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

Typology of family care situations

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1 Introduction

One contribution of WP8 was to work out a typology of care situations showing differences and similarities in the six core countries. Furthermore the typology of care situations can be helpful to solve or at least to control two problems which are relevant for all country comparison studies:

■ there could be a bias because of different recruitment strategies in the countries (selection distortion) or / and

■ country specific care structures could also affect the observed phenomenon, for example if in one country there is more intra-generational care or a higher occupation rate of caring women.

These effects should be controlled if possible and that could be achieved by cluster building. Each interview conducted with a caregiver represents a specific relationship to the cared-for that is embedded in further relevant informal and formal social relationships. If you want to abstract from each individual case and combine comparable cases into groups that, in turn, each represent different possible constellations, you require a listing of characteristics. Here, you have to be modest regarding the number of characteristics, their degree of differentiation, and the dimension of time. Thus, what we have here at the moment is a snapshot of the care-giving situation at the specific time of the interview.

The catalogue of variables we use for our subsequent analysis consists of characteristics which were assumed, when designing the survey instruments, to be critical to the definition of a care-giving situation. Then and today the list of characteristics can surely be expanded, but there were and are limitations with respect to both the surveys and the analysis.

The following general aspects may be suitable to define care situations:

■ Does the situation result in a significant burden on the caregiver's well-being?
The burden experienced by the caregiver is an important aspect to be assessed. Research in the area of care-giving outcomes has repeatedly reported the clinically relevant consequences of giving care, in terms of both the caregiver's anxiety and depression (Barinaga, 1998; Macdonald & Dening, 2002; Marshall, 2001; Pinquart & Sorensen, 2003; Schulz et al., 1995; Vitaliano, 1997) and there is also evidence that care-giving may be an independent risk factor for mortality (Schulz & Beach, 1999).

■ Is there an increased demand of financial / material support for the cared-for?
This is another crucial aspect to be taken into consideration in evaluating a care-giving situation, since care-giving may have profound consequences on the available material resources of the carer (e.g. Covinsky, 1994), placing on him / her considerable additional burden.

- Can the caring be assumed by others if needed (sickness, downtime)?
  This aspect aimed at obtaining an indication of the caregiver's available social support, which is an important protective factor for keeping psychological balance / mental health (e.g. Zunzunegui et al., 2002).

- Is the caregiver working or not?
  This fact could be taken as a measure of involvement in extra-caring activities in combination with the correspondingly increased demands of care (incl. organizational demands). The demands of care can only be combined with work with great difficulty and it can be presumed that such a double burden affects both the physical and mental well-being of the caregiver. If caregivers work, they are often faced with a necessary reduction of working hours which brings about less chance of advancement and loss of income (Dallinger, 1997).

- Does the caregiver form a household with the elder?
  Many family caregivers, often together with the person they care for, are confined indoors because they have to be available around the clock. Consequently, they can rarely take part in social activities outside the home and thus do not have the opportunity of relaxing by taking part in leisure activities or talking to friends. They get more and more socially isolated and this could also be a factor that will increase the strain on the caregivers.

- Are caregivers and cared-for of the same generation or does the caring take place across generations?
  With different generations, diverging experiences have to be assumed (Mannheim, 1964; Höpflinger, 2004) that may manifest as a potential conflict in the relationship between caregivers und cared-for.

- Degree of impairment of elder?
  Studies show that the degree of impairment influences the caregivers' burden. In particular caring for individuals suffering from dementia leads to extreme physical and mental burden (Infratest 2003).

- How the caregiver perceives her / his own well-being?
  Perceived well-being will be related to a number of different factors, but it can be assumed that the caregiver perceived well-being will be influenced by the care-situation.

- For how long has this caring situation existed?
  The early stages of care giving (less than 2 years) can be a difficult period as the carer adapts to his / her role. Research evidence suggests that taking up the care role is a more burdensome period for a carer than the period when the care role is established.

- Do elder and caregivers live in an urban or a rural area?
  The carer's place of residence will influence not only the services and resources that can be accessed, but also the extensiveness of the informal social support network.

From this, we can develop a typology of care-giving situations that is to be understood as an explorative, simplified description that identifies cluster of similar care giving situations which differ as much as possible. Distributions are not aspired but rather a "control" variable for important differences of individually definable care-giving situations is created. Against this background, further questions can be analyzed.

2   Methodology

For clustering care-giving situations we took into consideration the following caregiver related variables (see also TEUSURE chapter 3): caregivers demographics as indicated by caregivers <u>gender</u>, <u>educational level</u>, <u>working status</u> and <u>generation</u> with respect to elder, and the characteristics of <u>caregivers place of residence</u> (i.e., location). We also took into consideration variables more strictly related to the care giving situation, namely <u>duration of care</u>, <u>availability of help if ill</u> and <u>availability of help if in need of break</u>.

As for the caregivers well-being, we included the <u>perceived burden</u> associated with care giving as indicated by the Cope Index's negative impact subscale (McKee et al., 2003, see also TEUSURE chapter 3), and measures of caregivers <u>reported state of health</u> and <u>quality of life</u> (World Health Organization, 1998).

As for the elder-related variables, we took into consideration elder's <u>age</u> and <u>gender</u>, elder / caregivers <u>cohabitation</u> status and whether the elder had a need for <u>financial support</u>. Measures of elder's functional disability were elder's <u>cognitive status</u> and <u>IADL</u> abilities.

Here, we have to take into consideration that some aspects should not be weighted more than others because they are included multiple times by the variables used. We have collected, e.g. for elder's functional impairment, several measures (IADL, Barthel-index), but only used one of them. Such multiple measurements may also occur with other characteristics that we could use.

A **dimension analysis** (factor) performed beforehand can offer insight in to the extent to which correlations between the selected characteristics exist, suggesting overlapping constructs. This applies to the reported state of health and the subjectively perceived quality of life of the caregiver. In this case, we have dropped reported state of health as an indicator and used the more general concept of quality of life for the cluster analysis. In other cases correlations also occur, e.g. between the fact that caregiver and the cared-for belong to the same generation and live in the same household. However, this correlation does not reflect a single underlying construct, and so both characteristics are used to create the care-giving situation. The same is true for measuring cognitive and functional limitations of the cared-for, as subgroups exist in which both characteristics do not co-occur.

Altogether 15 characteristics (see table 1) remain after this selection that reflect both metric and nominal scales. In such cases of "mixed" variables three strategies can be followed:

- Perform separate analyses for metric and nominal scales;

- Create a dummy variable for each category of a nominal variable and treat it as metric (Bacher, 1994: 186-191);

- Separate each characteristic – both metric and nominal – in a corresponding dummy variable and thus scale to the smallest common denominator.

We have decided to use variant c) for this analysis, as we aspire a simultaneous typing for all characteristics, which excludes the first strategy from the outset. In variant b) the number of dummy variables would have quickly increased to two or three dozen, which would have made the later description of the cluster very intricate (and possibly difficult to interpret). However, we have to accept that variant c) leads to loss of information, as with the selection of the cutting points for 0 and 1 other – possible – differentiations are lost. In return we gain a much simpler model in which the selected characteristics with the same weights for the cluster separations are entered. The following table 86 shows the variables that are included in the analysis:

Table 1:   Variables for the cluster analysis

ELDER	
Elder's age	0 = 65-79
	1 = 80-highest
Elder's sex	0 = male
	1 = female
Cohabitation status	0 = different houses
	1 = same house
Cognitive status	0 = no cogn disorder or age assoc memory impairment
	1 = behavioural disorder or probable dementia
IADL	0 = low to moderate iadl dependency
	1 = more severe iadl dependency
Financial support	0 = no need
	1 = need
CARER	
Carers educational level	0 = higher level
	1 = lower level
Duration of care-giving	0 = up to two years
	1 = more than two years
Working conditions	0 = non working
	1 = working
Negative impact of caregiving	0 = lower impact_7 to 10
	1 = higher impact_11 to 28
Quality of life	0 = worse qual of life_0 to 14
	1 = better qual of life_15 to 25
Carers sex	0 = male
	1 = female
Help if ill?	0 = Yes I could find someone
	1 = I could find someone with difficulties or no
Generation	0 = not the same generation as elder
	1 = same generation as elder
Place of residence	0 = rural
	1 = urban
Not included (because of high correlations with "help if ill")	
Help if break needed	0 = Yes I could find someone
	1 = I could find someone with difficulties or no
Not included (because of high correlations with "quality of life")	
Self-perceived health	0 = better health_1 to 3
	1 = worse health_4 to 5

3 Main findings

3.1 Number of cluster

We have to take into consideration that with the 15 dummy variables (0 means: "characteristic does not apply"; 1 means: "characteristic applies") more than 30,000 combinations are possible. It becomes apparent which high degree of data and thus information reduction can be reached with less than ten care-giving arrangements that are homogenous. To achieve this we have selected a cluster fusion procedure (Ward procedure) to provide information about the possible number of cluster first.

Such agglomerative procedures first combine all same characteristic combinations to cluster. As soon as identical care-giving situations cannot be combined anymore, two cluster are fused by which means internal heterogeneity is least increased. This process is performed until the last fusion step when the last two remaining cluster are merged into one. From this point, you follow the individual fusion steps backwards in order to determine with the inverse screen test at which step the heterogeneity increased erratically (Elbow criterion). This is the termination condition and the definition of number of cluster, because this increase in dissimilarity is not tolerated.

The inspection of the fusion table shows that with the change from six to five cluster noticeably more heterogeneity is added than with previous fusion steps. Previously this value has increased steadily (220, 230, 240) and then "jumps" (elbow criterion) by 300 points. This increase means that from now on two cluster are fused and form a new – comparatively heterogeneous – cluster. Thus, a solution with 6 cluster is to be seen as the limit of simplification possibilities (see table 2).

Table 2: **Agglomeration schedule**

Number of cluster	Heterogeneity in all cluster	Increase of heterogeneity in the next fusion step
12	12.910	…
11	13.080	170
10	13.250	170
9	13.460	210
8	13.680	220
7	13.910	230
6	14.150	240
5	14.450	300
4	14.800	360
3	15.280	470
2	16.640	1360
1	18.370	1730

3.2 Quality of cluster partition

In order to verify the selectivity between the cluster, a **discriminant-analysis** is used. It takes our 15 variables for separation of the six subgroups (cluster) and then tries to reproduce the individual group membership only on the basis of the 15 original characteristics. The degree to which this is successful can be interpreted as a quality factor for the cluster solution. The present cluster solution results in a rate of 81 % correctly classified cases. This relatively low value can be traced to the fact that in two of the six cluster only two out of three cases can be assigned to the "correct" (from the cluster solution) subgroup. The fusion procedure used here does provide good criteria for the number of possible cluster. Its disadvantages, however, are that objects (care-giving situations) that are assigned once cannot be "moved" to different cluster, even if after one cluster was enlarged an alternative assignment would make sense.

The necessary flexibility can be provided by adding a **non-hierarchical cluster-approach** (quick cluster in SPSS) in order to use the possibility of "re-sorting" this offers. The optimizing algorithm of quick cluster checks for each case whether the previous assignment from the hierarchical analysis is really best or whether with another assignment the homogeneity of the new target cluster is less affected than with the previous one.

Our newly arranged cluster deliver 92 % correctly classified cases with the discriminant analysis based on the new classification, and the corresponding value in each individual cluster now reaches at least 85 %.

3.3 Description of cluster

The description of the different care giving situations is at first performed with few characteristics and then, step by step, with the entire listing of characteristics used for this clustering, to determine the characteristics that best define the cluster. In the first step, a sorting is performed that at first shows the impairments of the cared-for (measured by functional IADL abilities and cognitive status of the cared-for) and in the second column (table 3) the subjective impairments (measured by negative impact of care giving and quality of life) of the caregiver in a sequence from "relatively high" to "relatively low" burden.

Table 3:   Main characteristics of cluster

Cluster	Objective burden	Subjective burden	Generation	Working
1 (n = 946)	high	high		
2 (n = 937)	high	high		yes
3 (n = 838)	high	high	same	
4 (n = 436)	high	high	same	
5 (n = 943)	high	low		
6 (n = 1,266)	low	low		

In cluster 1 and 2 the reported objective impairment of the cared-for, as well as the subjectively perceived burden of the caregiver, dominate (table 4). As compared to cluster 1, in cluster 2 most care-giving women are working and they mostly have a higher education. Cluster 3 and 4 mainly include couples, but cluster 4 consists primarily of men caring for a female partner, while cluster 3 consists of women giving care to their male partners. Here, the relevant actors are members of the same generation and live in the same household. Cluster 5 displays the special characteristic that the subjective burden strain is perceived as comparatively minor, with a very small proportion of caregivers reporting high negative impact from care-giving, while most report a good quality of life. This appears in contrast with the higher functional – but only average cognitive – disability showed by elders in this cluster. The relatively large group 6 includes those care giving situations in which the cared-for does not show severe IADL impairment and in the lowest percent of cases report a cognitive impairment. Only a minority of caregivers in this cluster show a higher negative impact from care-giving while the majority reports a better quality of life. In this group, most of the caregivers are able to combine care giving with work.

The need for additional financial support for elder generally varies with the subjectively perceived burden of the caregiver. A closer look at the fusion steps has shown, however, that the second group before the last combination existed of two cluster that could only be differentiated with this variable. Thus, it has to be taken into consideration when characterizing this care-giving situation that the additional financial need was only voiced by a subgroup.

In groups 3 and 4 the cared-for are usually relatively younger. Older cared-for persons can be found more often in the care-giving situations formed by the first two cluster, and to some extent in cluster 5.

In general, alternatives for support in case of sickness of the care-giving person are only reported by caregivers from the last two care-giving situations. In all other care-giving cluster the majority of caregivers (from 57 % to 73 %) do not have such possibilities.

To summarize: We found two situations (cluster 1 and 2) where the caregivers have high objective and subjective burdens and the two cluster differ in so far as the caregivers are not working in the first cluster; both cluster are about the same size. Then we have two situations where "spouses" care for each other and they also have subjective and objective higher strain (cluster 3 and 4), and differ only in the fact that one cluster consists of caring women (cluster 3) and the other one of caring men (cluster 4). The latter is also the smallest cluster in our sample. In our final two cluster support is available to caregivers if they need it (cluster 5 and 6). The cluster differ in the fact that cluster 5 has objective burden but no subjective burden, while cluster 6 has relatively little subjective and objective burden; this last cluster is also the largest in our analysis.

Table 4:   **Characteristics of cluster**

Cluster	Carer related variables									Elder related variables					
	Gender: % female	Education: % lower	Working status: % working	Generation: % same	Place of residence: % urban	Caregiving duration: % > 2 years	Help if ill: % only with difficulties or no	Negative impact: % higher	Quality of life: % better	Gender: % female	Age: % 80+	Cohabitation status: % same house	Financial support: % needed	Cognitive status: % higher impairment	IADL abilities: % higher impairment
1 (n = 964)	89.9	34.7	0.6	3.4	63.9	70.9	69.4	92.4	22.7	85.0	82.7	52.0	50.1	74.3	90.4
2 (n = 937)	81.2	**9.8**	**99.2**	2.0	75.4	62.7	56.9	95.4	32.9	77.4	55.6	35.3	49.1	71.7	81.9
3 (n = 838)	99.3	47.7	5.7	97.3	67.8	71.8	72.9	71.0	35.8	1.9	30.7	91.5	35.6	58.7	78.8
4 (n = 436)	**3.4**	35.1	3.9	**86.9**	75.7	73.2	72.7	57.3	53.2	**96.6**	23.4	92.4	47.0	44.5	69.3
5 (n = 943)	76.5	14.7	50.9	4.4	64.6	62.7	26.5	5.2*	77.3*	74.1	67.9	29.8	28.2	48.3*	99.8*
6 (n = 1,266)	72.9	14.5	60.2	8.0	69.6	53.1	**28.9**	**14.7**	**73.0**	77.1	40.8	21.1	15.8	**17.5**	**0.0**

Highlighted in bold: main characteristics.
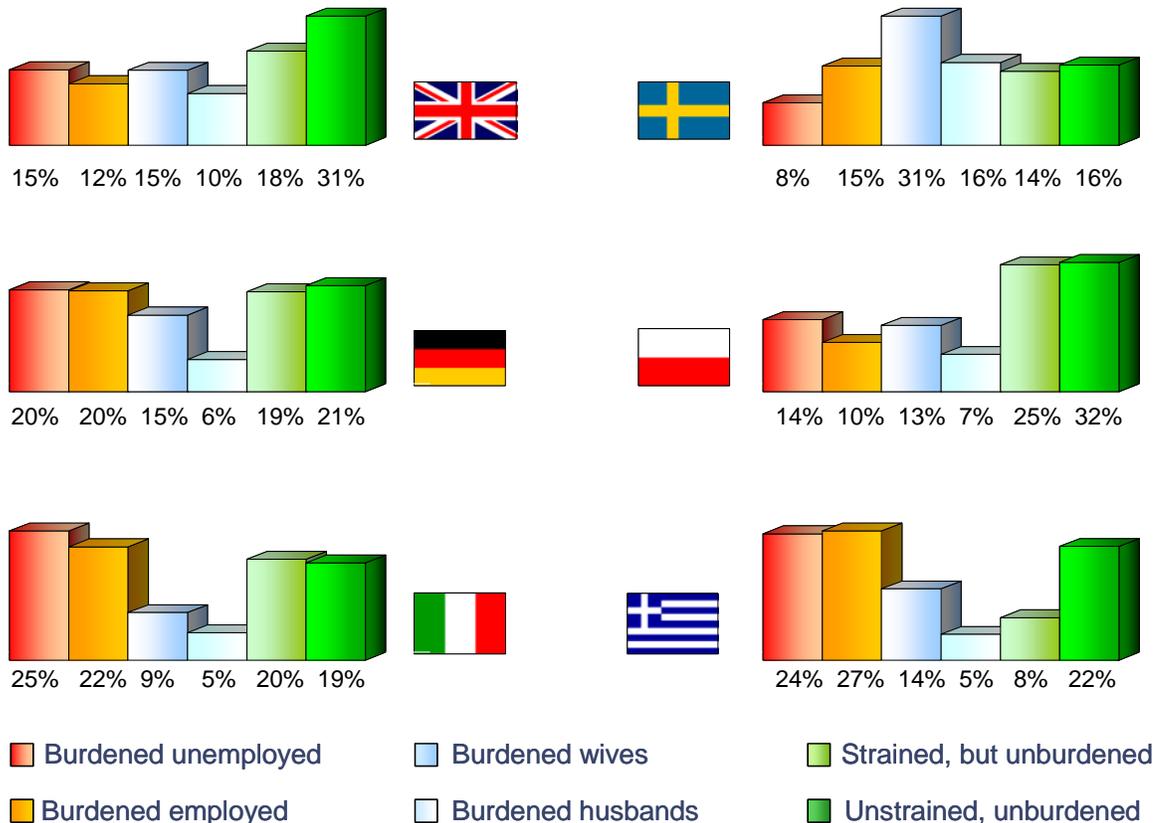* Contrast: lower subjective burden and higher objective burden.

3.4   Distribution of cluster in the six countries

If you look at the distribution[1] of cluster in the six countries it becomes apparent that care-giving couples occur almost twice as often in Sweden than in the other countries (cluster 3: SW = 30.7 % vs. GR = 13.8 %, I = 9.2 %, UK = 14.5 %, PI = 12.8 %, GE = 14.8 %; cluster 4: SW = 16 % vs. GR = 5.0 %, I = 5.3 %, UK = 10.0 %, PI = 7.2 %, GE = 6.2 %), which is, at the same time, the biggest country-specific characteristic (figure 1). In Poland, a focus lies on those two care-giving situations that feature the least subjectively perceived burdens (i.e. cluster 5 = 24.5 % and cluster 6 = 32.2 %). The distribution in the UK looks more or less like the Polish one and the cluster with relatively low subjective and objective burdens occurs most often (cluster 6 = 30.7 %).

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[1]   Again, it is to be noted that the distribution of the individual cluster in the countries does not necessarily represent the actual distributions in these countries due to different recruiting strategies and representativeness. However, these cluster allow – independent of the marginal distribution – the comparison of countries.

Southern Europe, represented here by Greece and Italy, shows a high percentage in the first two groups in which both the objective and the subjective burdens are above average (cluster 1: GR = 24.4 %, I = 25.4 % vs. UK = 14.6 %, SW = 8.2 %, PI = 13.9 %, GE = 19.7 %; cluster 2: GR = 26.5 %, I = 21.9 % vs. UK = 11.9 %, SE = 15.3 %, PI = 9.5 %, GE = 19.5 %). Germany displays all types of situations at a relatively equal magnitude.

Figure 1:   Care situations in the six countries

15% 12% 15% 10% 18% 31%   8%   15% 31% 16% 14% 16%

20% 20% 15% 6% 19% 21%   14% 10% 13% 7% 25% 32%

25% 22% 9% 5% 20% 19%   24% 27% 14% 5% 8% 22%

- 🟥 Burdened unemployed   🟦 Burdened wives   🟩 Strained, but unburdened
- 🟧 Burdened employed   ⬜ Burdened husbands   🟩 Unstrained, unburdened

These country-specific differences in care-giving situations first of all display the structure of local opportunities and chance events. Beyond this, however, they could be attributed to differences in the survey designs, sampling and recruitment strategies. The magnitude of these two possible effects cannot be separated. They can however be simultaneously controlled within country comparisons on other variables, e.g., we are able to view other care-relevant variables or system differences between the countries independently of local chance structures or country-specific requirements for the survey. Examples of this approach follow.

4 Discussion

We have selected a method of analysis that identified a care giving typology consisting of a relatively low number of care situations derived from comparatively detailed information regarding individual care circumstances. Using this information, we display at the core burden differences for the individual caregiver and are able to differentiate intra and intergenerational care relationships. As another interesting cluster a care giving situation forms that – even though the elder is functionally more impaired – the caregiver perceives the care as less burdensome. At the same time, this situation is characterised by the fact that the caregiver can more easily find help for the cared-for (in the sense of replacement when they cannot do it themselves) than in other care situations.

The use of this typology allows for the "control" (as a statistical strategy) of the different distribution to these groups in country comparisons, e.g. more low burdened caregivers in Poland and the UK, more intra-generational care in Sweden and a greater number of high burdened caregivers in Greece and Italy. The typology can be used for performing country comparisons within the individual cluster. Country-specific structures are taken more seriously if they not only occur in one type of care situation that occurs often in one country and are the sole reason this country differs from others. Vice versa, this allows for specifics of a subgroup in a country to be emphasised that were not discovered in the overall view.

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