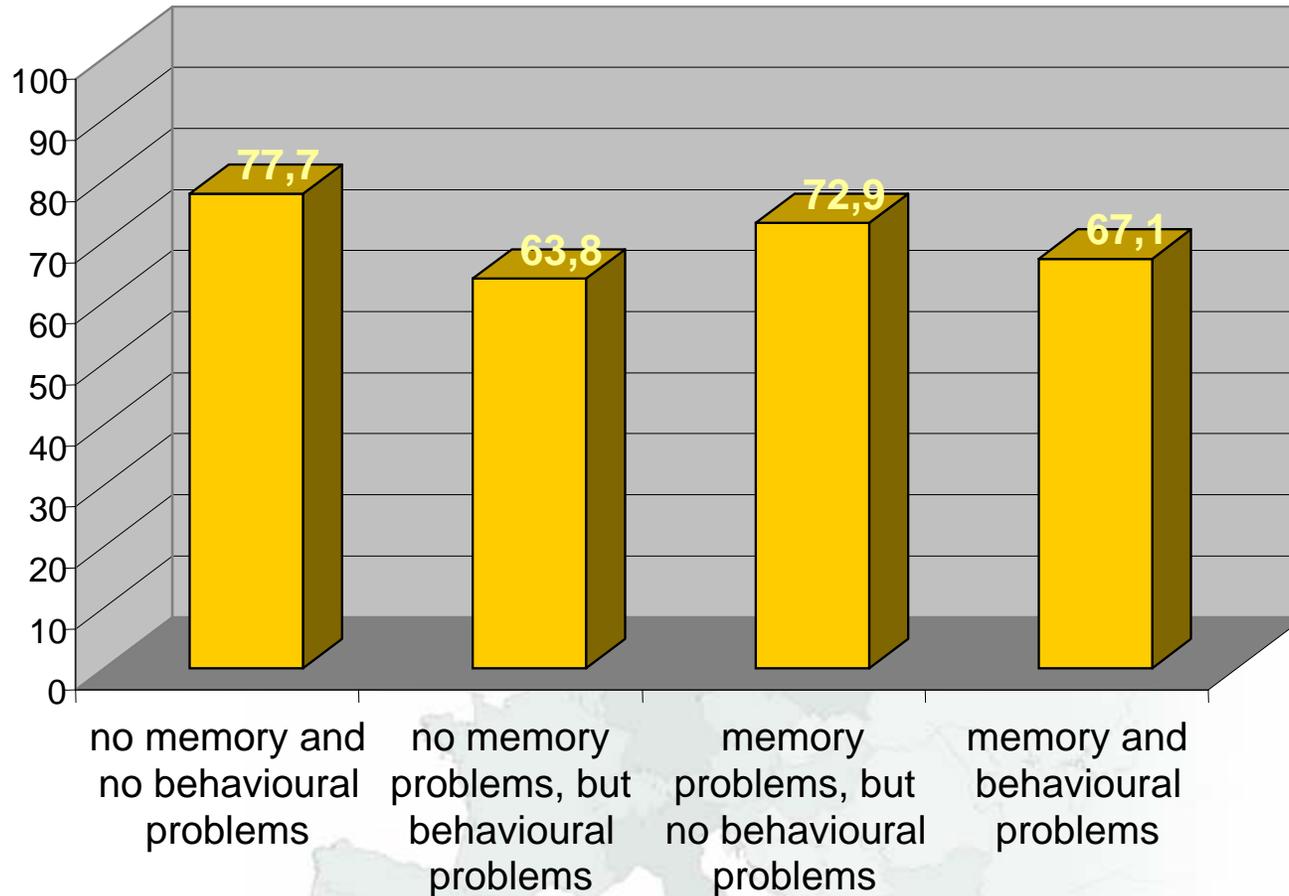
■ Do you feel **well supported** by friends/neighbors?
(always/often in %)



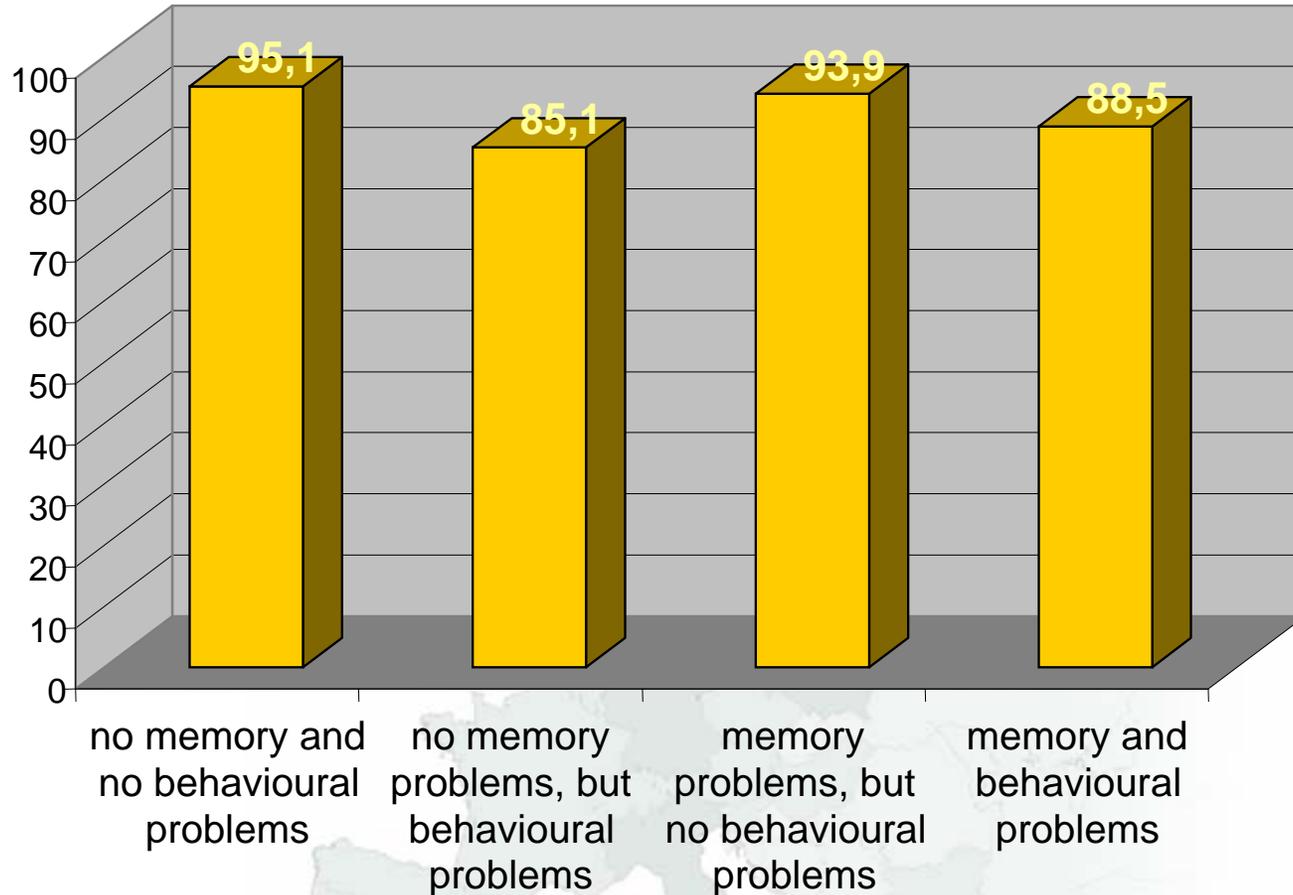
■ Do you feel you **cope** well as a caregiver?
(always/often in %)



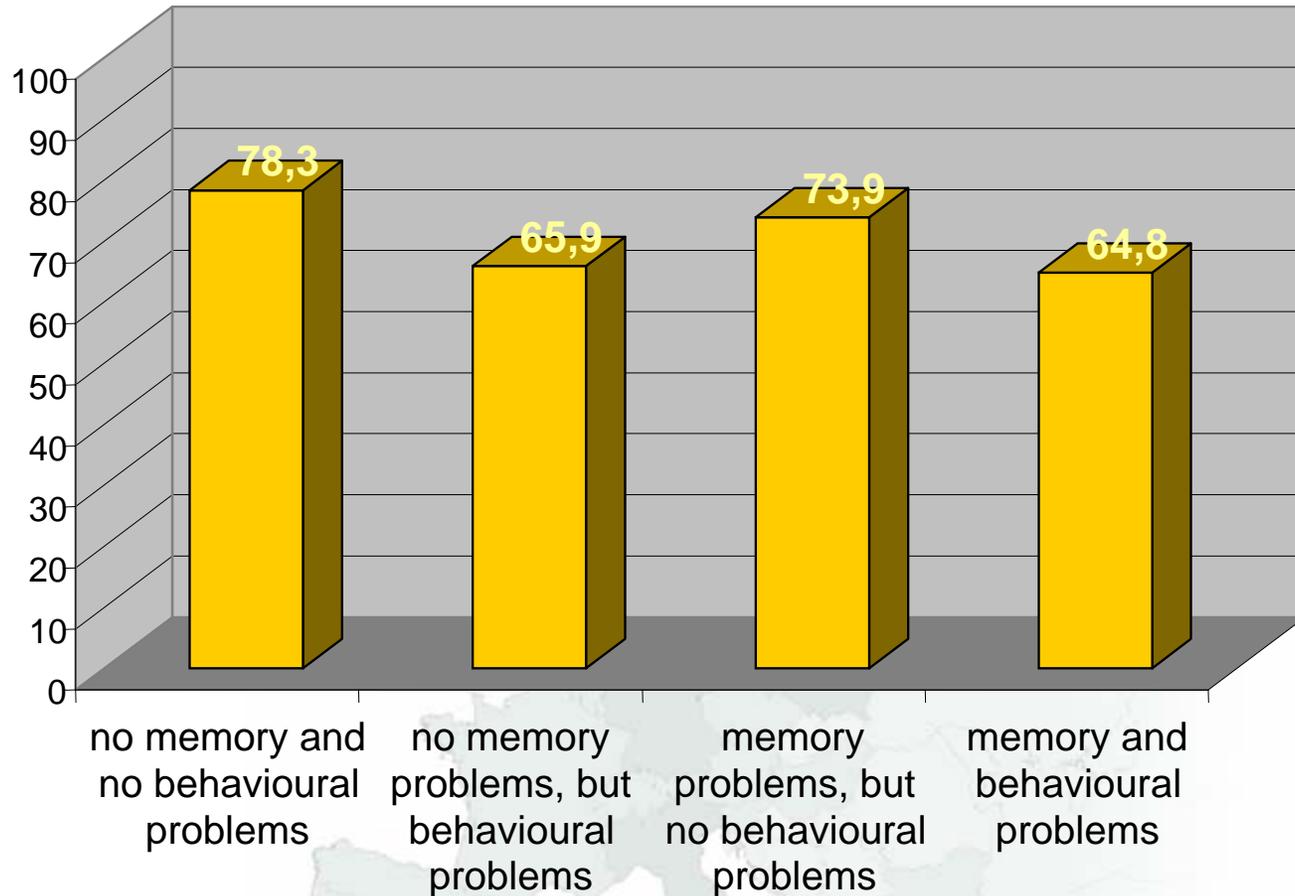
■ Do you find **caregiving worthwhile?**
(always/often in %)



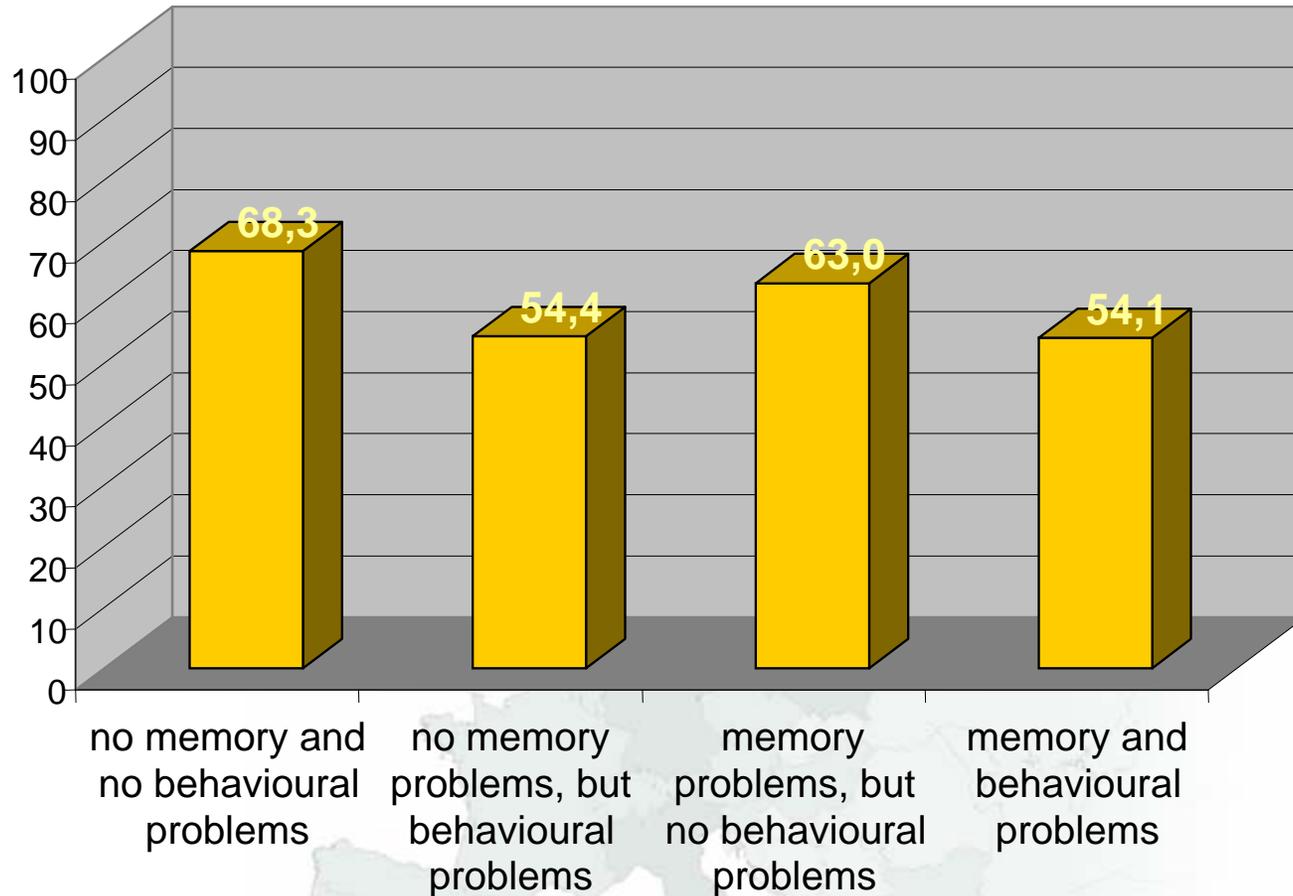
■ Do you feel **well supported** by your **family**?
(always/often in %)



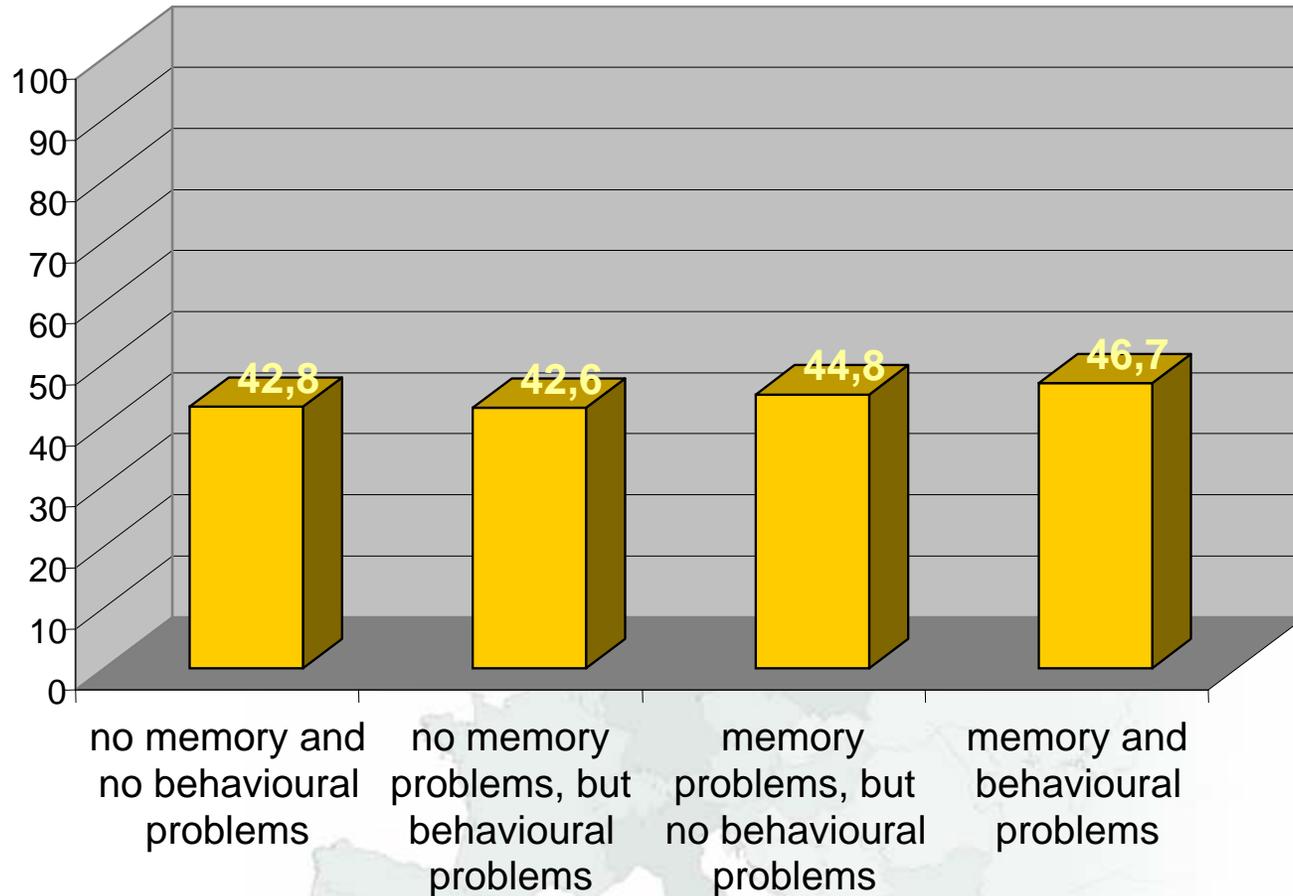
■ Do you have a good **relationship with elder?**
(always/often in %)



■ Do you feel that anyone **appreciates you** as a **caregiver**?
(always/often in %)



■ Overall, do you feel **well supported** in **your role of caregiver?**
(always/often in %)



■ Do you feel **well supported** by **services**?
(always/often in %)

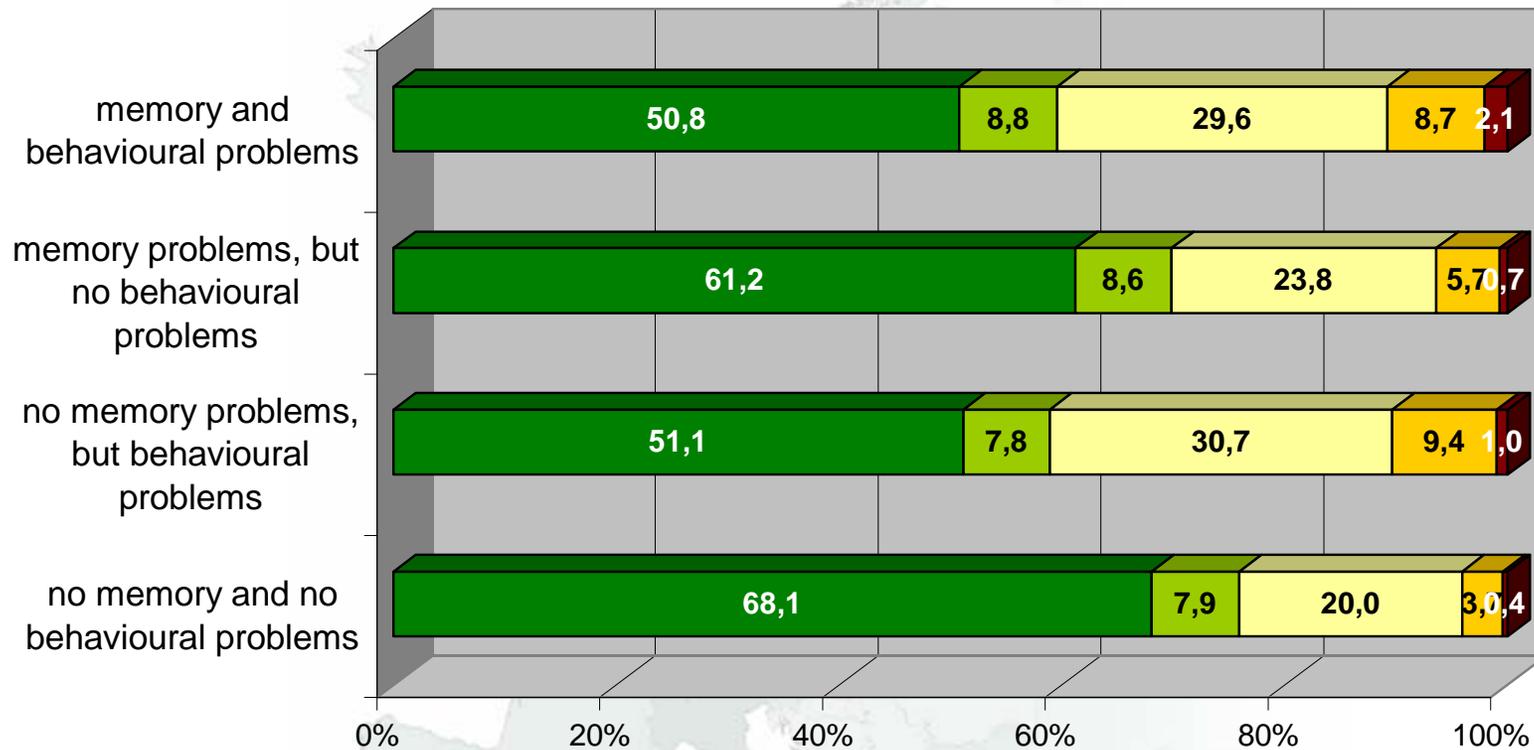


In the next year, are you willing to continue caring for the elder?





In the next year, are you willing to continue caring for elder?



- yes, and I would even increase
- yes, and I would increase for a limited time
- yes, if the situation remains the same
- yes, but only with more support
- no, no matter what extra support I receive

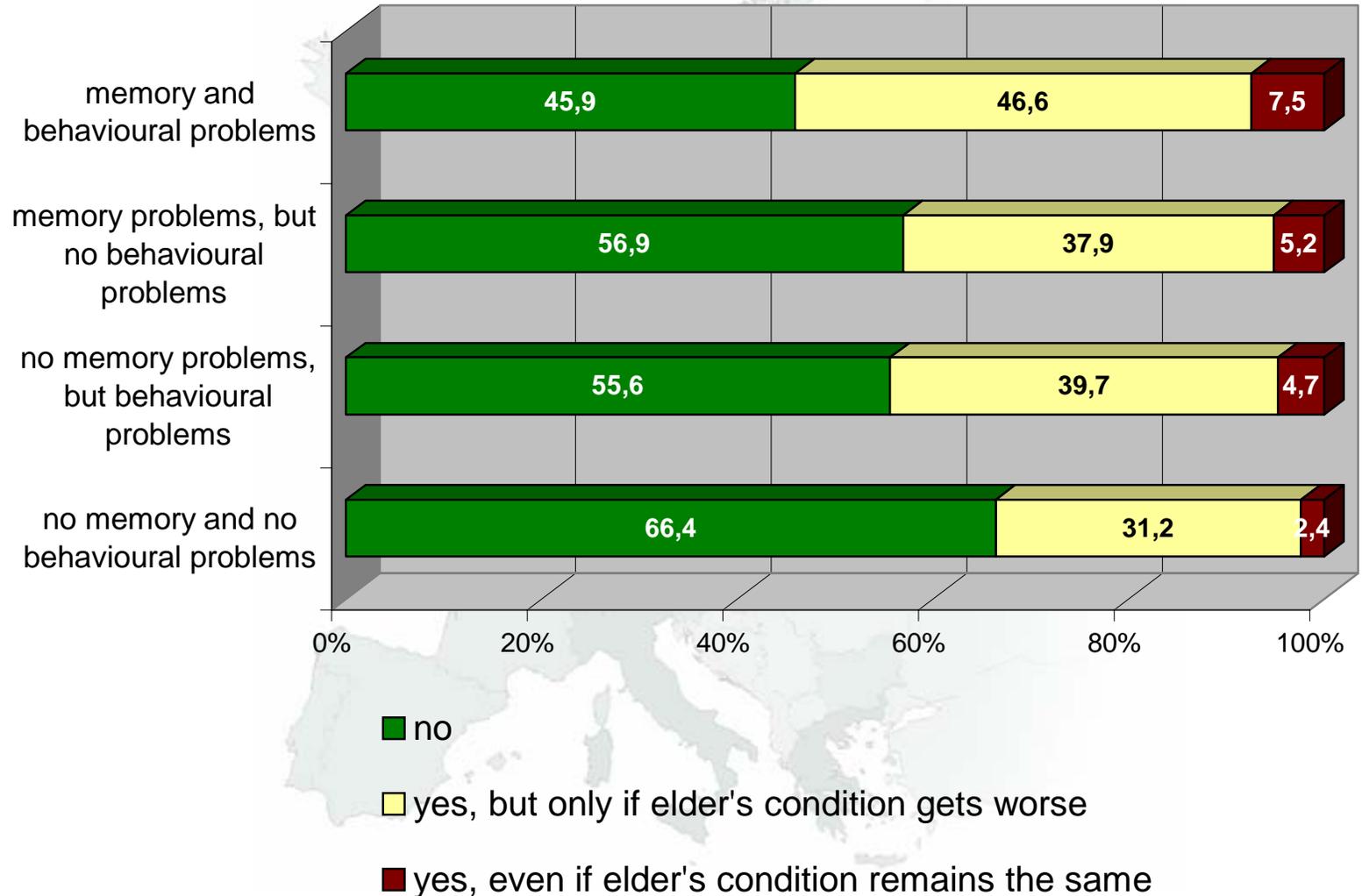


Would you be prepared to consider elder's placement in a care home?





Would you be prepared to consider elder's placement in a care home?





Consideration of care home admission and care situation after 12 months (N=2610)

“Would you be prepared to consider elder's placement in a care home?”	Care home (n=123)	Other family member (n=83)	Prof. carer (n=35)	Other carer (n=23)	Same carer, no change (n=2346)	total
No						
Yes, but only if elder's condition gets worse						
Yes, even if elder's condition remains the same						

Consideration of care home admission and care situation after 12 months (N=2610)

“Would you be prepared to consider elder's placement in a care home?”	Care home (n=123)	Other family member (n=83)	Prof. carer (n=35)	Other carer (n=23)	Same carer, no change (n=2346)	total
No	12,2%	69,9%	57,1%	47,8%	63,3%	60,9%
Yes, but only if elder's condition gets worse	62,6%	27,7%	25,7%	47,8%	34,2%	35,3%
Yes, even if elder's condition remains the same	25,2%	2,4%	17,1%	4,3%	2,5%	3,8%
	100%	100%	100%	100%	100%	100%



Memory problems and care after 12 months (N = 2724)

	Care home (n=152)	Other family member (n=88)	Prof. carer (n=37)	Other carer (n=27)	Same carer, no change (n=2420)	total
No memory problems						
Memory problems						



Conclusions

- The results on carers' burden reinforce the results from other studies with regard to the importance of behavioural problems.
- However, memory problems become just as significant as behavioural problems when carers are asked about satisfaction with support from services, and older people with memory problems have a higher risk of being in a care home after a year.
- 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 – the next presentation will consider this.



