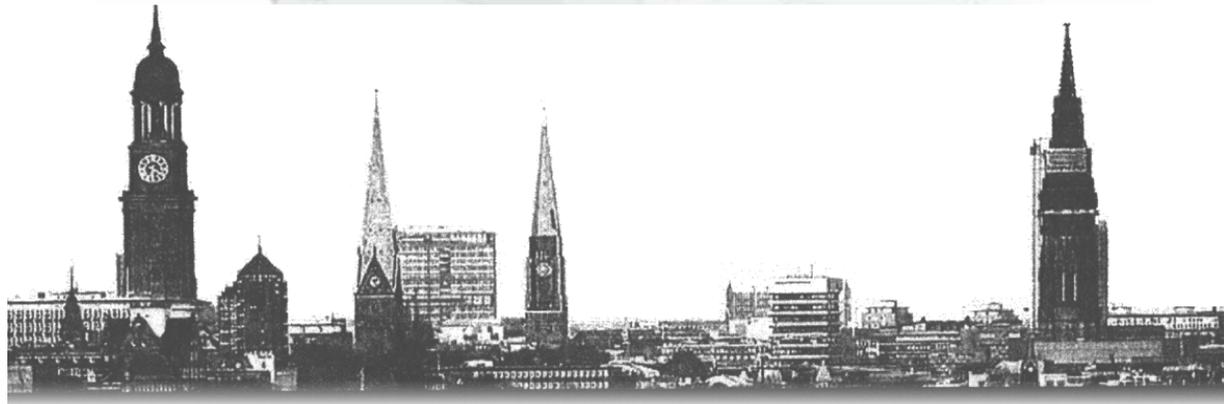# Welcome to Hamburg!

EUROFAMCARE Final Conference
Hamburg 18th of November 2005

Family Care of Older People in Europe

Core
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Network

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

Services for Supporting Family Carers of Elderly People in Europe:
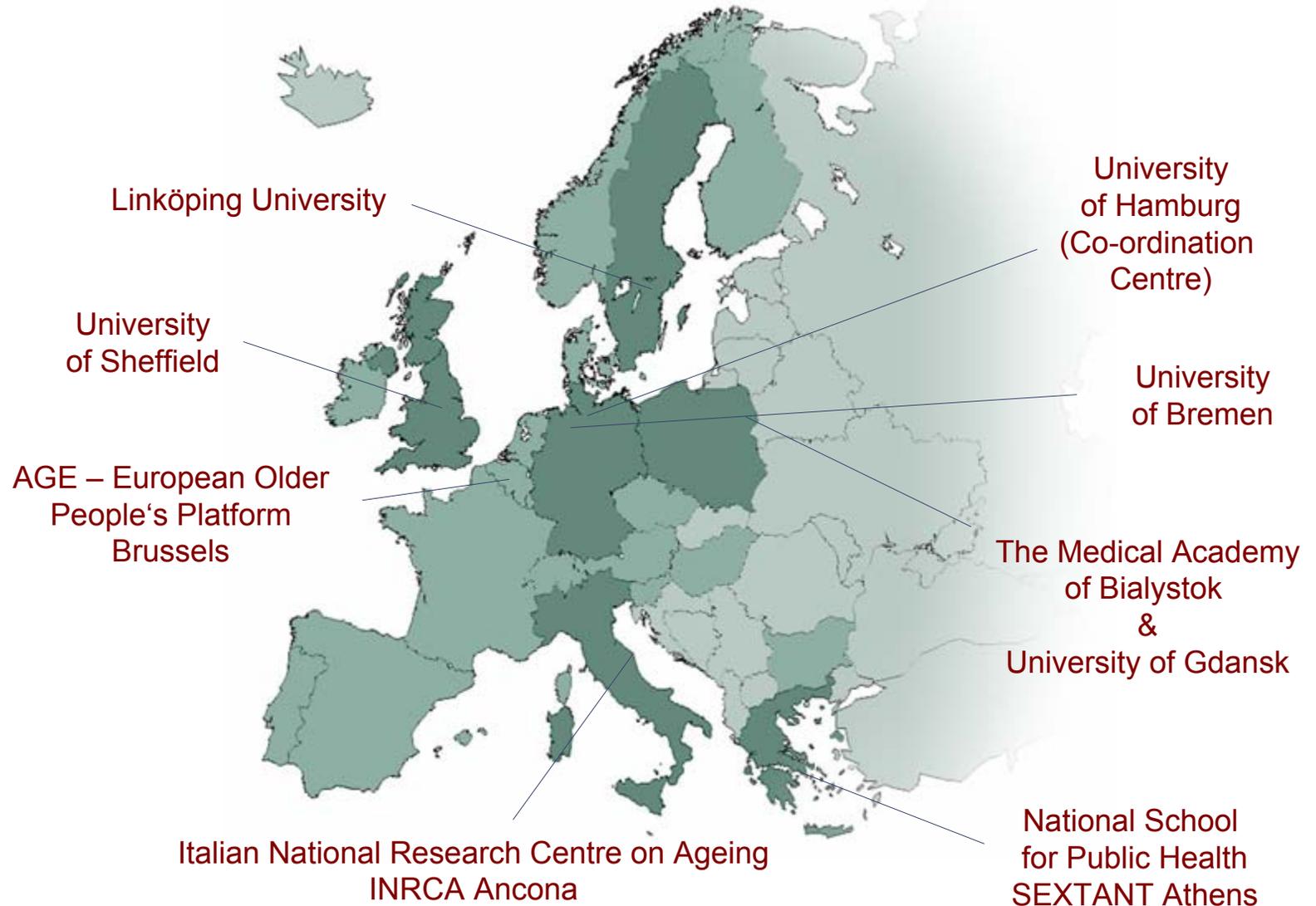
Characteristics, Coverage and Usage

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EUR❤FAMCARE

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

E U R ◉ F A M C A R E

Consortium

National
Advisory
Groups

Core
Group

Pan-European
Network

International
Advisory
Board

Linköping University

University
of Hamburg
(Co-ordination
Centre)

University
of Sheffield

University
of Bremen

AGE – European Older
People's Platform
Brussels

The Medical Academy
of Bialystok
&
University of Gdansk

Italian National Research Centre on Ageing
INRCA Ancona

National School
for Public Health
SEXTANT Athens

Patterns of change in caregiving situations over one year

Preliminary results of the EUROFAMCARE Follow-up Study

Barbara Bień, Heinz Rothgang, Bozena Sielawa, Mikolaj Rybaczuk, Roland Becker

Background

- Family caregiving for the dependent older people is not fixed in time, but changes along with the situation of the person cared-for, the family carer, as well as the supportive framework available at any time;

- The longitudinal design of the study reveals the complex dynamics of change in terms of

  (1) objective stressors of caring,

  (2) subjective outcomes in carers,

  (3) causally consecutive interdependency between them (predictors), as well as

  (4) recognition of interdependency between the costs and effects of the supportive network

Contents of the presentation

Discontinuity of care over one year:

- What were the reasons for withdrawal from caring over one year?

- What was the mortality in the sample of cared-for people?

- What were the possible predictors and outcomes for stopping care amongst family caregivers?

Continuity of care over one year:

- What were the changes in caring intensity and in living arrangements?

- What were the changes in the Older Persons' physical conditions and cognitive status?

- Were there changes in caring outcomes for family caregivers?

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Design of the Follow-up Study

Characteristics in time T1

Characteristics in time T2

Migration between groups from T1 to T2

Better or the same

Worse

versus

Better

Worse

The same

The BASELINE Study T1

FOLLOW-UP Study T2

What are the changes in the chosen characteristics?

What are the predictors of changes?

Measures and Analyses

- The follow-up data have been compared only for those carers that were re-surveyed;

- To reveal changes over time, most of the newly derived outcome measures/variables (T1-T2) were dichotomised (or trichotomised) into two (three) modalities, those situations which:

  - improved (maintained) versus

  - worsened (within the characteristics measured)

- To have more holistic and aggregated measure(s) of subjective outcomes of care & QoL in carers, one new variable has been created, by clustering data.
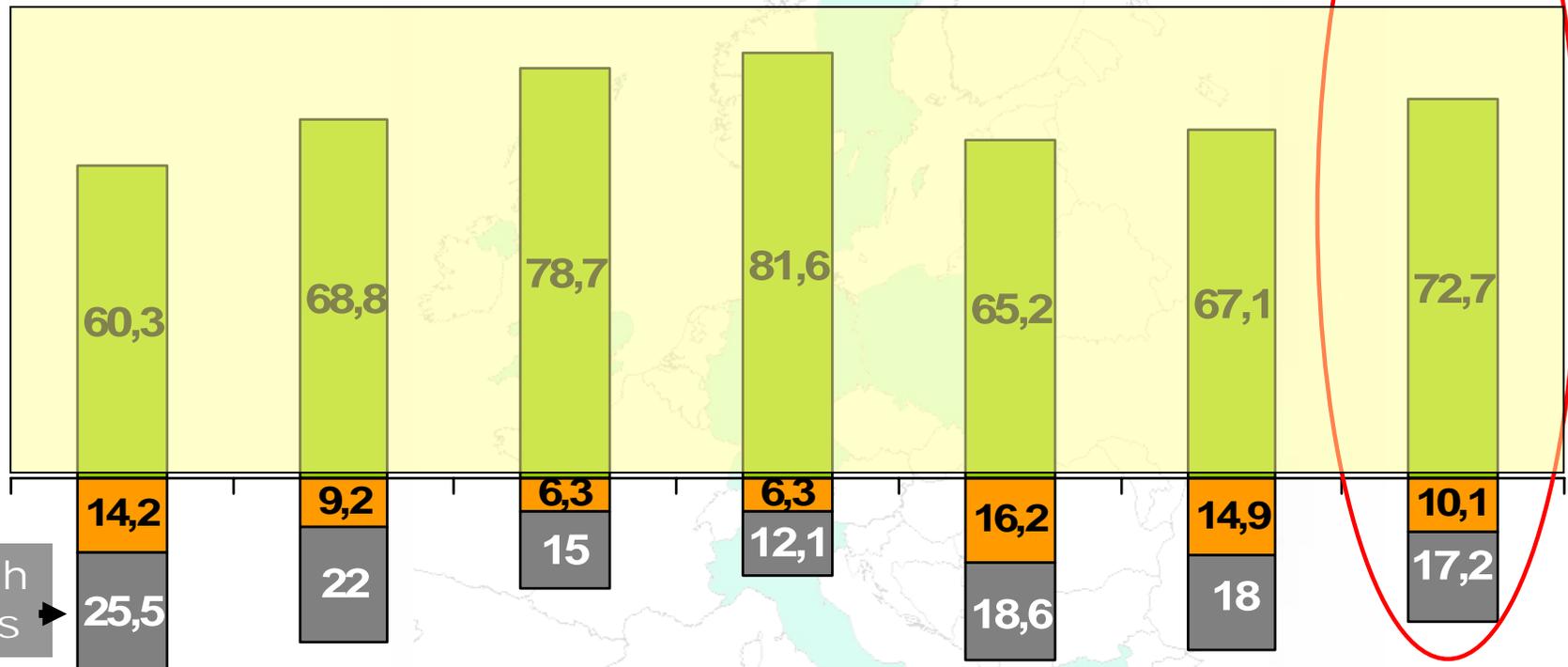
Multidimensional measure of the outcomes of care

- Three clusters of carers with different levels of **"OVERALL QoL"** [Higher; Intermediate & Lower], based on:

    (1) self-perceived carer's health;

    (2) 5-item QoL;

    (3) QoL in the last two weeks ;

    Clustering was done for carers re-surveyed, i.e. **"Ex-carers"** & **"Still caring"**

    [Total no = 3326; missing 36]

Transition of the T1 sample into T2 sample

	DE	EL	IT	PL	SE	UK	Total
Size of T1 sample	1003	1014	990	1000	921	995	5923
No of dropped cases	552	732	127	125	346	679	2561
Size of T2 sample	**451**	**282**	**863**	**875**	**575**	**316**	**3362**
% of re-surveyed	**44,9**	**27,8**	**87,2**	**87,5**	**66,4**	**31,8**	**56,8**
With short questionnaire	179 40%	88 31%	184 21%	161 18%	200 35%	102 32%	**914** 27%
With long questionnaire	272 60%	194 69%	679 79%	714 82%	375 65%	214 68%	**2448** 73%

"Continuity" vs. "Discontinuity" in caregiving
[in % of all re-surveyed cases after a year]

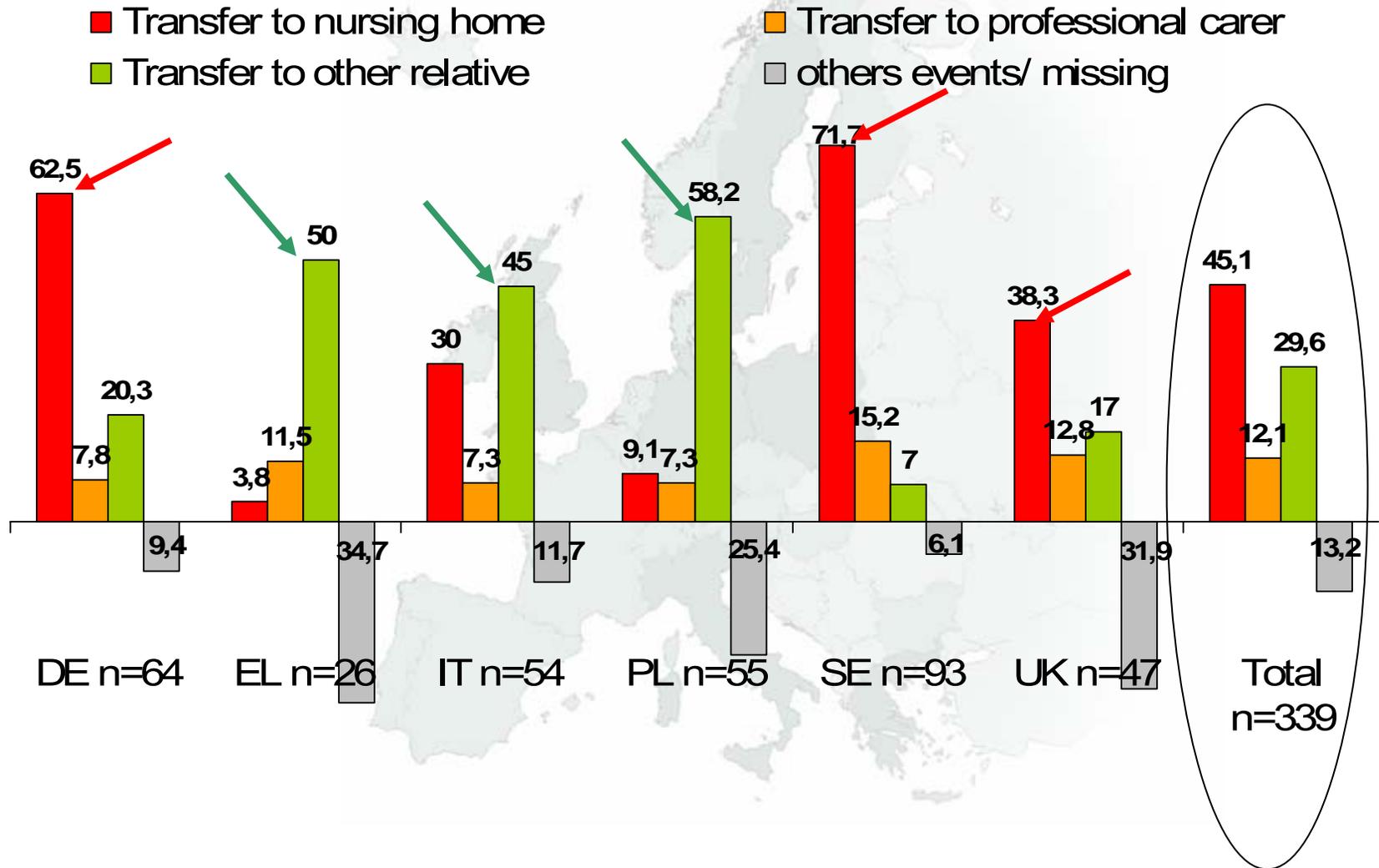|	DE n=451	EL n=282	IT n=863	PL n=875	SE n=575	UK n=316	Total n=3362
YES, I'm still caring	60,3	68,8	78,7	81,6	65,2	67,1	72,7
NO, but Older Person living	14,2	9,2	6,3	6,3	16,2	14,9	10,1
NO, Older Person died (Death rates)	25,5	22	15	12,1	18,6	18	17,2

■ YES, I'm still caring   ■ NO, but Older Person living
■ NO, Older Person died

Reasons for withdrawal from caring for OP [in%]
(besides of OP's death)

Legend:
- Transfer to nursing home (red)
- Transfer to other relative (green)
- Transfer to professional carer (orange)
- others events/ missing (grey)

DE n=64: 62,5 / 7,8 / 20,3 / 9,4
EL n=26: 3,8 / 11,5 / 50 / 34,7
IT n=54: 30 / 7,3 / 45 / 11,7
PL n=55: 9,1 / 7,3 / 58,2 / 25,4
SE n=93: 71,7 / 15,2 / 7 / 6,1
UK n=47: 38,3 / 12,8 / 17 / 31,9
Total n=339: 45,1 / 12,1 / 29,6 / 13,2

Chosen predictors of withdrawal from care
[ALL REASONS - tested in total sample within 78 variables]

DEPENDING on Older Person

- Advanced old age (80+) of cared-for person***
- Female gender of the cared-for*
- Living alone***
- Completely relying on others to meet
  - Health needs***;
  - Physical/Personal***;
  - Mobility***;
  - Emotional***;
  - Domestic***;
  - Financial management***;
  - Financial support***;
  - Organising/managing care***, and
- More severe physical dependency in elder***
- Cognitive disorders in elder***

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Chosen predictors of withdrawal from care
[ALL REASONS - tested in total sample within 78 variables]

DEPENDING on CARER

- Less religious ***
- Shorter duration of caring (up to two years) ***
- Living apart from elder*** (longer distance)
- Non-workers*
- Lower level of meeting the needs by carer*** [less engaged in caring]
- Tendency to be less willing to continue caring at Time 1***
- Decision to care: *"there was no alternative"*;
- Higher negative impact of care at T1***
- Worse QoL in T1** [but not health];

NOT SIGNIFICANT:

- Carer's gender, Carer's level of education; Carer's income, Locality, Hours of caring; Possibility of having a break in caring; Carer's health

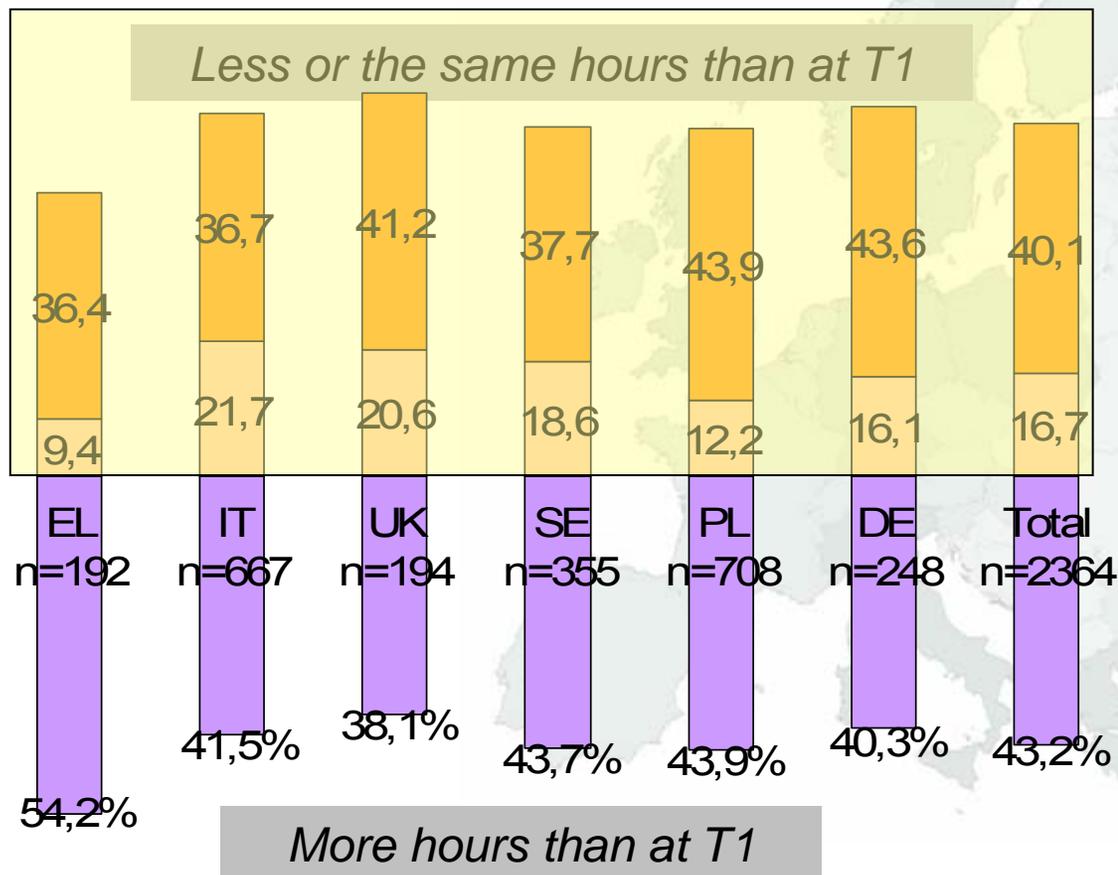# Changes in intensity of care (No of hours/week) for carers still caring between T1 & T2

Total:
T1=49 ±54,9 hours/week; 7 hours/day
T2=47 ±52,2 hours/week; 6,7 hours/day

Total - amongst carers who are caring "*less or the same*":

Time of caring <u>decreased</u> from 66,5 (T1; n=1343) to 42,7 hours/week (T2; n= 1342), i.e by 23,8 hours/week = -3,4 hour/day

Less or the same hours than at T1

|	EL	IT	UK	SE	PL	DE	Total
Upper	36,4	36,7	41,2	37,7	43,9	43,6	40,1
Lower	9,4	21,7	20,6	18,6	12,2	16,1	16,7
n	n=192	n=667	n=194	n=355	n=708	n=248	n=2364
%	54,2%	41,5%	38,1%	43,7%	43,9%	40,3%	43,2%

Total - amongst carers who are caring „*more*":
Time of caring <u>increased</u> from 24,5 (T1; n=1021) to 52,5 hours/week (T2; n=1021), i.e by 28 hours/week = +4 hours/day

More hours than at T1

Transition of carers' employment status between time T1 & T2 (in % of country-sample)
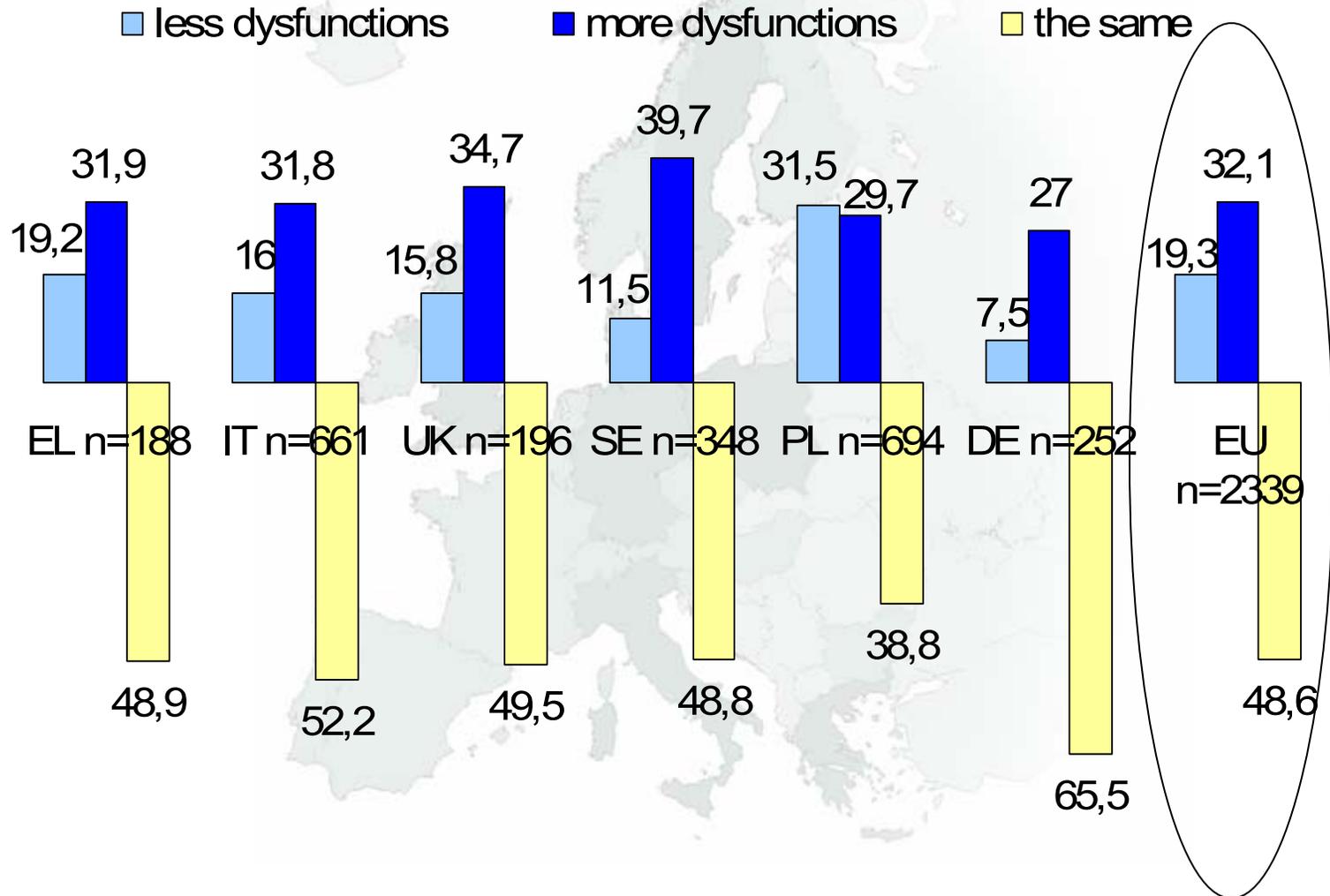

Still not employed
Still employed
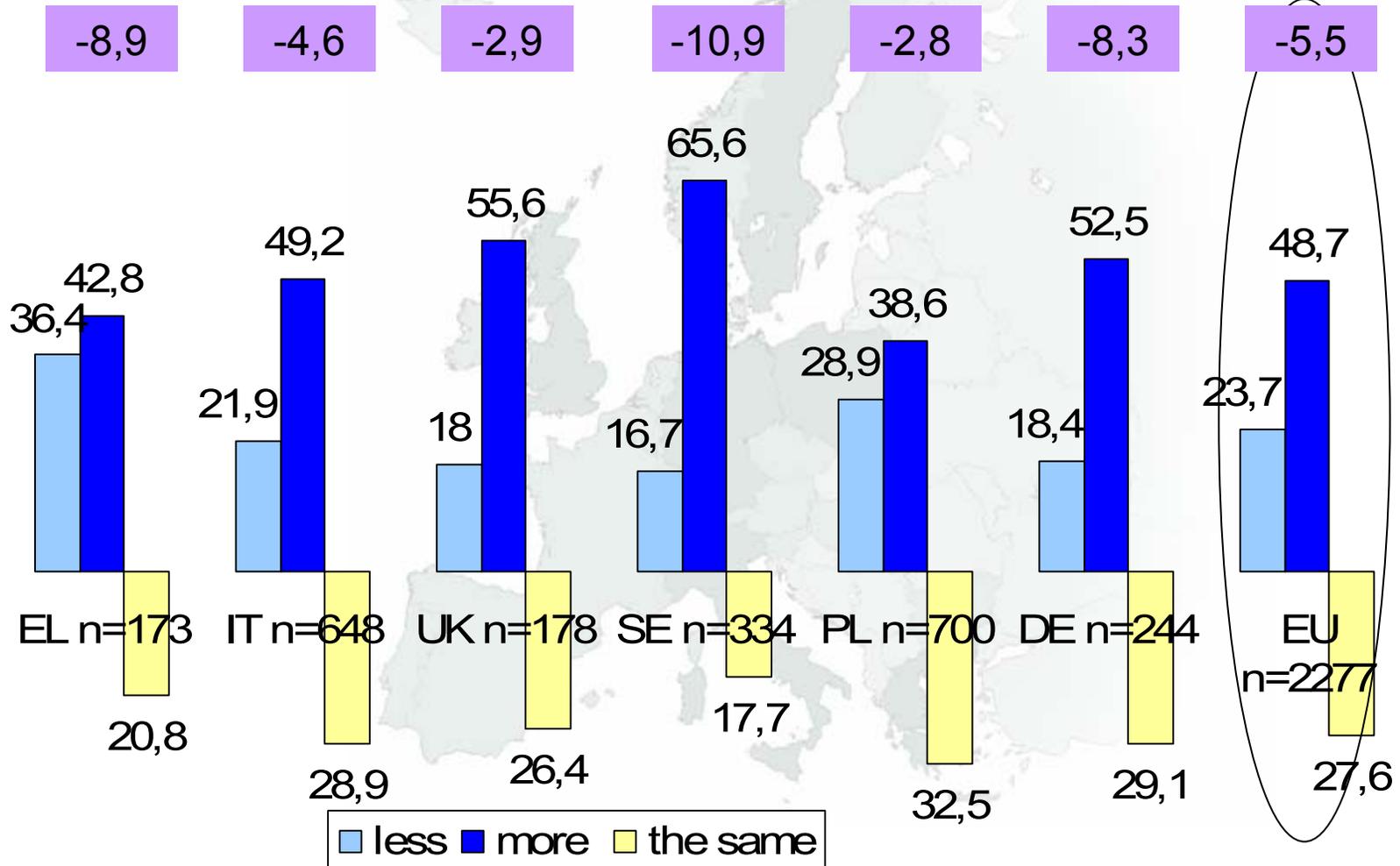**Withdrawn from employment**
Started employment
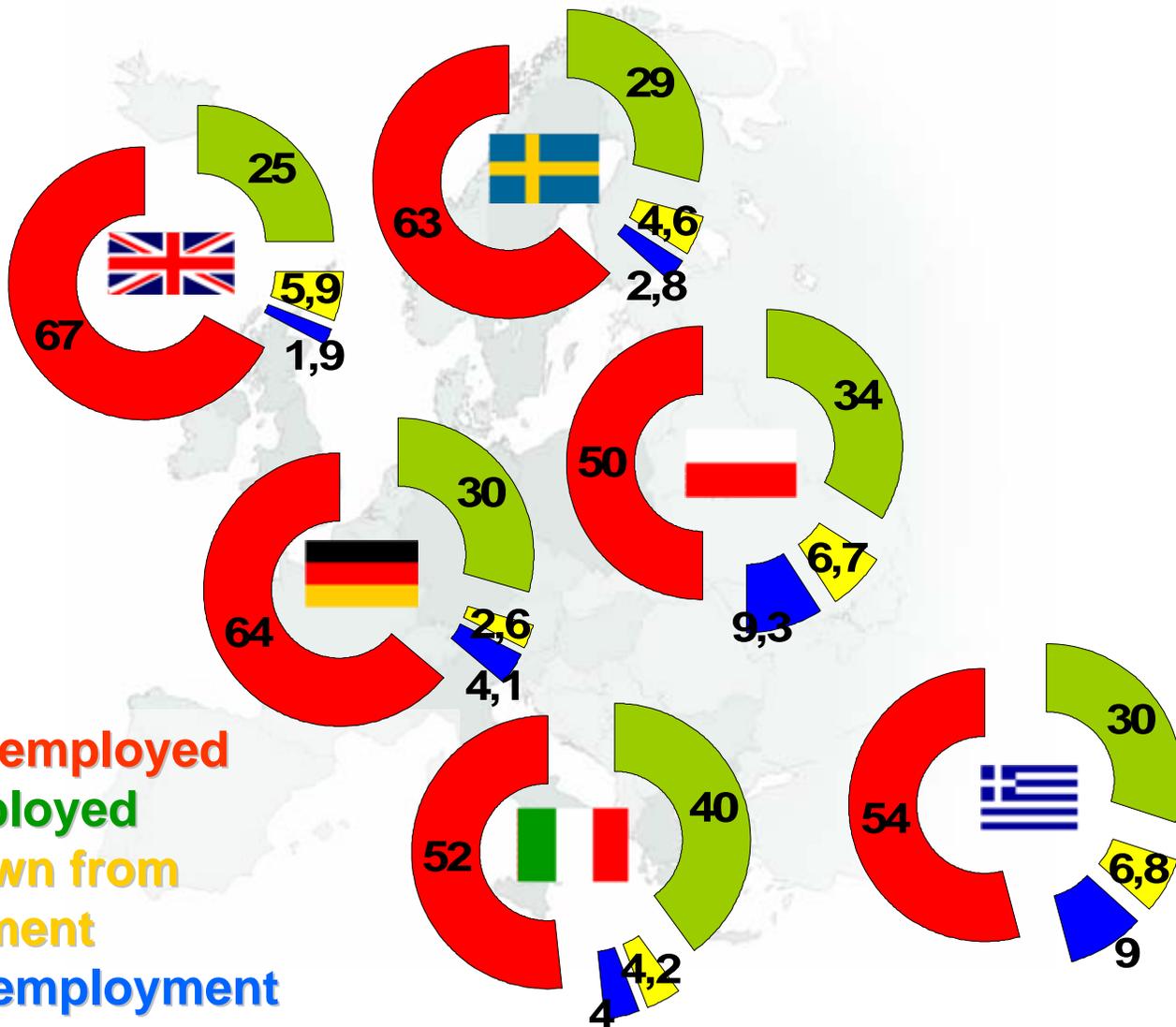
Changes in I-ADL-dependency between T1 & T2
(No of dysfunctions – "not able or able with help") (in %)
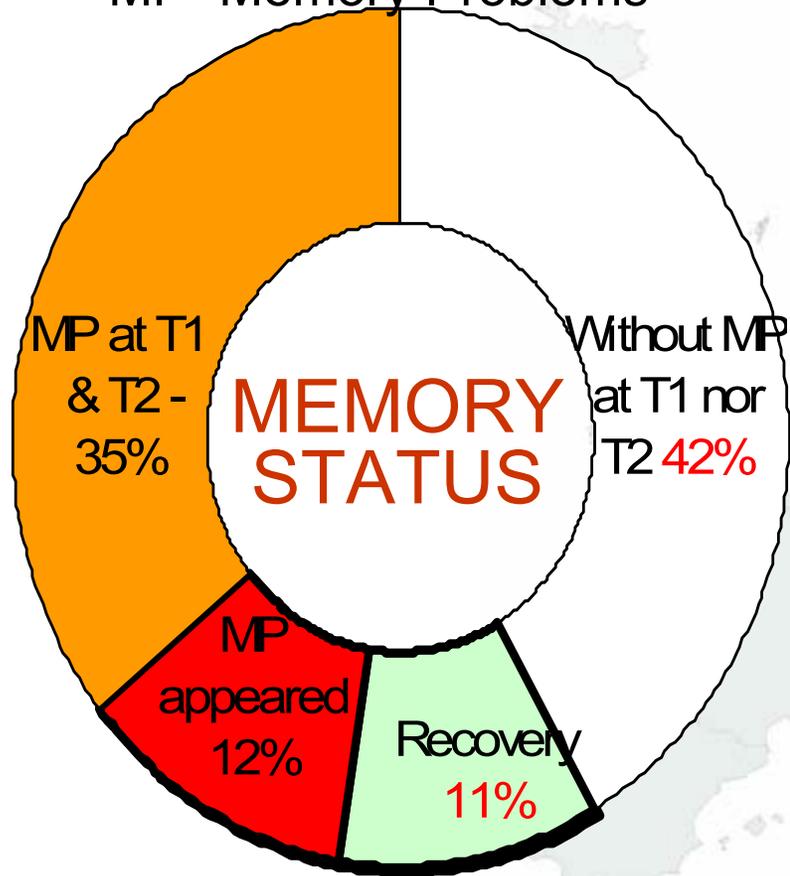
Changes in Barthel-dependency between T1 & T2
(No of dysfunctions – "not able or able with help")

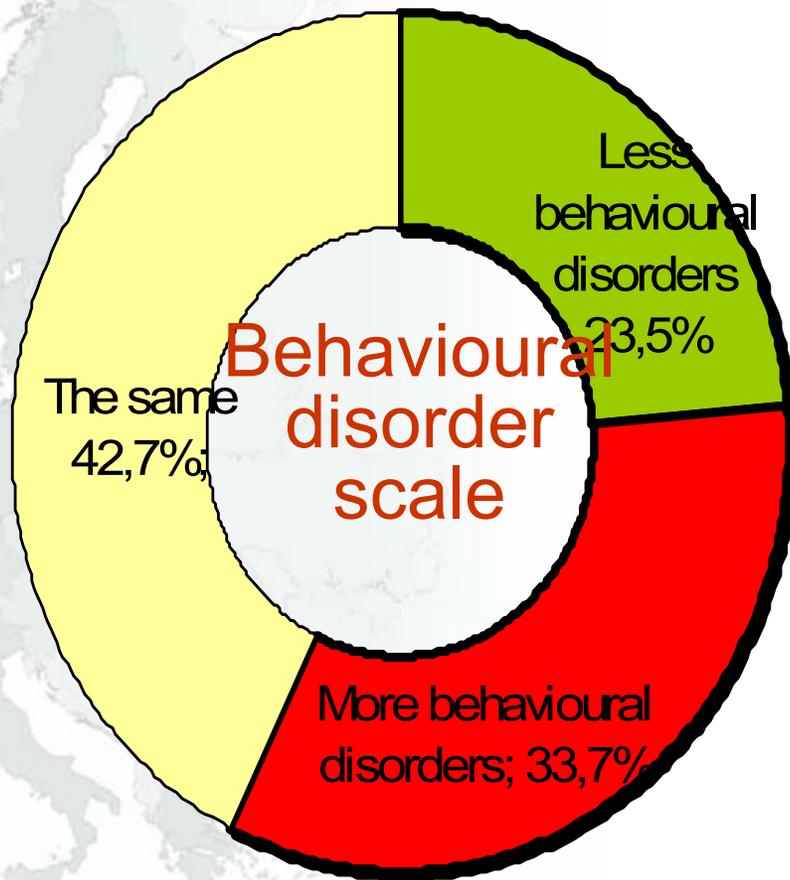Decrease in Barthel-Index (0-100 between T1 & T2)

| -8,9 | -4,6 | -2,9 | -10,9 | -2,8 | -8,3 | -5,5 |

EL n=173   IT n=648   UK n=178   SE n=334   PL n=700   DE n=244   EU n=2277

EL: less 36,4 | more 42,8 | the same 20,8

IT: less 21,9 | more 49,2 | the same 28,9

UK: less 18 | more 55,6 | the same 26,4

SE: less 16,7 | more 65,6 | the same 17,7

PL: less 28,9 | more 38,6 | the same 32,5

DE: less 18,4 | more 52,5 | the same 29,1

EU: less 23,7 | more 48,7 | the same 27,6

Legend: ☐ less ■ more ☐ the same

Changes in the memory status & behavioural disorder's scale between T1 & T2 (in %)

MP=Memory Problems

MEMORY STATUS

- Without MP at T1 nor T2 42%
- MP at T1 & T2 - 35%
- MP appeared 12%
- Recovery 11%

Total n=2409

Behavioural disorder scale

- Less behavioural disorders 23,5%
- The same 42,7%;
- More behavioural disorders; 33,7%

Total n=2333

Changes in OPs' cognitive status
between time T1 & T2; Total longitudinal data

100   12,5 / 5,6 / 17,2 / 64,7   T1 T2

100   28,2 / 5,4 / 34,6 / 31,8   T1 T2

100   38,1 / 22,9 / 14,5 / 24,5   T1 T2

100   74,8 / 7 / 8,9 / 9,3   T1 T2
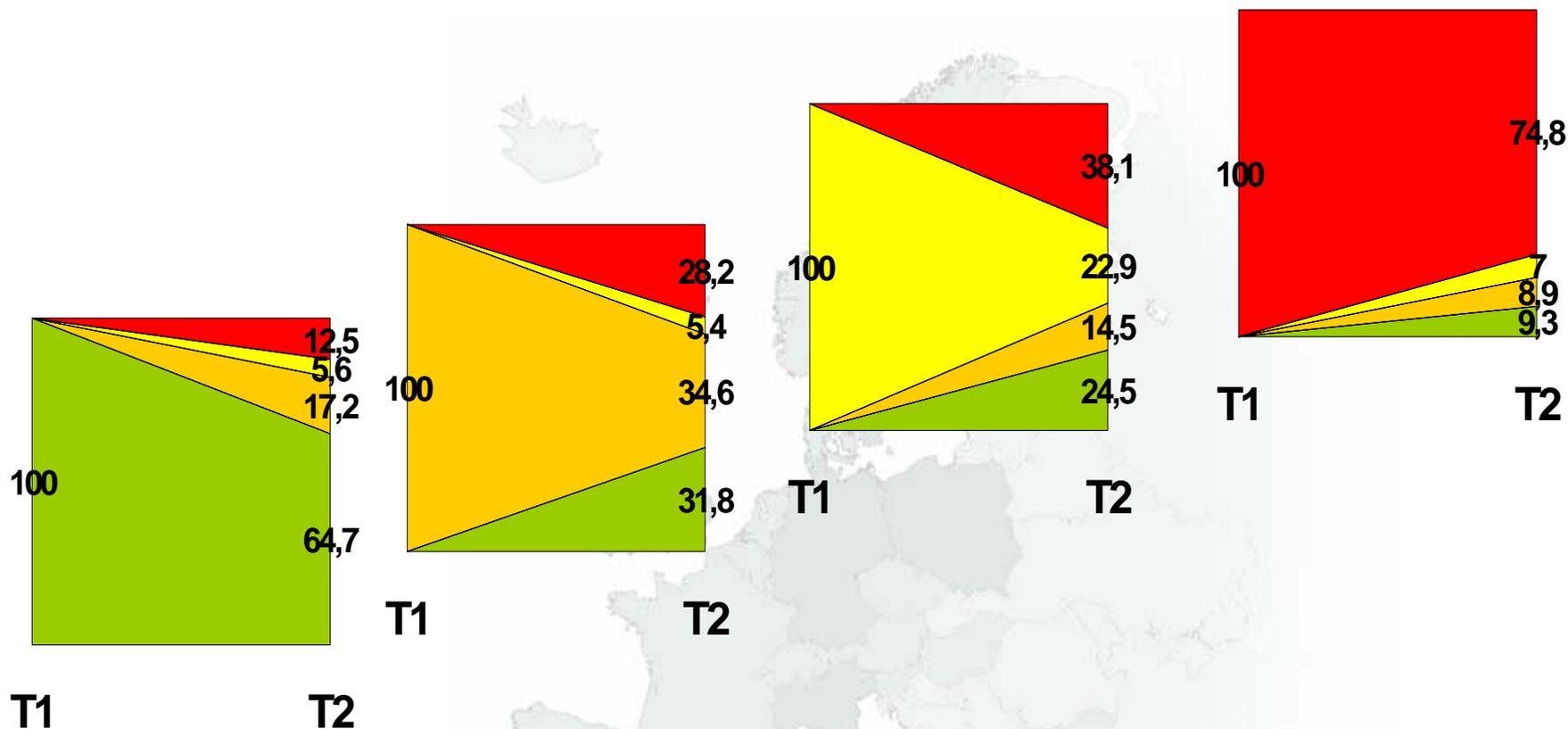
No disorders = intellectually able (T1 n=949; T2 n=850)

Only behavioral disorders (T1 n=249; T2 n=380)

Only memory impairments, without behavioral (T1 n=315; T2 n=380)

Memory & behavioral disorders = Probable dementia (T1 n=810; T2 n=909)

Comparison of overall QoL between "Ex-Carers" & "Still caring" between T1 & T2;
Total longitudinal data [in %]
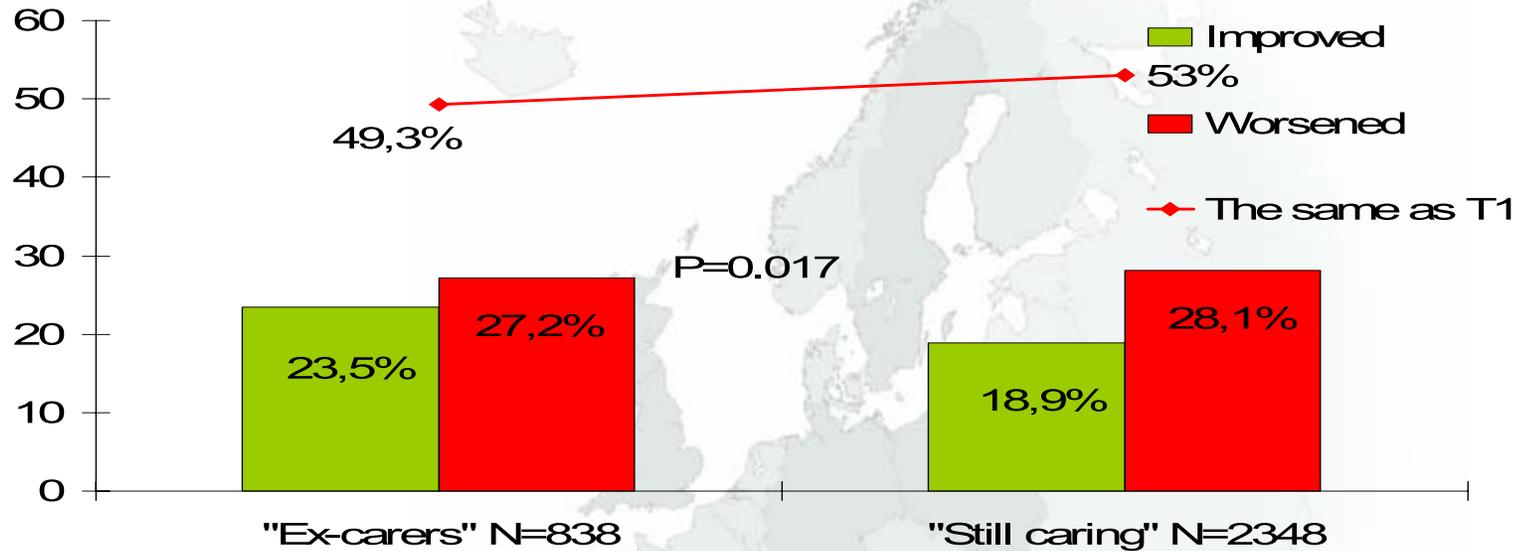
	T1	T2	
"Ex-carers" Health [qol1]	n=909; 3,2 +1	n=883; 3,4 +0,9	[6,3% worse]
"Still caring" Health [qol1]	n=2436; 3,2+0,9	n=2426; 3,4 +0,9	[6,3% worse]
"Ex-carers" QoL [qol5]	n=904; 13,1 +6,3	n=859; 12,3 +6,2	[3,8% worse]
"Still caring" QoL [qol5]	n=2433; 13,8+5,9	n=2397; 12,6 +5,9	[8,9% worse]
"Ex-carers" QoL overall [QoL7]	n=913; 2,5+0,9	n=881; 2,6 +0,9	[4% worse]
"Still caring" QoL overall [QoL7]	n=2443; 2,4+0,8	n=2426; 2,6 +0,8	[8,3% worse]

Changes in negative impacts of care [in %]
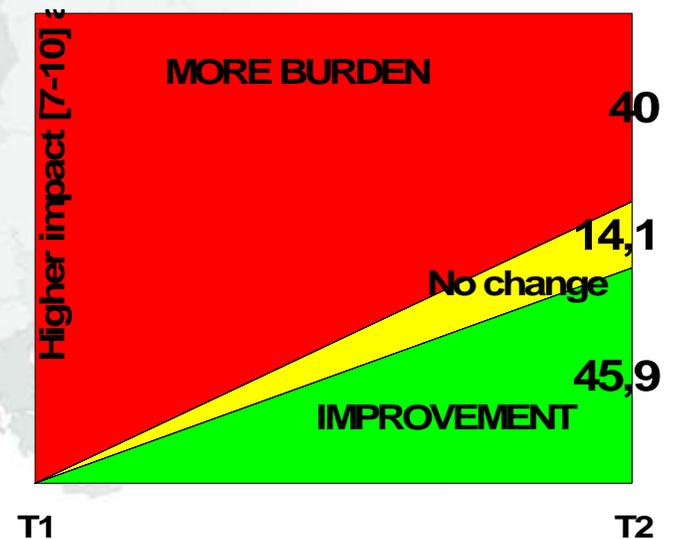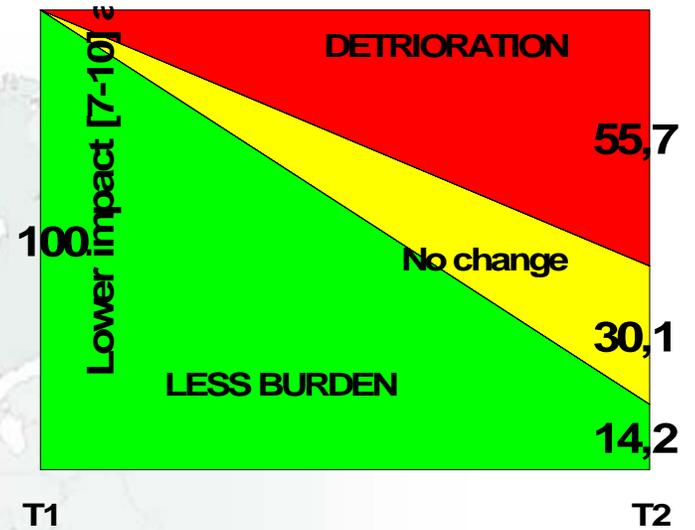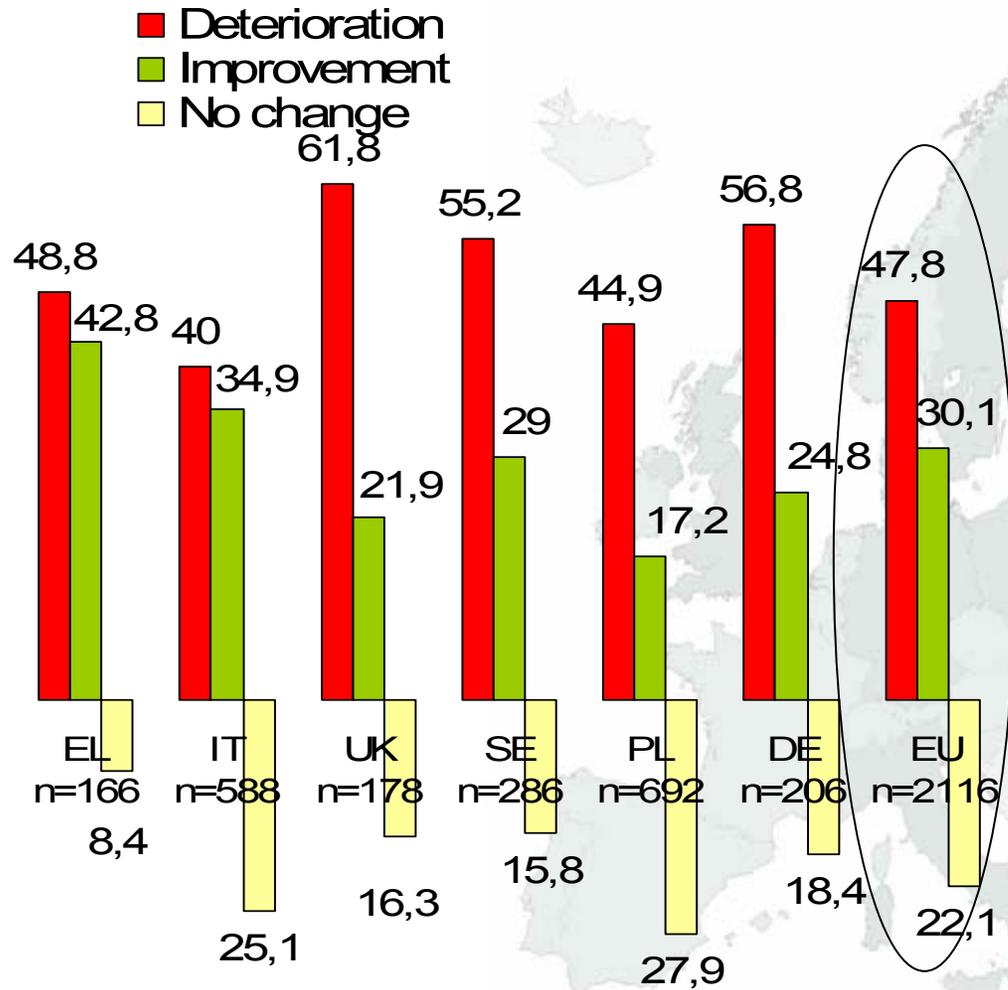
Summary remarks (1)

- The vast majority of initial family caregivers were still caring after one year. Mortality amongst the persons cared-for was the main reason for carers' withdrawing from care over the year and affected approximately one fifth of primary caregivers. The second cause for discontinuing care was the transfer of the person cared-for to another place: to another family member (predominately appearing in PL, EL and IT) or to a nursing home (predominately present in Sweden, Germany and UK).

- The most important predictors for discontinuing care that depended on the OP were: being female and of advanced age; living alone; more severe physical and mental disability and high requirement for help.

- The most significant predictors for discontinuing care that depended on the CARER were: shorter duration of caring, low religiosity, longer distance from OP's residence, lack of motivation in caring for elder, non-working status, less direct involvement in care, higher negative impact of care and lower QoL.

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Summary remarks (2):

- Amongst the re-surveyed sample of family carers still caring, the intensity of caring over the year remained approximately at the same level with a slight decreasing tendency. However, amongst almost every second carer the intensity of care increased by almost double compared to the original baseline study situation;

- Similarly, there were few changes in the employment status of carers over the year, especially in DE, IT, SE and UK. In PL and EL the proportion of carers becoming employed or unemployed was almost double the rate of that in other countries.

Summary remarks (3):

- Physical disability in the persons cared-for worsened over the one-year of observation. Progressive dependency in OP is evident especially with respect to the Basic ALD (5,5% per year on the 100-item Barthel scale), and to lesser extent on an Instrumental ADL scale.

- Memory status seems to be rather stable over the one year of observation. Only amongst a tenth of the cared-for persons does memory loss appear, while for the same proportion memory impairment improves.

- Behavioural disorders in the persons cared-for showed high variations in intensity – disorders diminished in every fourth person, and increased for every third OP after a year.

Summary remarks (4):

- Degree of progression in cognitive disorders over the one-year period depends on the initial level – lower in people without any memory problems, and highest in people with memory and behavioural disorders (and vice versa with respect to possible regression of disorders);

- QoL worsens both amongst "ex-carers" and "still caring" carers over the one-year, however for the latter group it worsened significantly more than for those who gave up caring for elders.

- There were changes in the negative levels of care impact amongst the vast majority of carers but in both positive and negative directions, though there was overall a more negative than positive direction of change over the one-year. This was unstable and changeable – thus for almost every second carer her/his initially (at T1) better outcome of care deteriorated, while the same proportion improved her/his initially worse outcome of care after a year.