



**“Dementia Matters”**

**15th Alzheimer Europe  
Conference**

**9-12 June 2005**



# **“Dementia Matters”**

## **Family carers of older adults in 6 European Countries: The impact of cognitive impairment**

Christopher Kofahl<sup>1</sup> & Marie Victoria Gianelli<sup>2</sup>

(1) University of Hamburg, Germany (Co-ordination Centre)

(2) University of Genova

& Italian National Research Centre on Ageing - INRCA Ancona

on behalf of the EUROFAMCARE group



The **EUROFAMCARE** group: **Germany**: Döhner H. (project co-ordinator), Kofahl C., Luedecke D., Mnich E. (Hamburg) and Rothgang H., Becker R. (Bremen); **Greece**: Mestheneos E. (PI), Triantafillou J. (PI), Prouskas C., Mestheneos K.; **Italy**: Lamura G. (PI), Balducci C., Melchiorre M.G., Quattrini S., Spazzafumo L.; **Poland**: Bien B. (PI), Wojszel B., Synak B., Czekanowski P., Bledowski P., Pedich W.; **Sweden**: Öberg B. (PI), Krevers B., Johansson S.L.; **United Kingdom**: McKee K. (PI), Barber L., Brown J., Nolan M.

**The 5<sup>th</sup> 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**

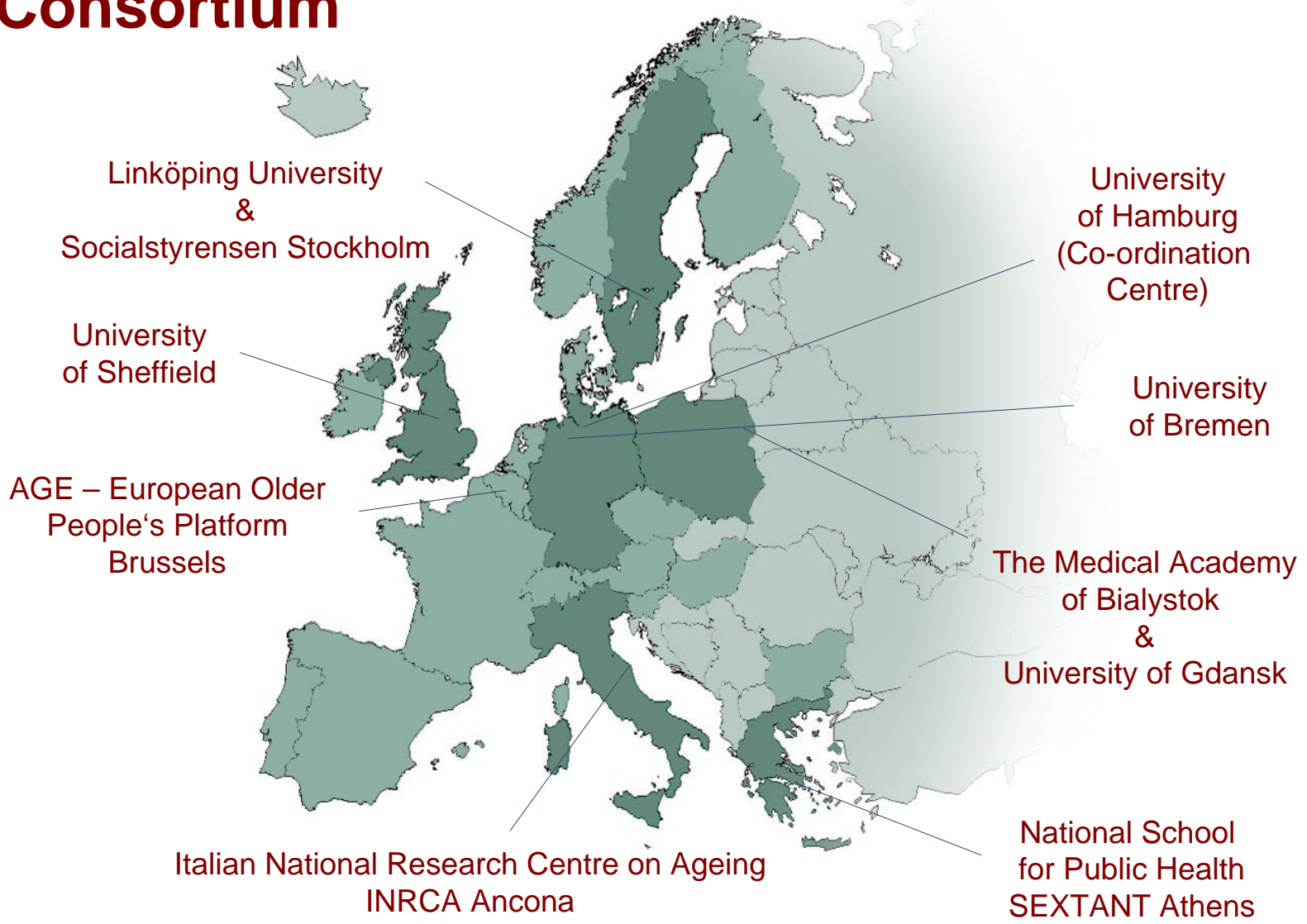
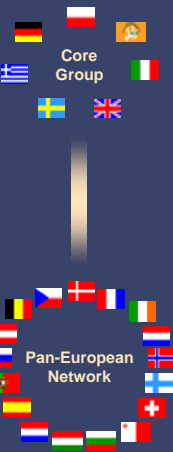
**1.1.2003 – 31.12.2005**

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




# EUROFAMCARE

## Consortium



# Overview

- **Aims**
  - **Methodology**
  - **National Background Reports**
  - **Pan-European Synopsis**
  - **Findings on memory problems**
  - **Conclusions?**
- 

# Aims



- EUROFAMCARE will provide 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 push a **change management process** at various policy levels to promote social and health policies towards a **partnership approach** between family carers, professional providers and cared-for.



# Methodology (1)

## Six Countries Comparative Study

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





## Methodology (2)

### Six Countries Comparative Study

- A 12-months follow-up study with carers to monitor main changes: Face to face, phone or postal interviews
- Socio-economic analysis
- Service providers study: Semi-structured interviews with 30-50 service providers per country

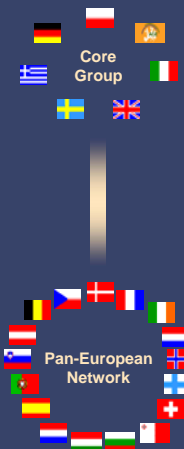




# Methodology (3)

## National Background Reports

Same structure in all 23 **NABARE** reports following a Standardised Evaluation Protocol (STEP for NABAREs)



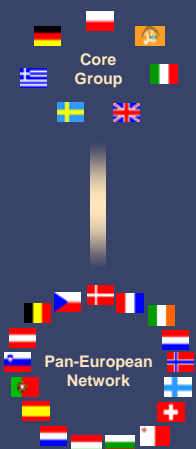


## Methodology (4)

# Pan-European Background Report

### NABAREs -> PEUBARE

The pan-European synopsis **PEUBARE** (Mestheneos & Triantafillou) contains the European situation of family carers' in the years 2003/2004 with respect to the similarities between the countries as well as wide differences in service provision, state systems and cultures and the effects of all these factors on family carers and the older people they care for. Current policy trends are described.









# Findings from the National Surveys

- **Sociodemographics (description of the samples)**
- **Memory problems / cognitive impairment**
- **Impact on Family Carers' QoL**
- **Impact on Family Carers' motivation to care**









# Sociodemographics (description of the samples)

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











## Relationship to ELDER (% within country)

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











# What factors influenced your decision to care for elder?

							all
emotional bonds (love, affection)	96,8	96,3	90,5	96,6	94,1	92,6	94,5
a sense of duty	89,3	73,3	79,5	67,7	91,6	85,8	81,4
personal sense of obligation towards elder as a family member	91,4	57,4	75,6	73,6	93,7	90,9	80,6
caring for elder makes me feel good	81,5	56,4	61,9	83,4	77,2	84,2	74,0
elder would not wish anyone else to care for them	43,5	45,4	62,9	46,1	53,6	62,1	52,3
there was no alternative	53,2	30,3	46,0	45,5	45,4	64,4	47,6
I found myself caring by chance without making a decision	37,8	31,5	61,5	65,3	32,3	29,5	42,7
my religious beliefs	40,0	38,0	22,6	8,2	67,7	24,7	33,9
cost of professional care too high	43,8	31,1	30,2	14,8	34,4	45,1	33,5
economic benefits for both carer and elder	8,0	4,3	8,7	13,2	8,1	12,3	9,1



# Amount of and main reasons for caring

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





# “Memory Problems”

*Some of the most stressful situations for Carers are related to problems which affect the memory and behaviour of the person they care for. The next questions relate to these issues.*

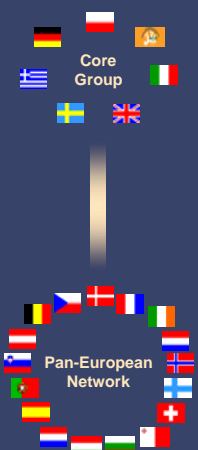
35 E35MEM1	<b>Has ELDER any memory problems?</b> (Such as having difficulty in remembering what day it is, or recognising friends or neighbours)	Yes ① Complete grey section	No ① Go to Q38
36 E36MEM2	<b>IF ‘YES’, has the doctor given you any cause of ELDER’s memory problems?</b>	Yes ①	No ① Go to Q38
37 E37MEM3 E37SPEC	<b>IF ‘YES’, please specify</b>  Specify ‘other’ here: <input type="text"/>	Dementia ①	Other ②



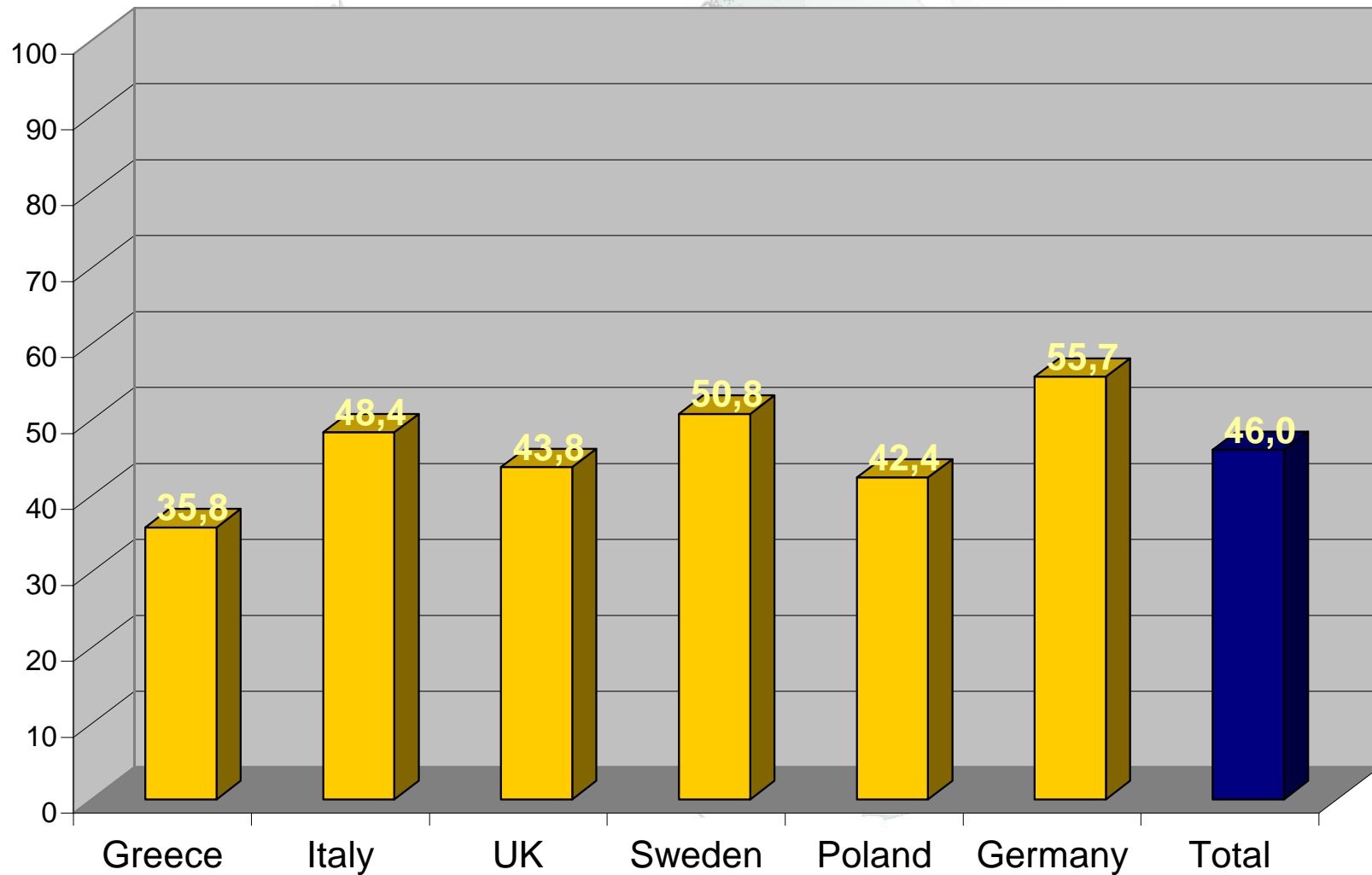
Core Group



Pan-European Network

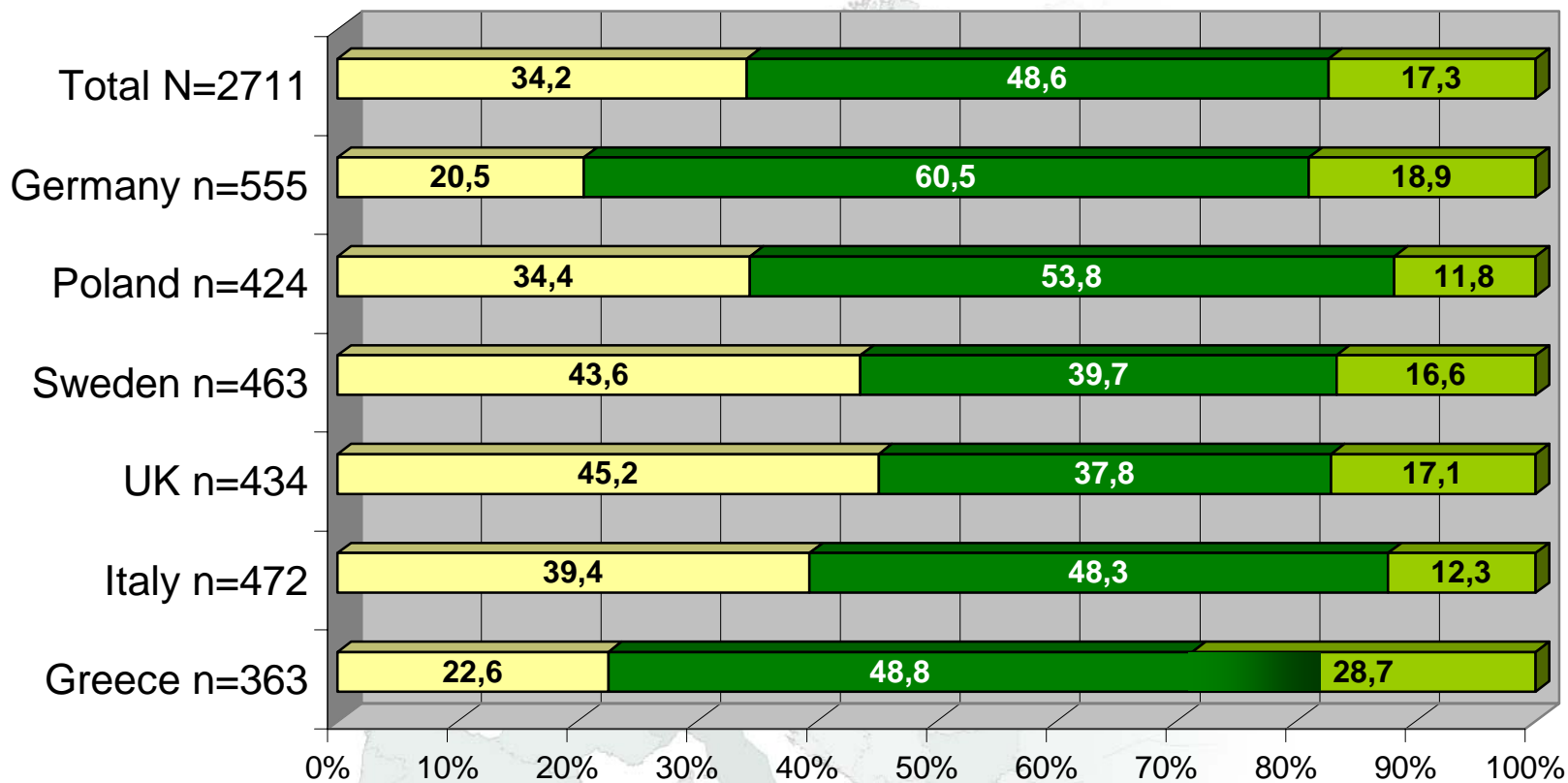


## Has ELDER any memory problems? (%)





## Memory problems explained by a doctor



□ memory problems, undiagnosed (% within country)

■ memory problems, dementia "diagnosed" by a doctor (% within country)

■ memory problems, other diagnosis/explanation by a doctor (% within country)

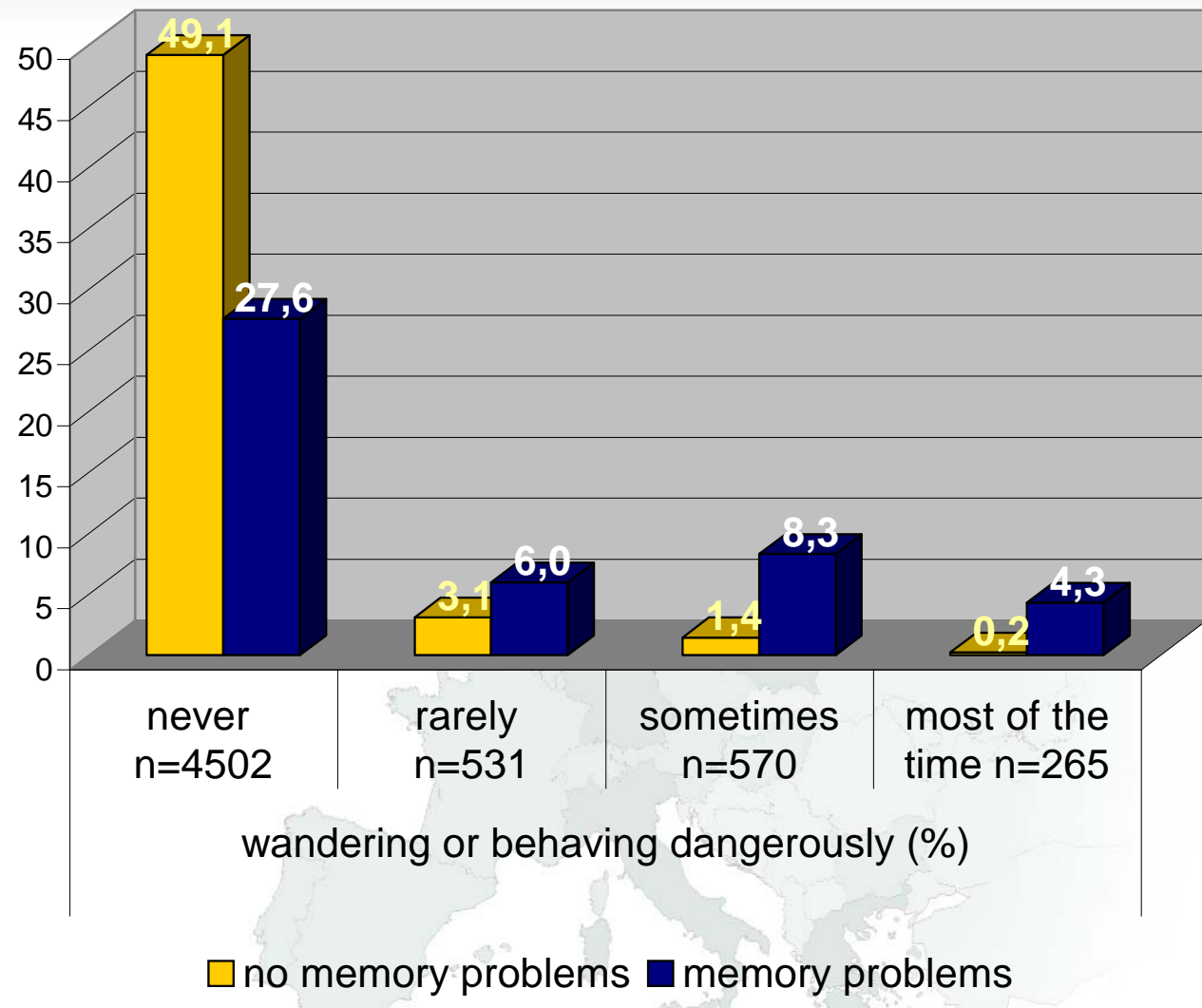
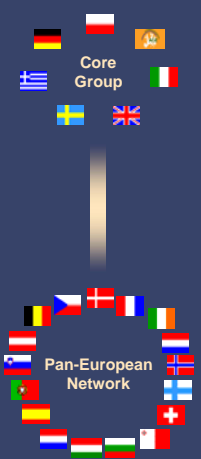


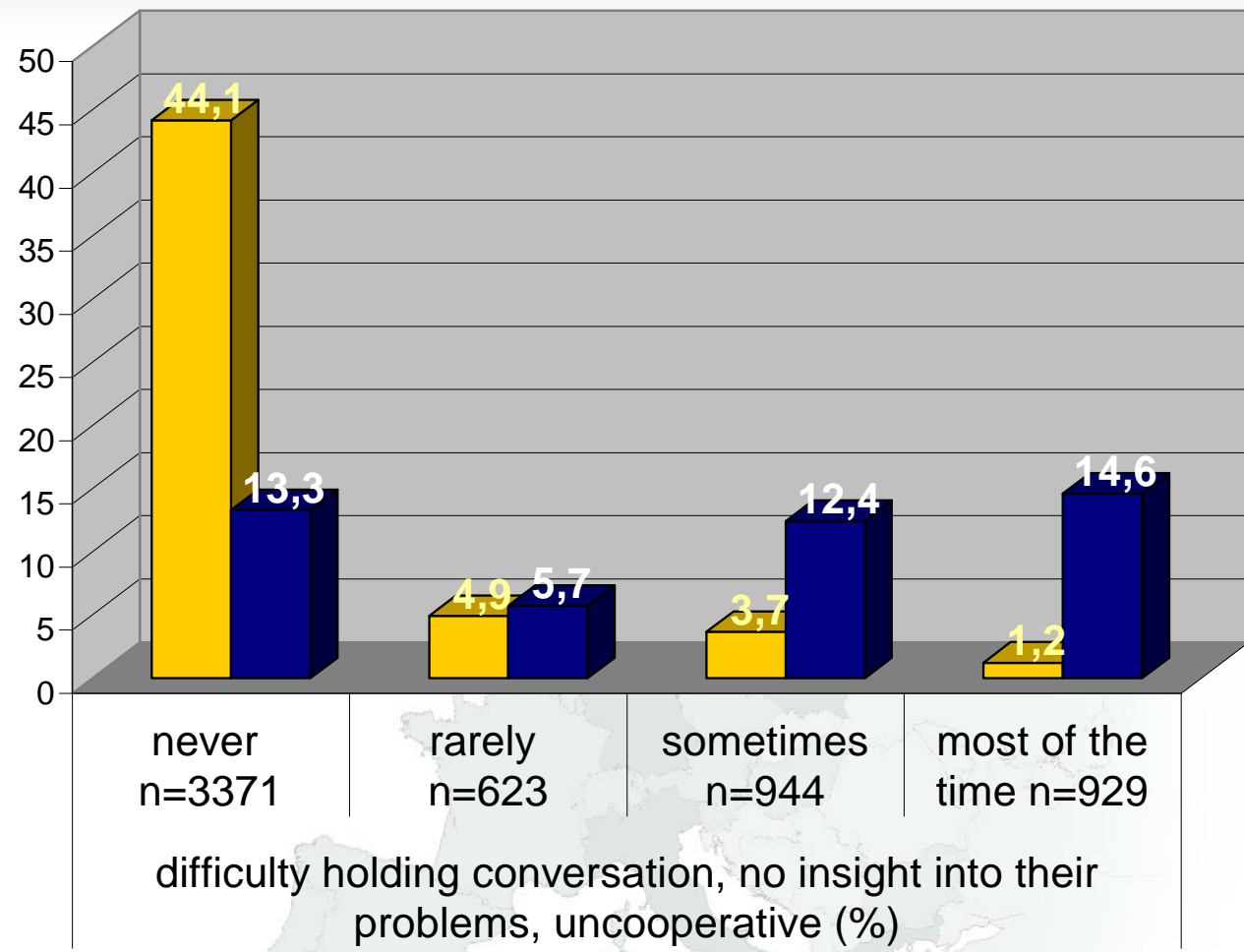
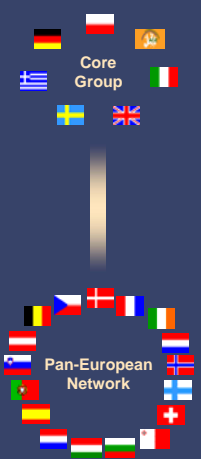


# “Behavioural Problems”

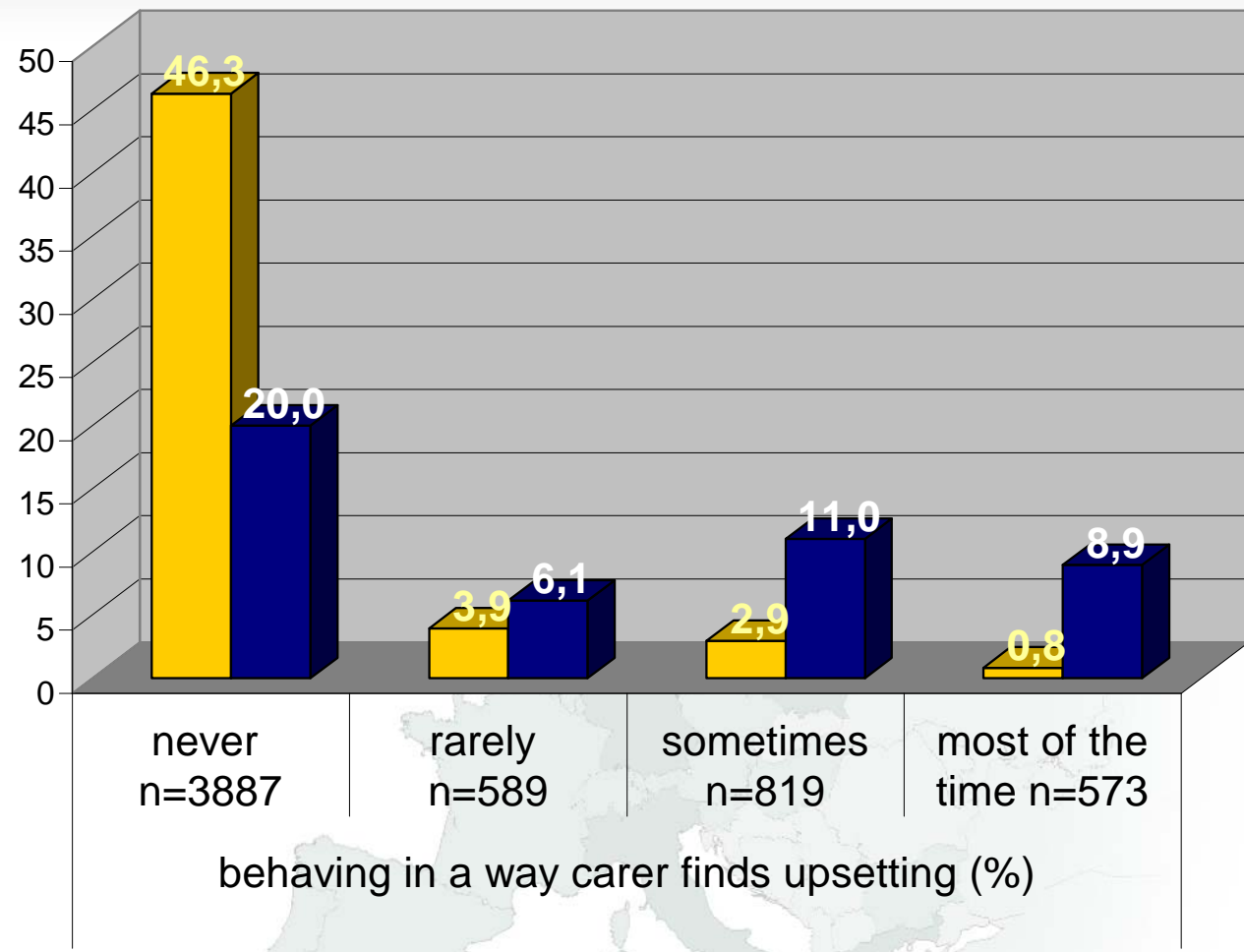
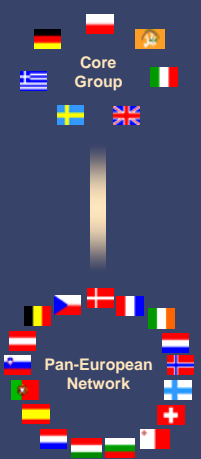
	How frequently, if at all, does ELDER demonstrate any of these behaviours?	Most of the time	Sometimes	Rarely	Never
39 E39BEHP1	<b>Wander in or outside the home environment or behaving in a way that endangers their safety?</b>	③	②	①	①
40 E40BEHP2	<b>Have difficulty holding normal conversation, have no insight into their problems, or become uncooperative with your requests?</b>	③	②	①	①
41 E41BEHP3	<b>Do they behave in ways that you find upsetting?</b> (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







■ no memory problems ■ memory problems

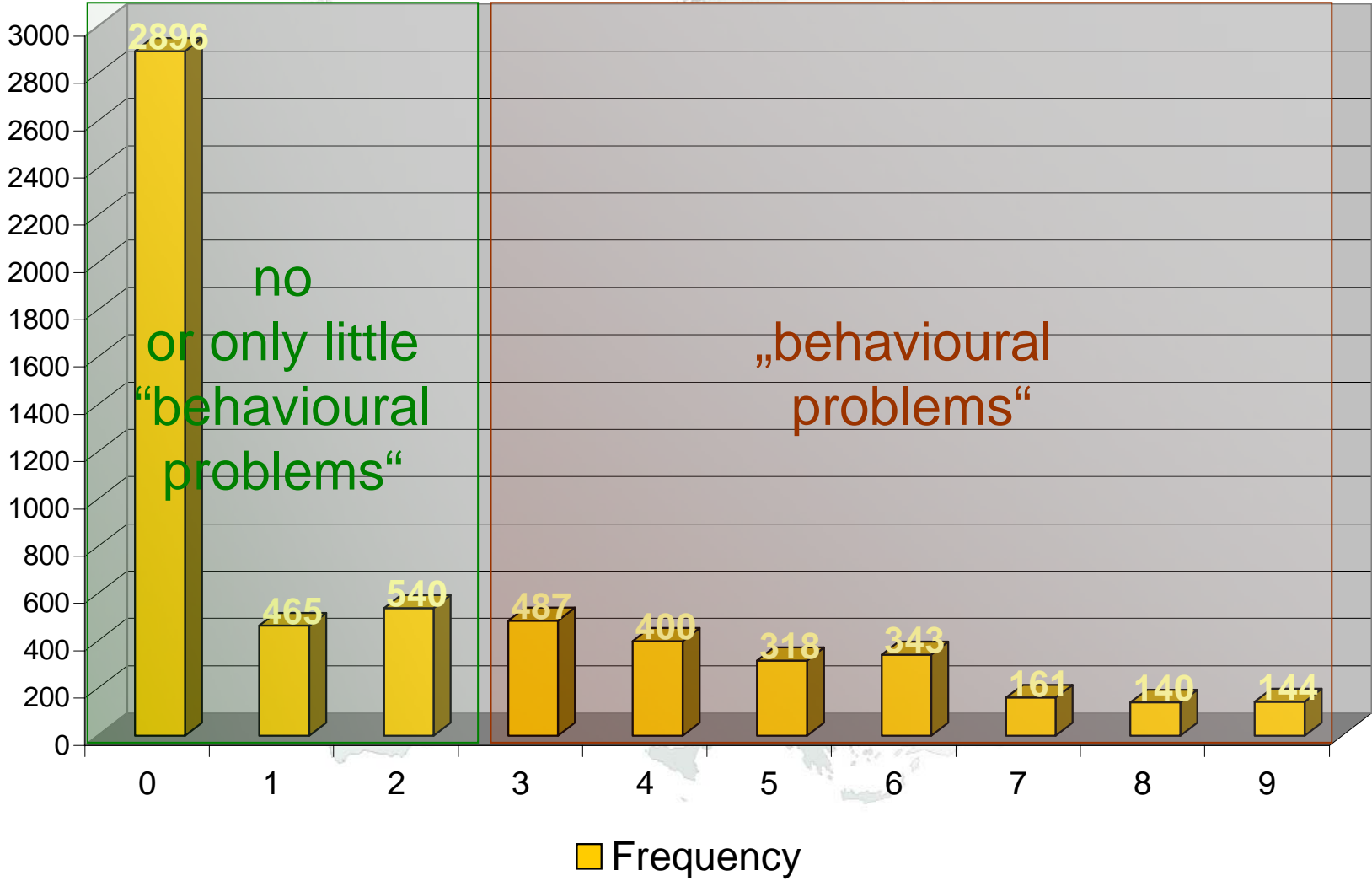
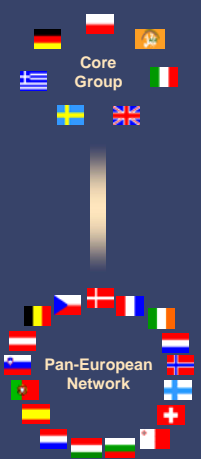


behaving in a way carer finds upsetting (%)

■ no memory problems ■ memory problems

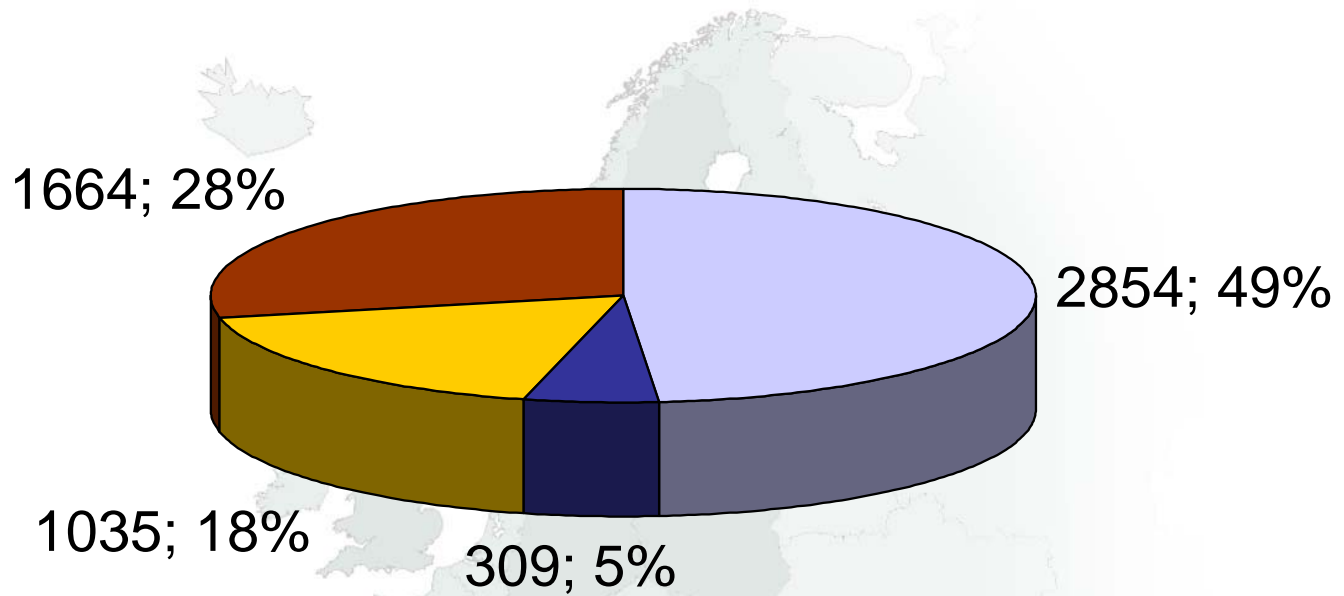


# Dichotomising „behavioural problems“



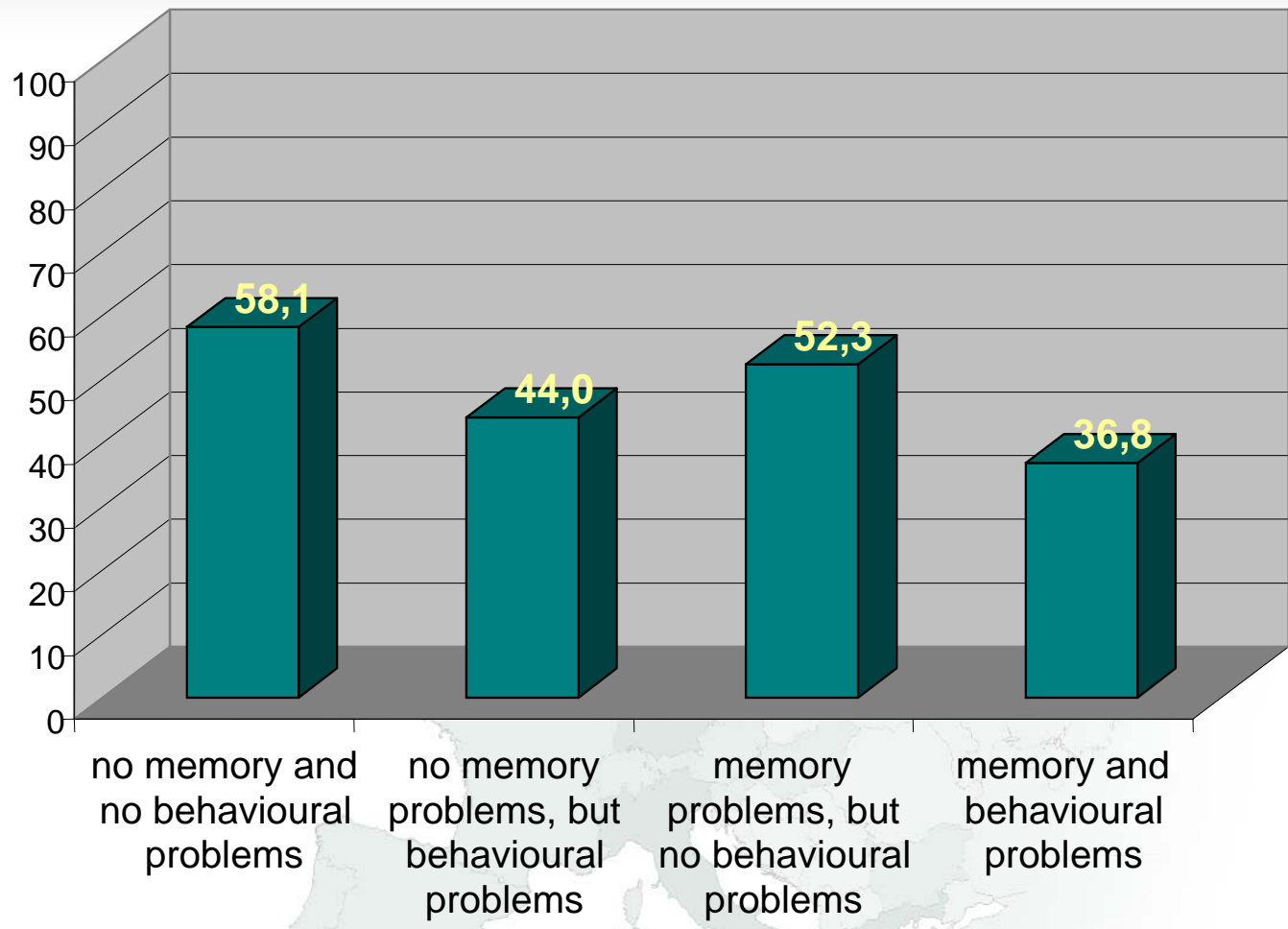
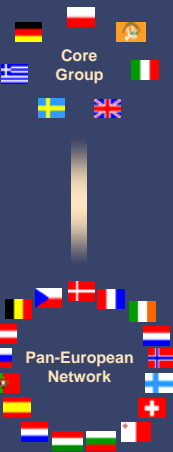


## Memory and behavioural problems, N = 5862

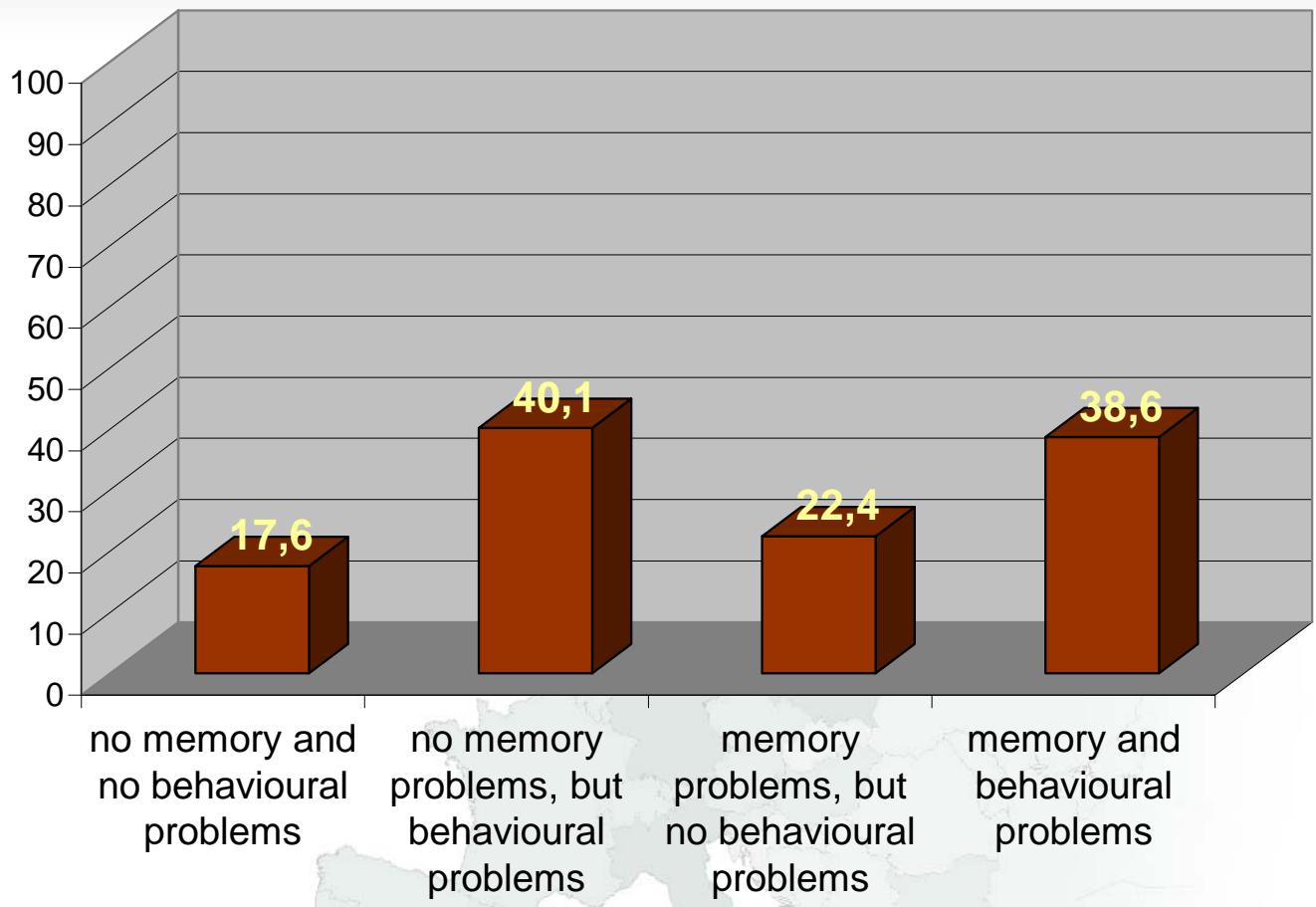
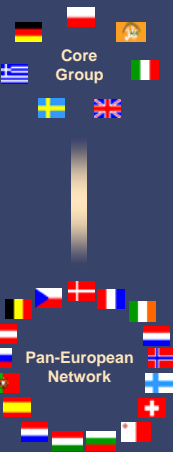


- no memory and no behavioural problems
- no memory problems, but behavioural problems
- memory problems, but no behavioural problems
- memory and behavioural problems

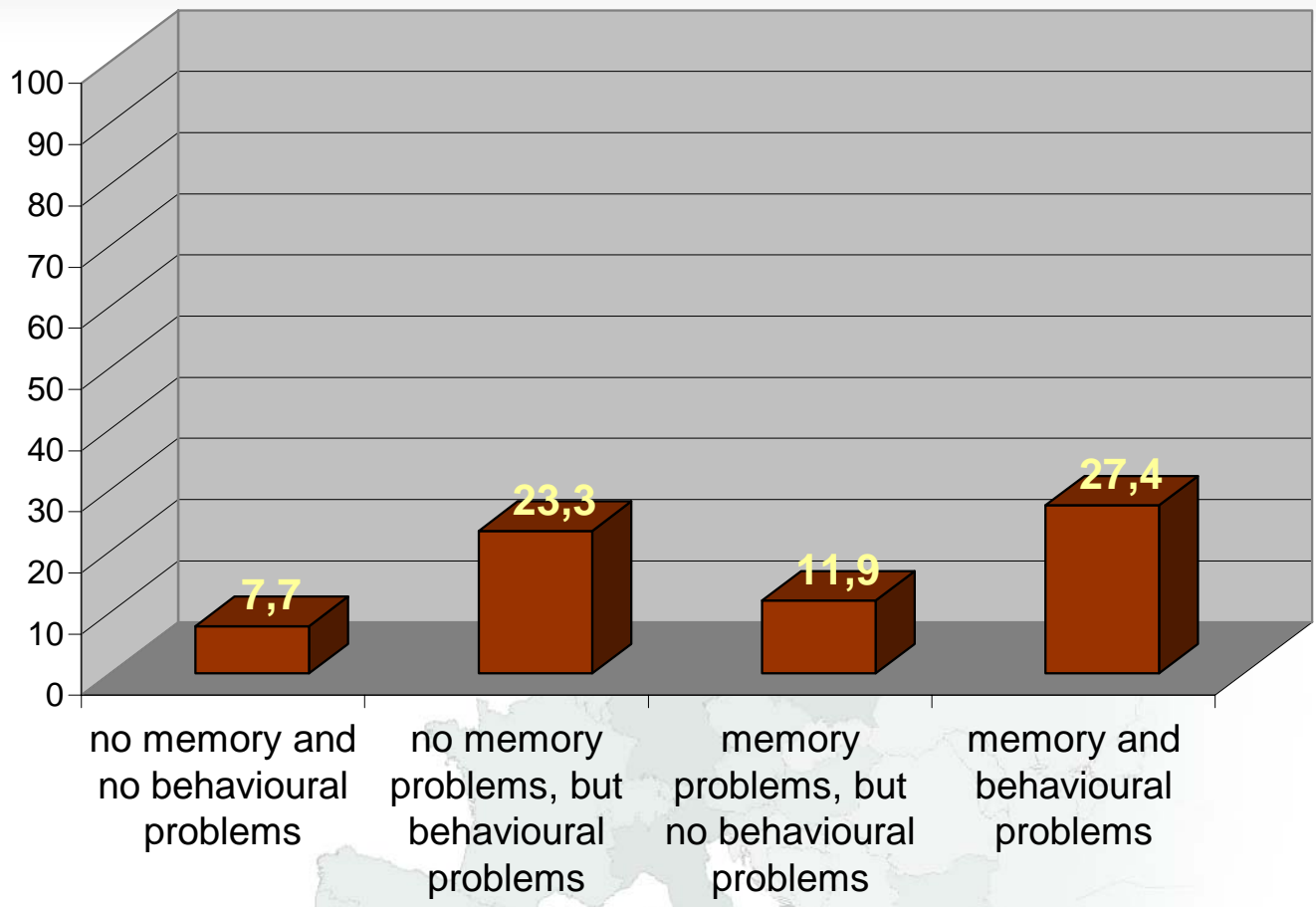
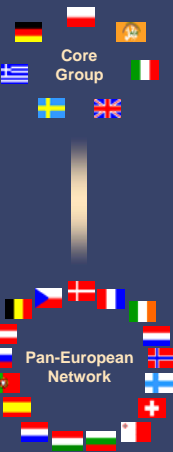




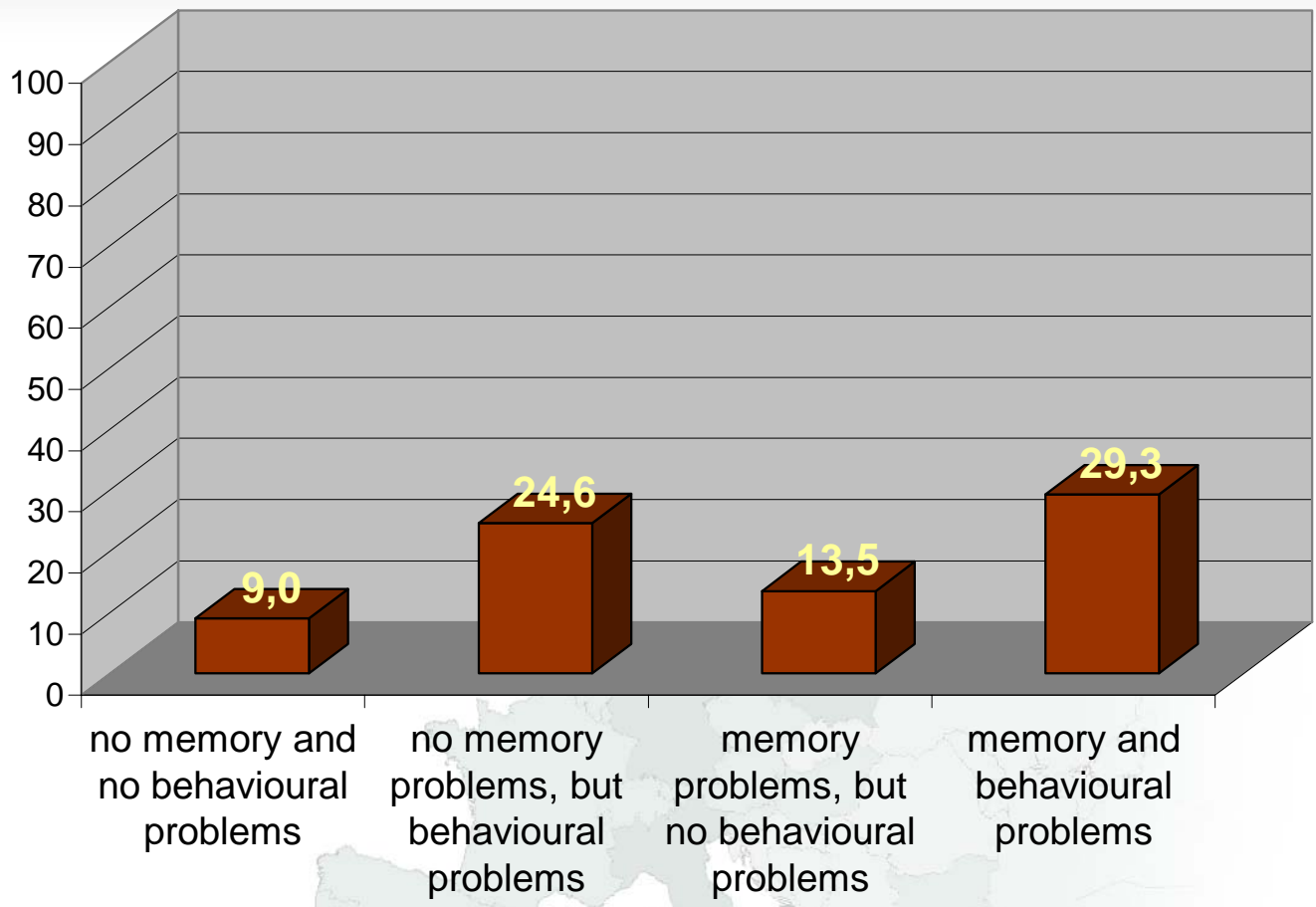
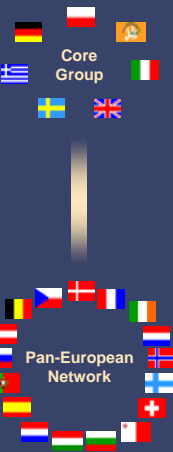
■ quality of life dichotomized: better quality of life in %



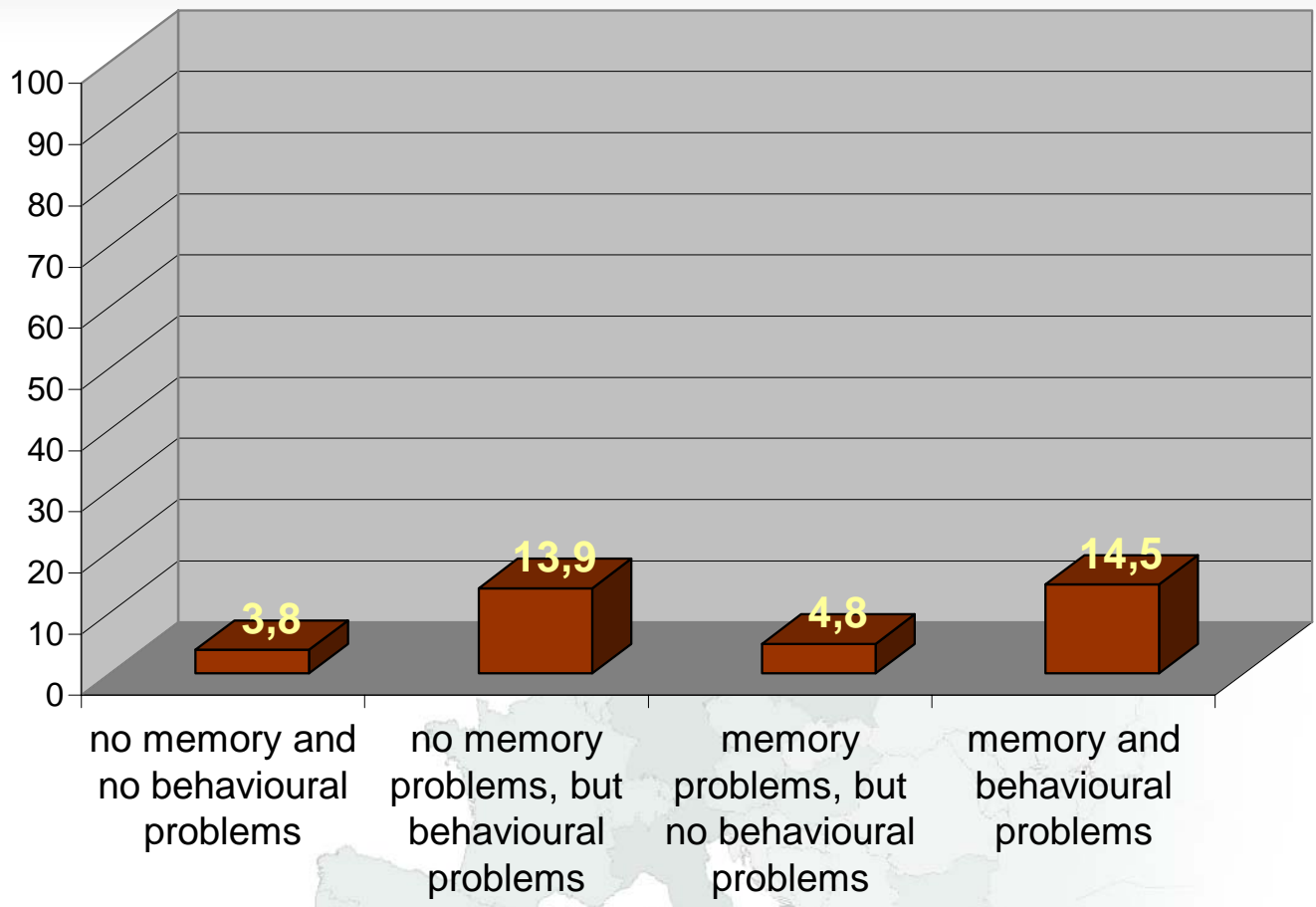
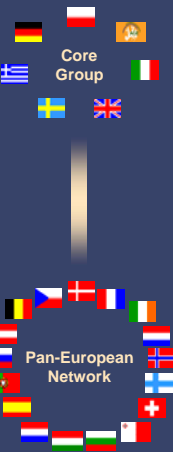
■ Do you find caregiving too demanding?  
(always/often in %)



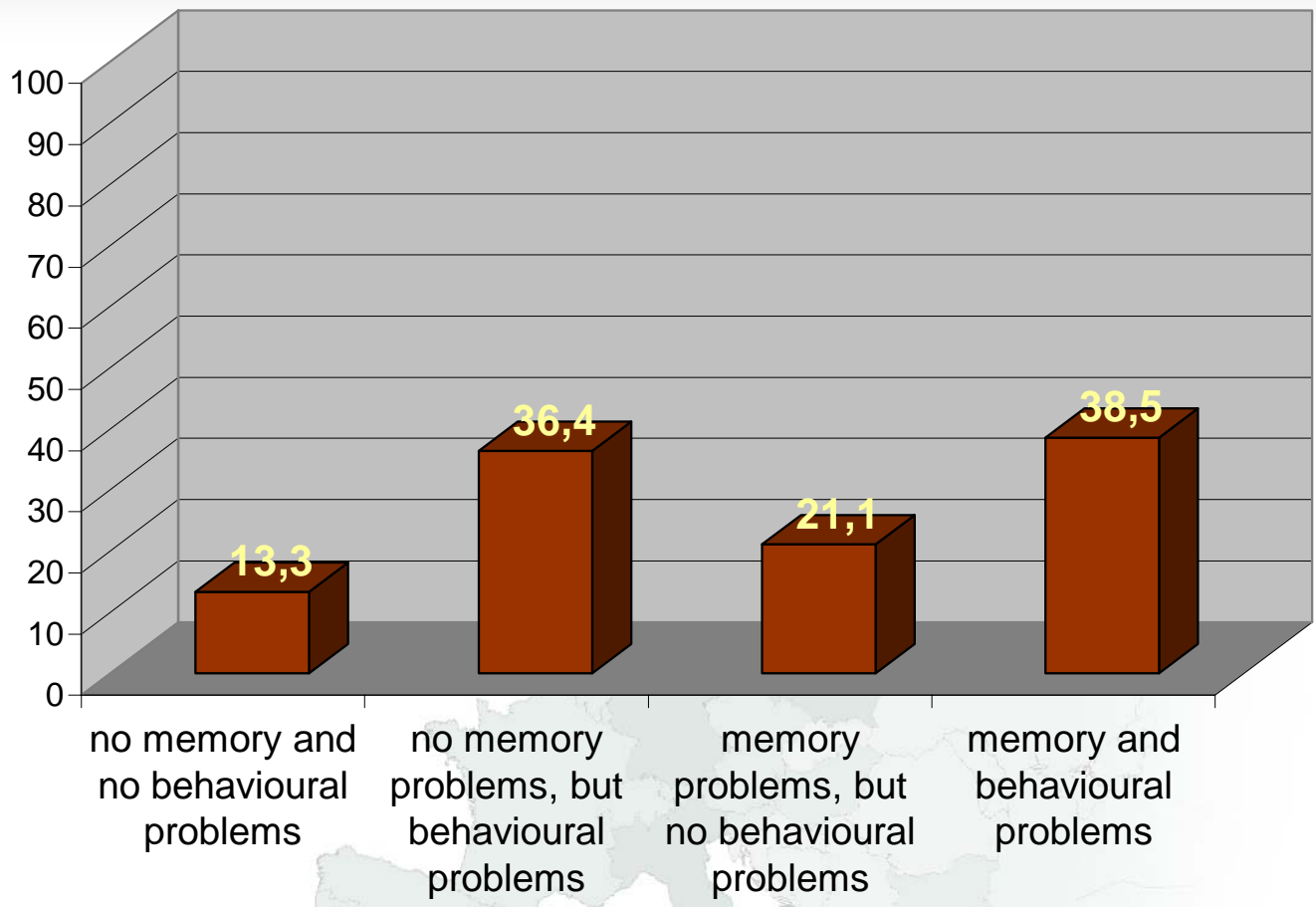
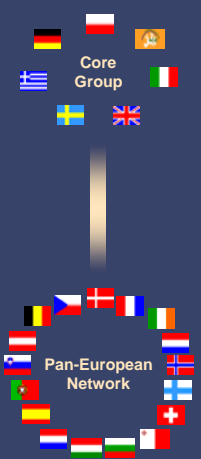
■ Does caregiving cause difficulties in your relationships with friends? (always/often in %)



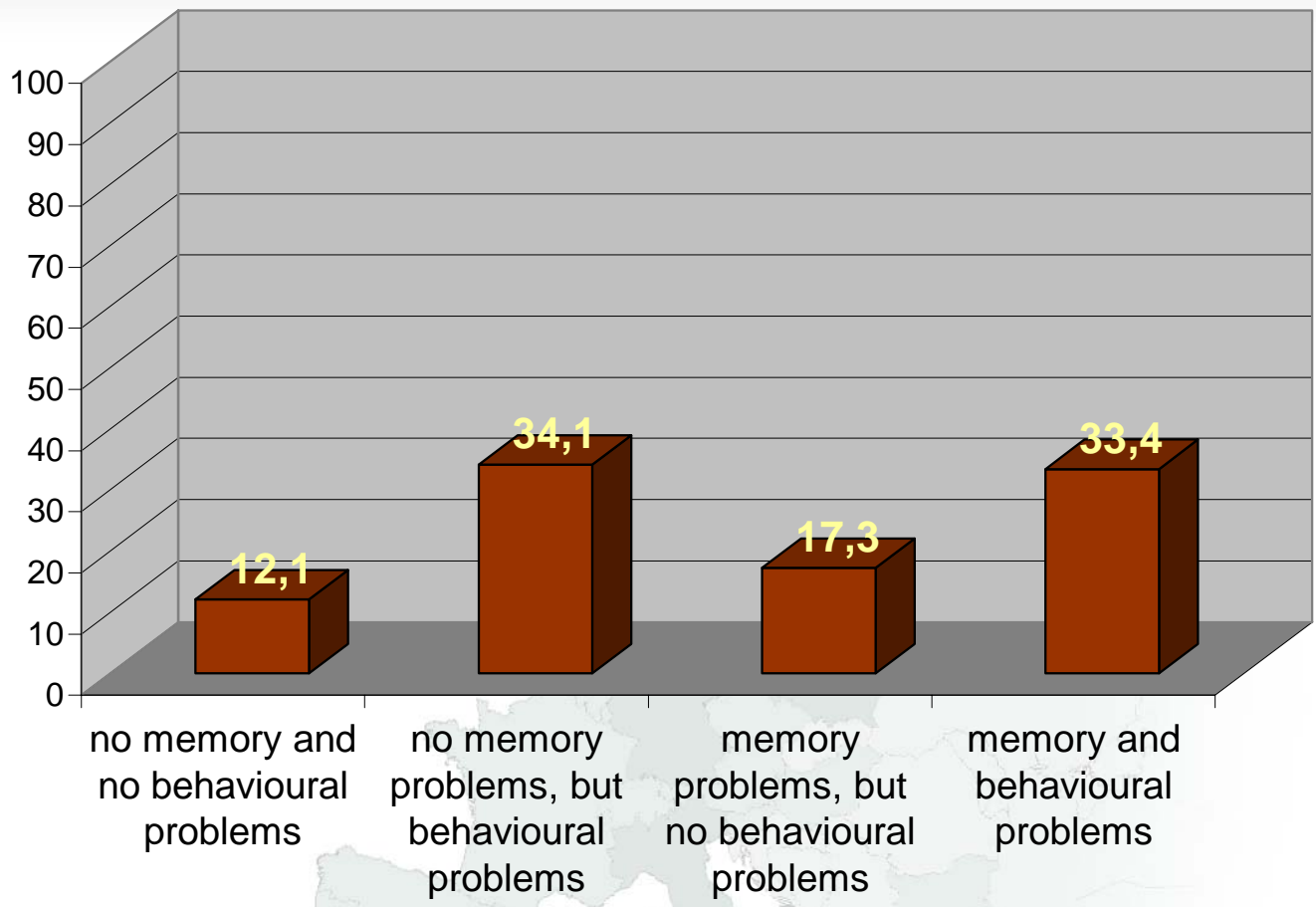
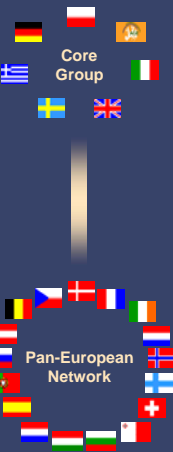
■ Does caregiving have a negative effect on your physical health? (always/often in %)



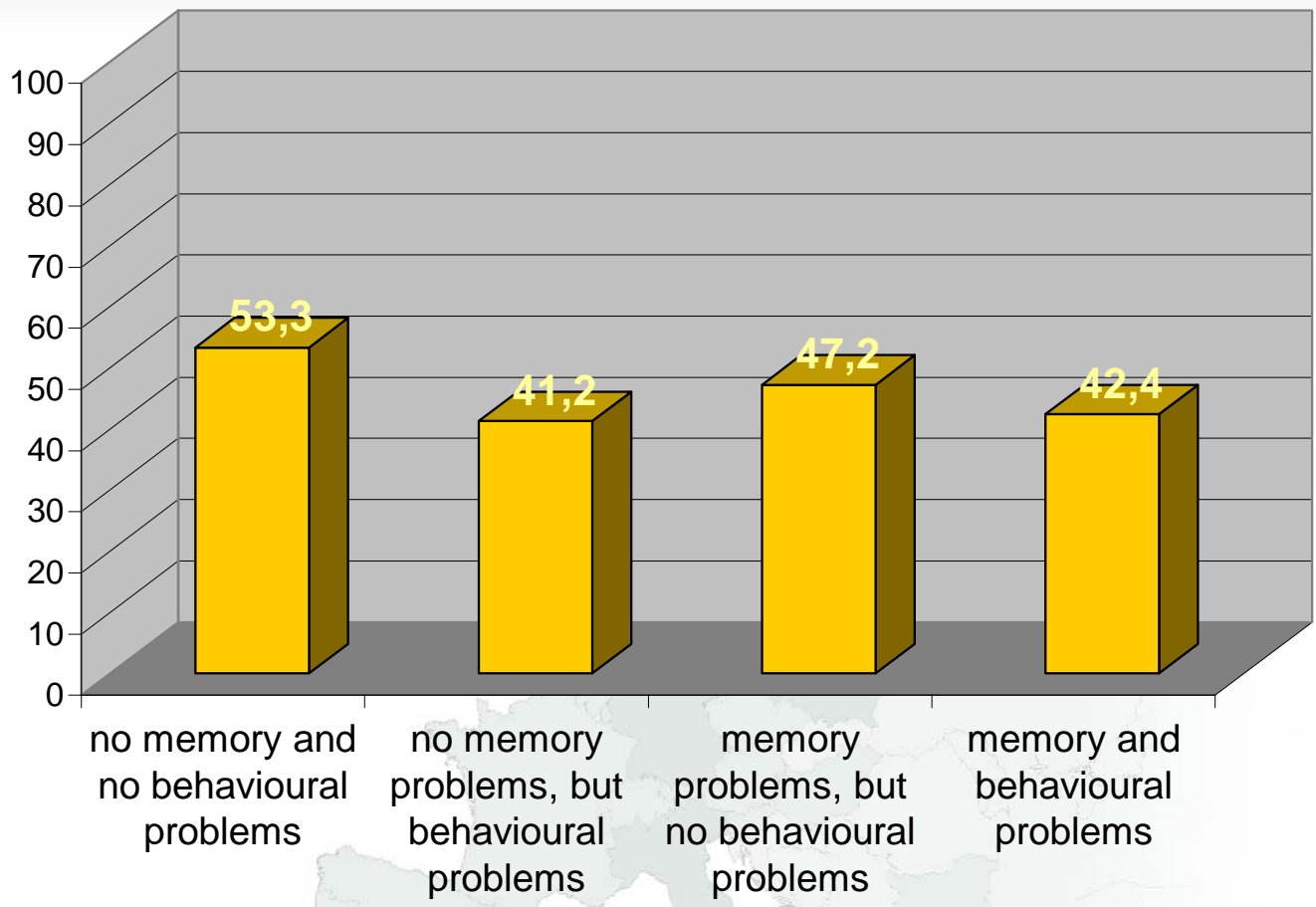
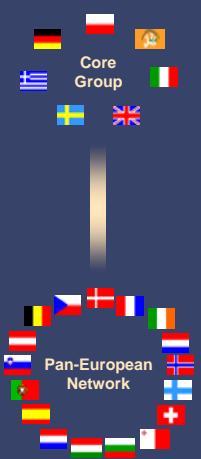
■ Does caregiving cause difficulties in your relationship with your family? (always/often in %)



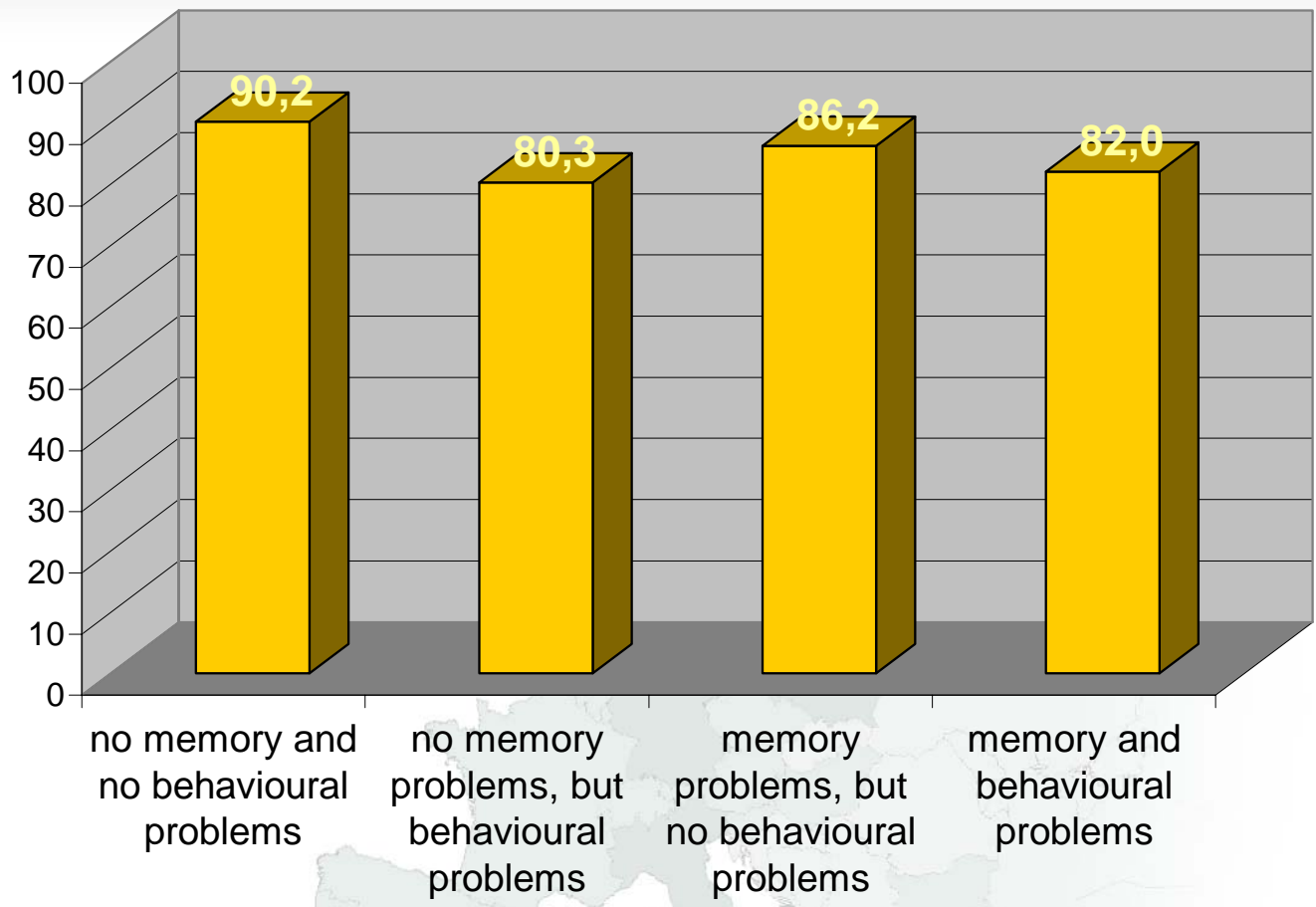
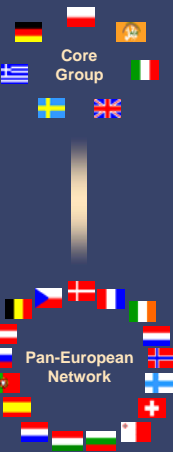
■ Do you feel trapped in your role as caregiver?  
(always/often in %)



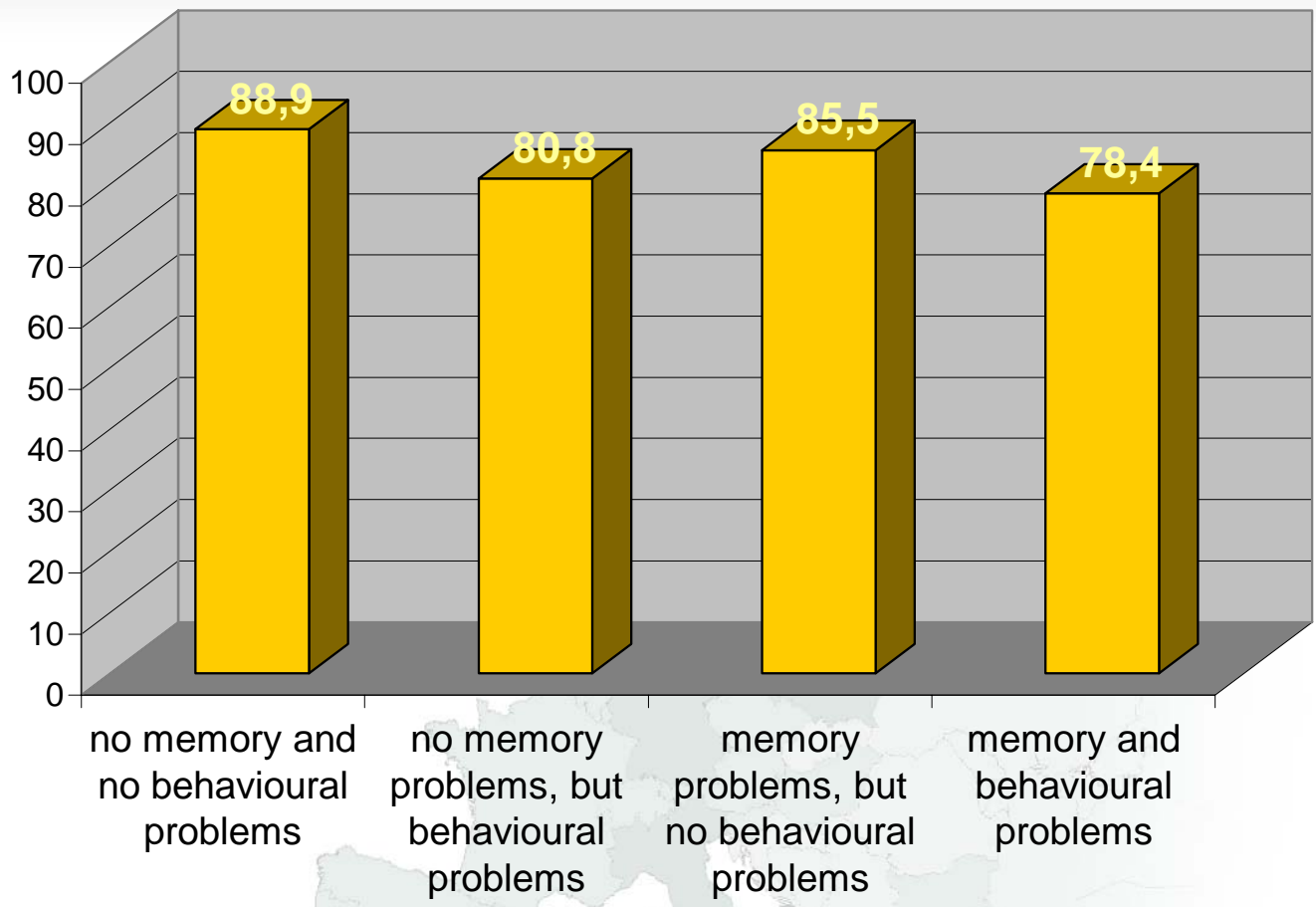
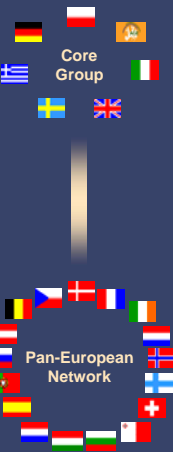
■ Does caregiving have a negative effect on your emotional well-being? (always/often in %)



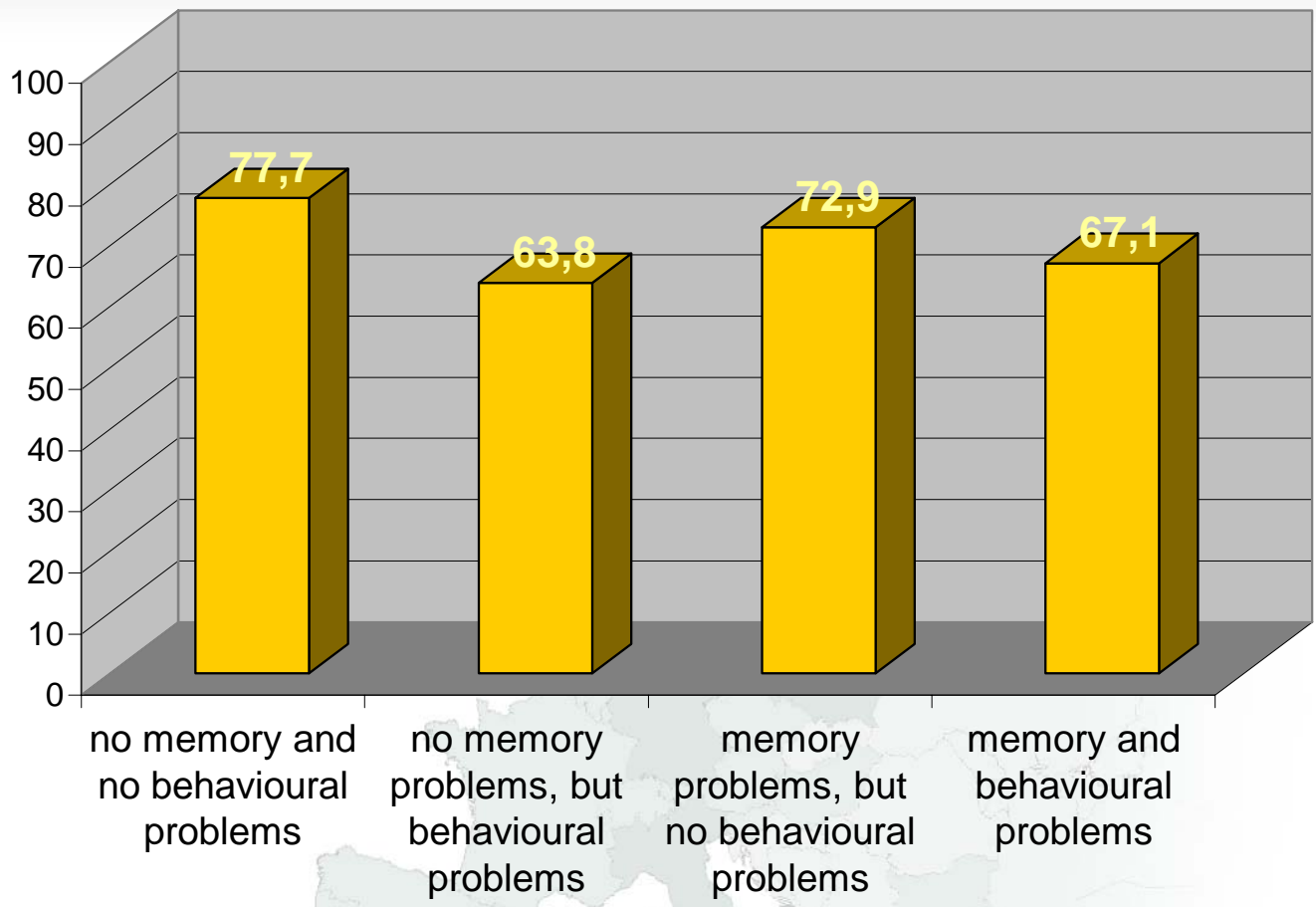
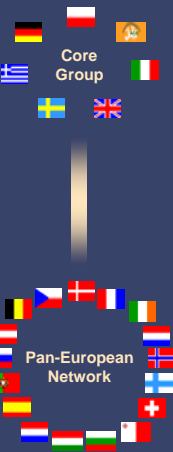
■ Do you feel well supported by friends/neighbors?  
(always/often in %)



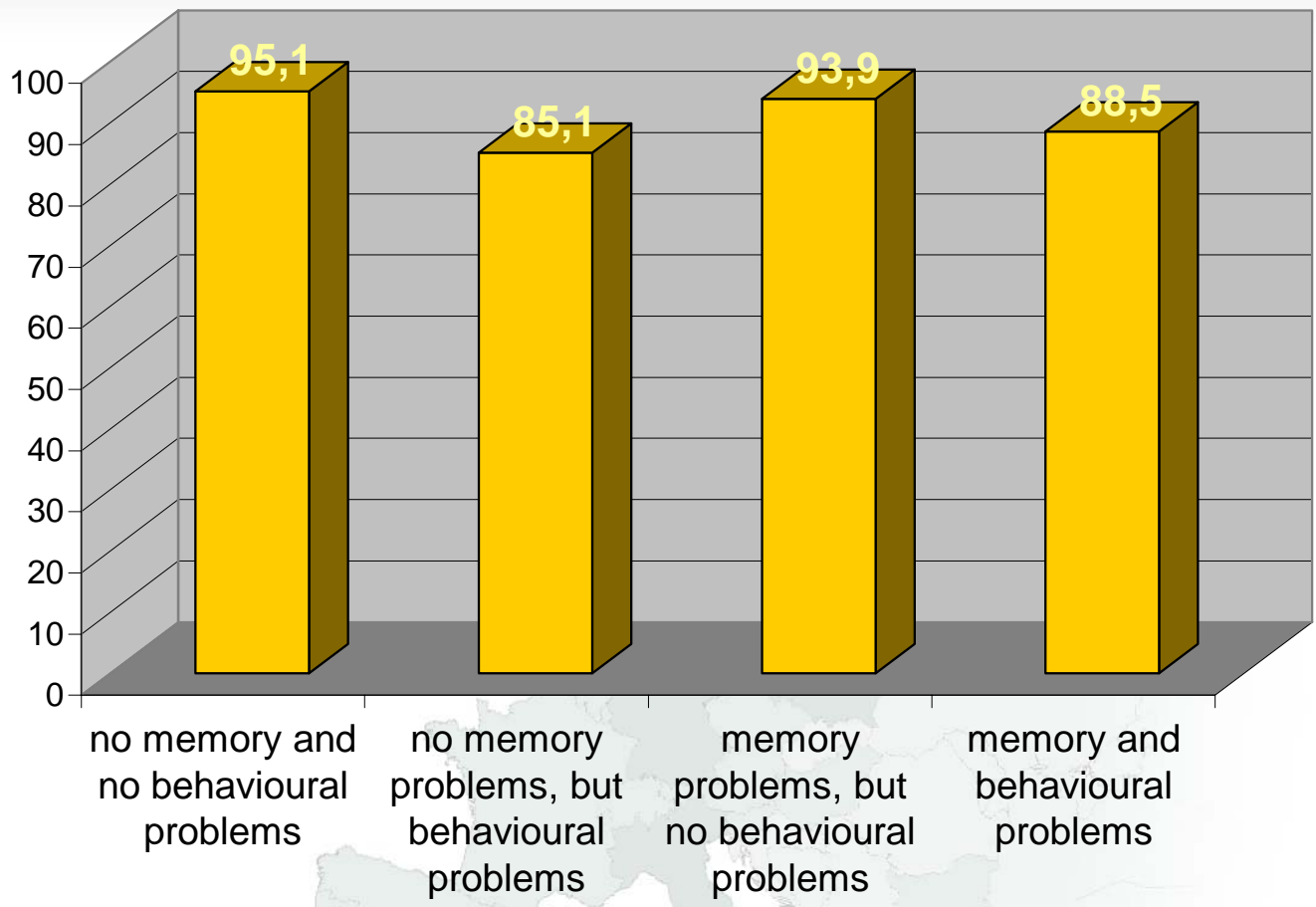
■ Do you feel you cope well as a caregiver?  
(always/often in %)



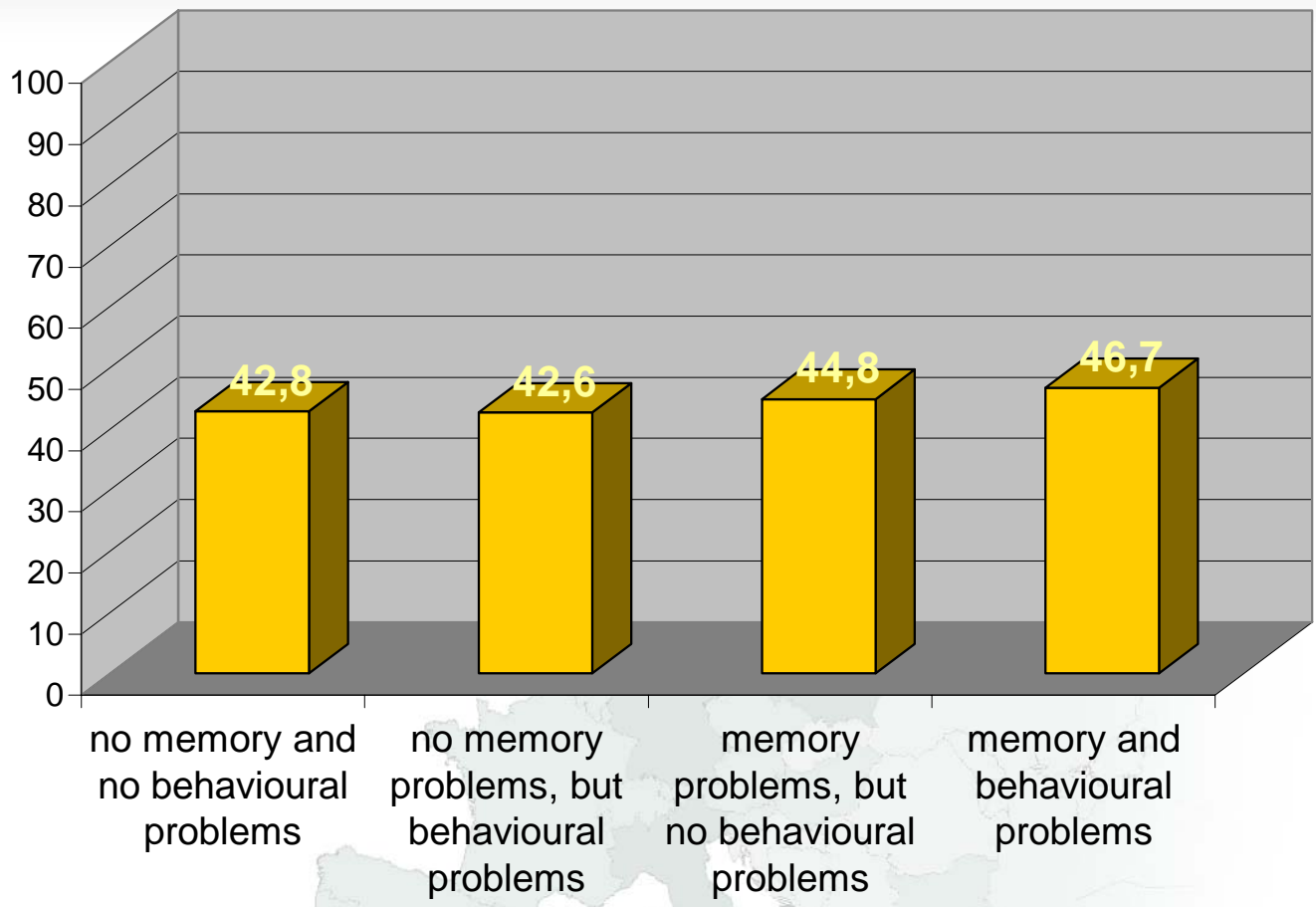
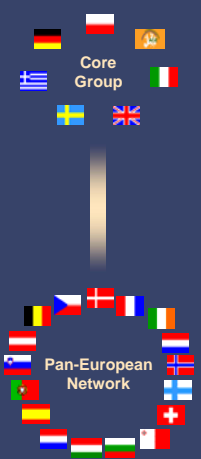
■ Do you find caregiving worthwhile?  
(always/often in %)



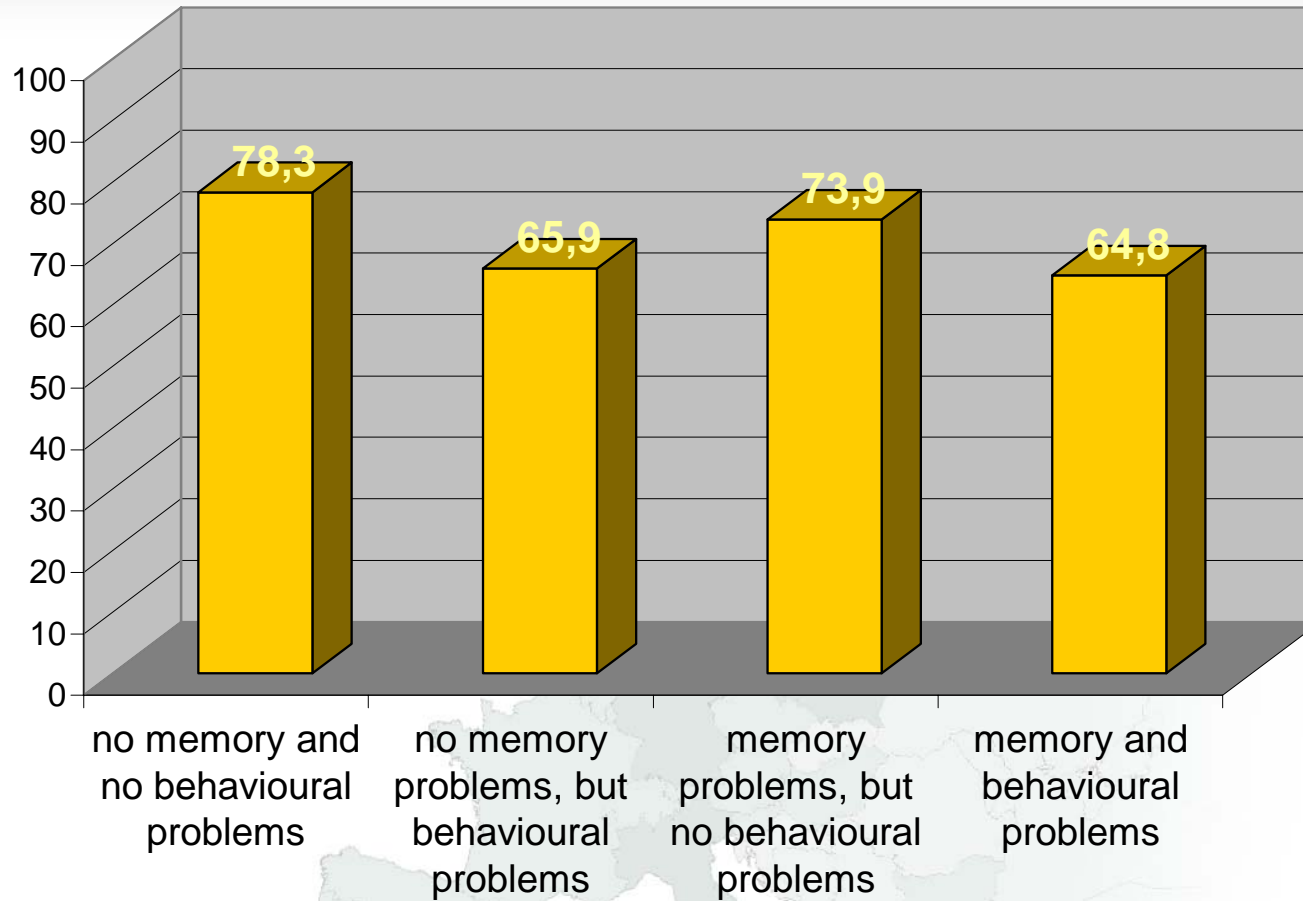
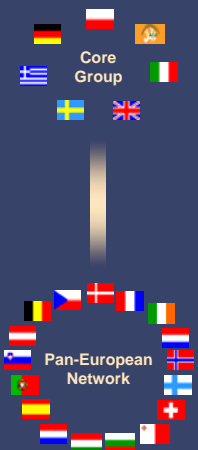
■ Do you feel well supported by your family?  
(always/often in %)



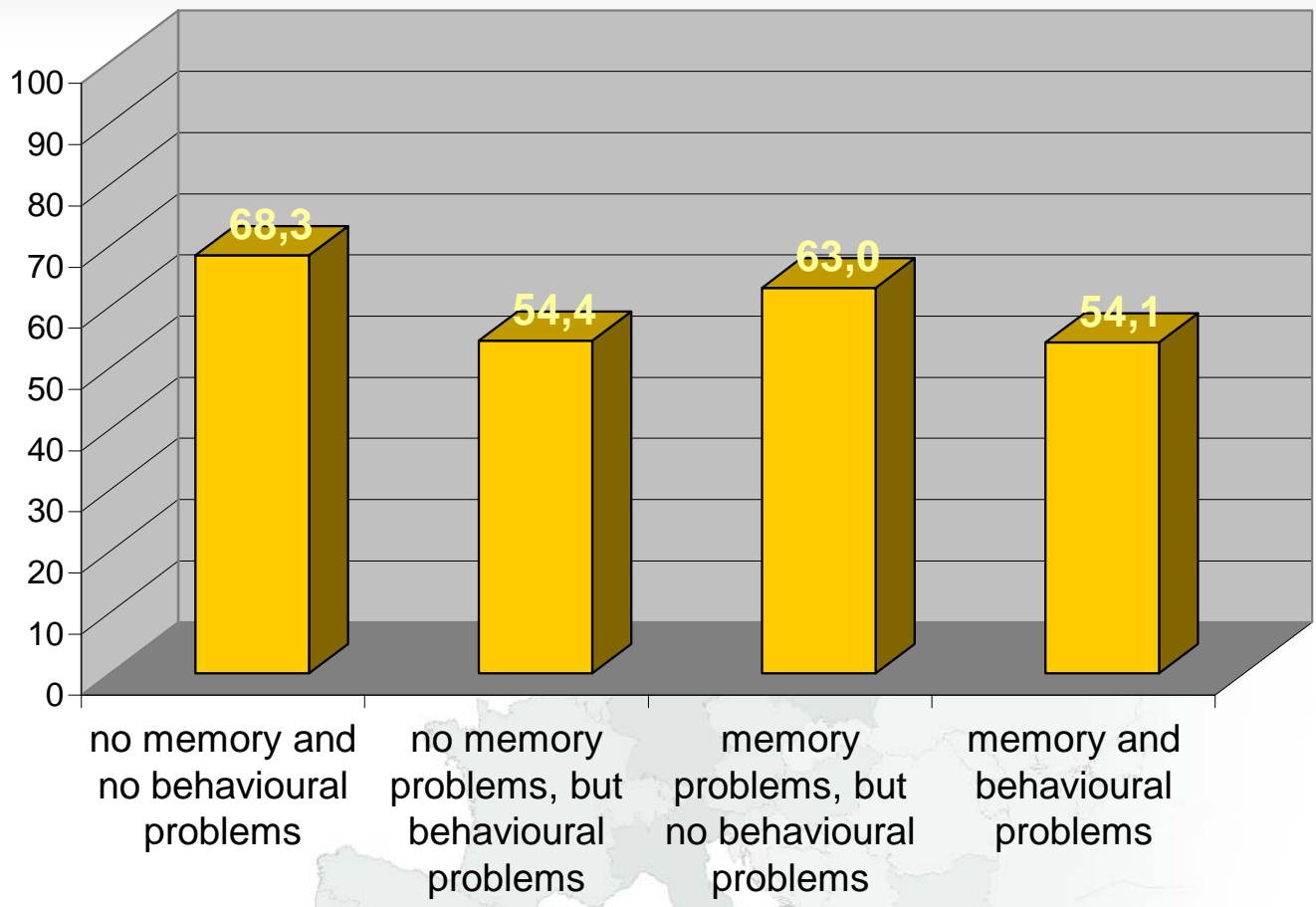
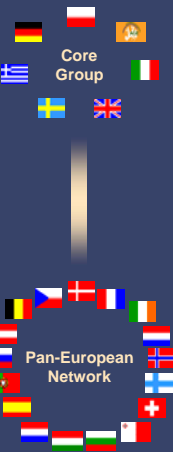
■ Do you have a good relationship with elder?  
(always/often in %)



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

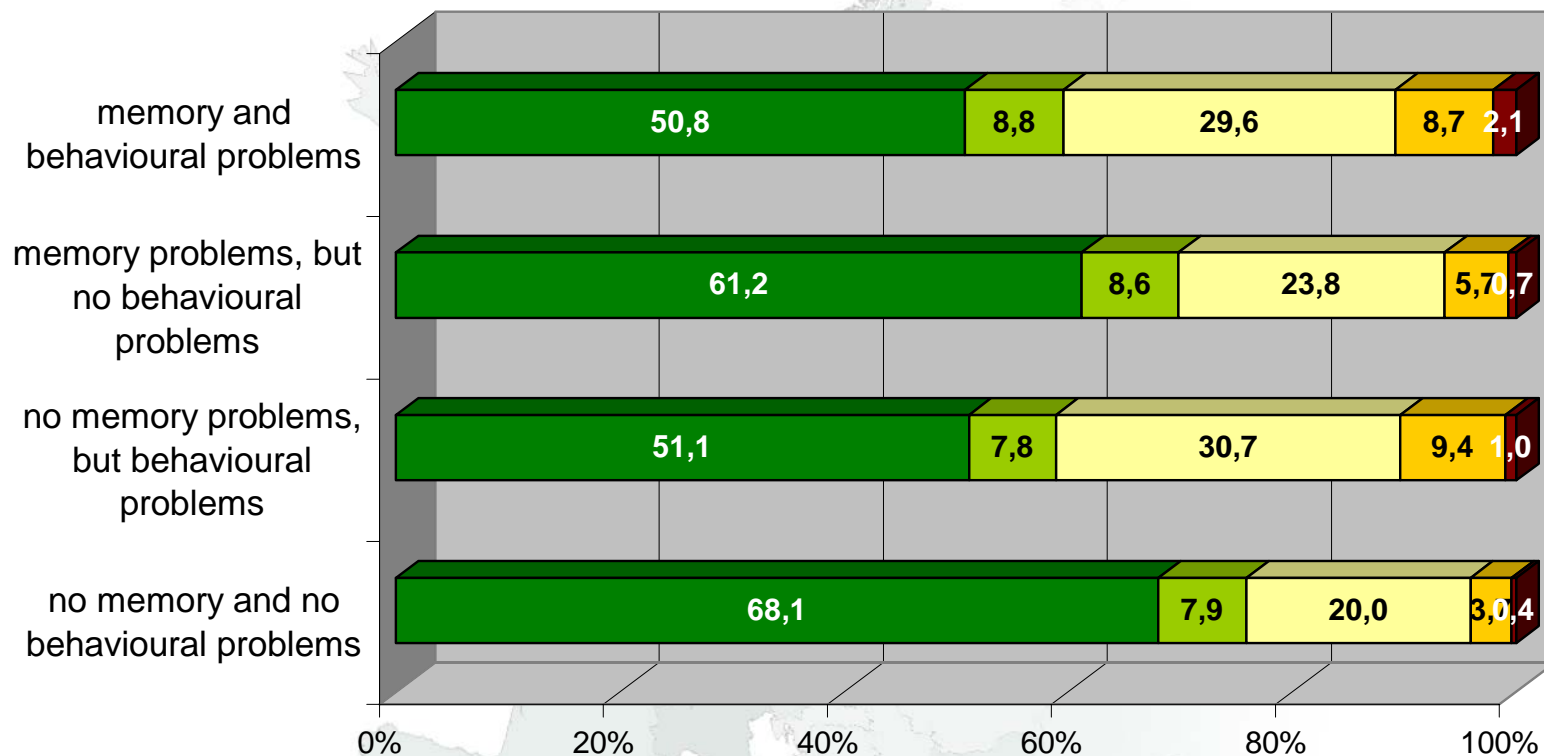


■ Do you feel that anyone appreciates you as a caregiver?  
(always/often in %)



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

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

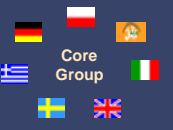
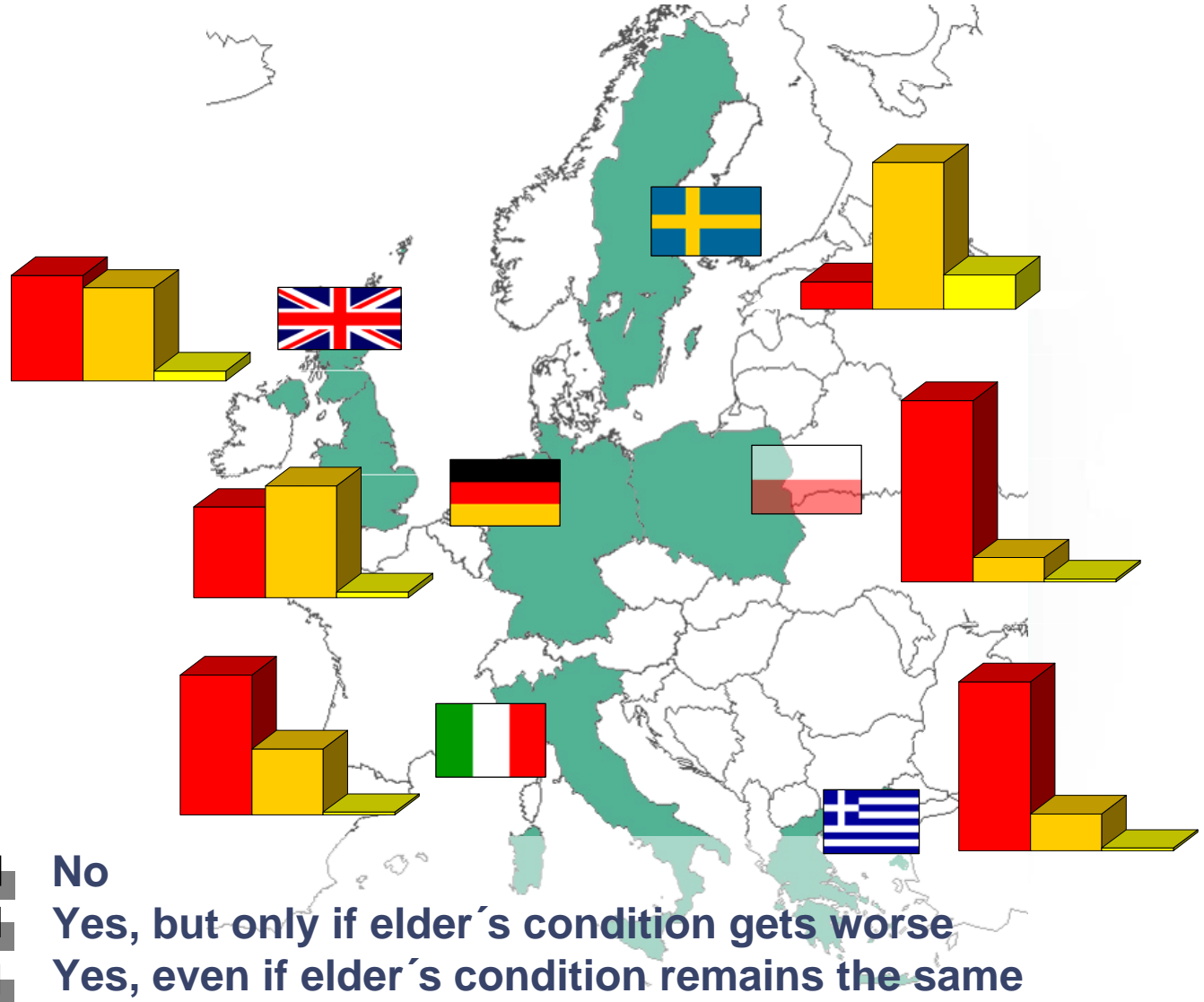


- yes, and I would even increase
- yes, and I would increase for a limited time
- yes, if the situation remains the same
- yes, but only with more support
- no, no matter what extra support I receive



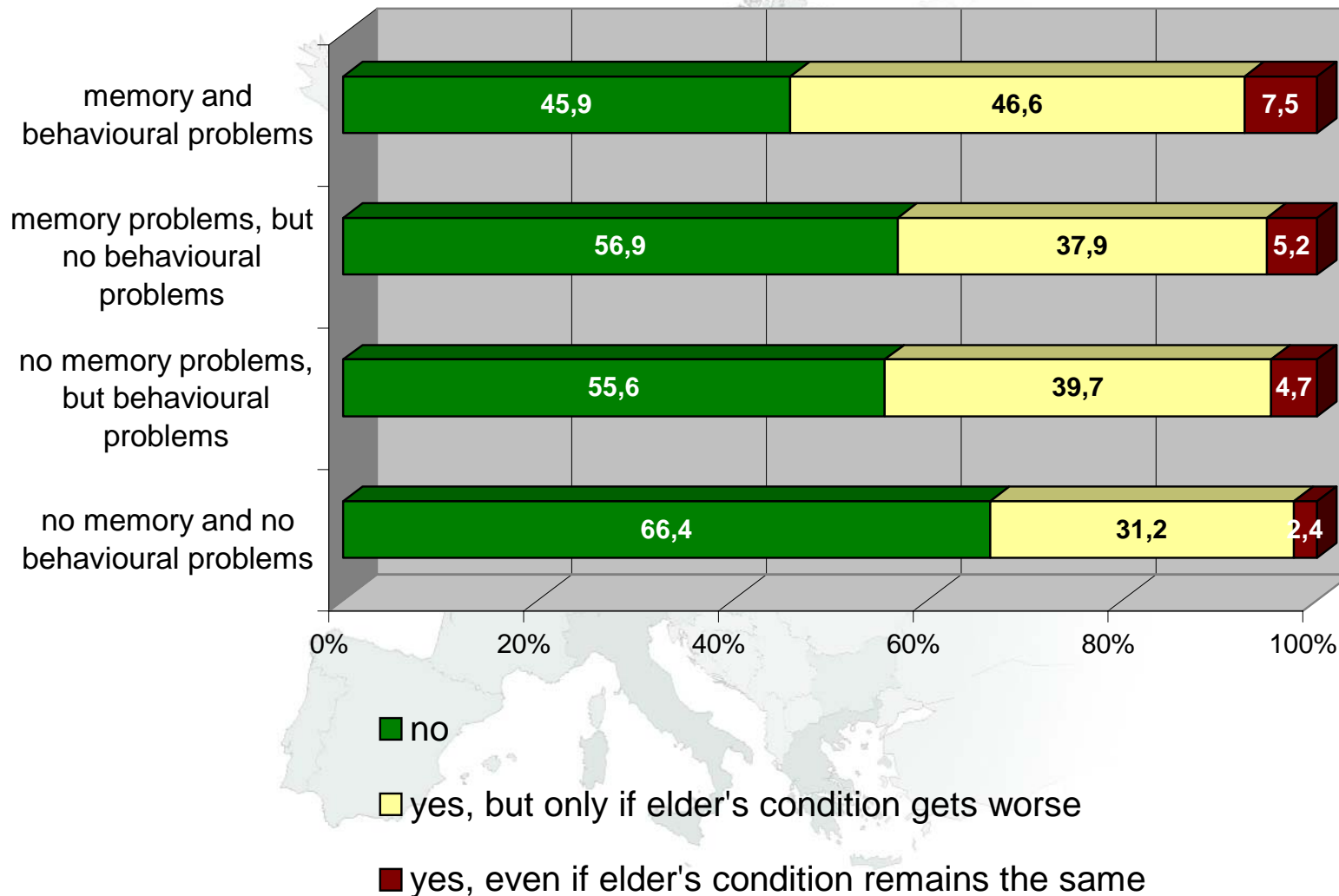


# Would you be prepared to consider elder's placement in a care home?





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



# Conclusions

**What do you think?**

**What do you suggest?**





**Findings of further analysis  
will be presented at the  
Final Conference of EUROFAMCARE  
on 18<sup>th</sup> November 2005 in Hamburg.**

**Thank you for your attention!**

**EUROFAMCARE website:**  
[www.uke.uni-hamburg.de/eurofamcare](http://www.uke.uni-hamburg.de/eurofamcare)