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The Last and the Previous Year of Life in Europe: A Comparative Analysis of Care Received and Daily Living Limitations

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Abstract: *Objectives:* We analyse the need for and the provision of care to individuals aged at least 50 years in their last year of life as compared with the previous year of life.

Methods: We explain the functional status in ordered logit and who provides care in multinomial logit using the data from the Survey of Health, Ageing and Retirement in Europe.

Results: We find a significant and heterogeneous in the cause of death increase in the number of daily living limitations between the previous and the last year of life. The percentage of respondents receiving care increases and more sources of care are observed between the previous and the last year of life. Regional disparities decline in the last year of life.

Discussion: Correlates to functional status and care receipt differ between the last and the previous year of life. These differences are specific to region and cause of death.

Keywords: ADL limitations, IADL limitations, caregiving, end of life, last year of life.

1. INTRODUCTION

The last year of life differs significantly from the previous one [1]. The last year of life is recognised as a particularly difficult time due to a severe decline in the ability to perform the activities of daily living [2, 3]. The needs for medical and personal care are especially large for frail older people [4].

The problem of care at the end of life concerns decedents [5], their families [6], a welfare state [7] and other institutions providing care [8]. For this reason, the results of research on the end of life are sensitive not only to cultural variations and wealth disparities, but also to differences in public health care systems and in the development of markets for care services. Therefore, research on the end of life must take into account regional disparities (*see* Hank and Jürges study [9] for a literature review and results for Europe). However, most studies focus on the United States (*e.g.* [10, 11]) and, to a lesser extent, Western Europe (*e.g.* [12, 13]).

Another dimension of diversity in the last year of life comes from the disease causing death [14]. The study of disability trajectories in the last year of life by Gill and others [2] confirms variation in the patterns of functional decline between different causes of death. In particular, individuals who died of cancer experienced a significantly more rapid decline in health than individuals who died of other diseases [6]. Not only the functional decline, but also the course of treatment in the last year of life is disease-specific (*e.g.* [15]). The disease causing death affects the need for hospitaliza-tion or other institutional care, which is linked to the substitution between informal and formal care. The ongoing discussion on individual end-of-life decisions [16] indicates that 'natural death' at home competes with 'medicalised death' in hospital. The retreat from futile medical care [17] might result in an increased proportion of care being provided by family members in the last year of life as compared with the previous year of life.

In this study we aim to conduct an analysis of demand for care and the source of care akin to Hank and Jürges [9], who analysed regional disparities in functional status and the source of care in the last year of life. The focus of our analysis, however, is on the comparison between the last year and the previous year of life, controlling for the cause of death. Thus, in our study the end of life contains the last and the previous year of life. Such comparative analysis has not been conducted yet. In particular, we hypothesise that the number of limitations in the activities of daily living (ADLs) and in the instrumental activities of daily living (IADLs) in the last year of life is larger than in the previous year of life; and the set of care providers differs between the last year of life and the previous year of life.

We use the most recent release of data from the end-of-life interviews from the longitudinal Survey of Health, Ageing and Retirement in Europe (SHARE) concerning the last 12 months prior to death combined with the regular interviews from the preceding wave of

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data collection in the SHARE survey. In sum, our contribution to the findings by Hank and Jürges [9] comprises a comparison between the last and the previous year of life; an extension of the analysis with the impact of the cause of death; an addition of IADLs to the functional status; and an inclusion of the data from the end-of-life interviews from SHARE wave 4. In this way, it provides a deeper insight into the dynamics of daily living limitations and care received at the end of life.

2. MATERIALS AND METHODS

2.1. The Sample

This analysis uses data from the Survey of Health, Ageing and Retirement in Europe (SHARE) conducted in 2004–2011. SHARE is a biannual longitudinal survey of individuals aged 50+ living in 19 European countries and Israel (Börsch-Supan and others [18] provide more details on that). Four waves of the survey have been released as of today (wave 1 for 2004–05; wave 2 for 2006–07; wave 3 for 2008–09; and wave 4 for 2010–11). SHARE consists of three types of interviews: regular (waves 1, 2, and 4); end-of-life (waves 2, 3, and 4); and life history interviews (wave 3). In this analysis we use regular and end-of-life interviews.

Regular interviews are conducted in each wave except the third one and collect information on the current health, medical and personal care, daily living limitations, and more. In the case of the respondent's death, end-of-life interviews concerning the last 12 months prior to death are conducted with the deceased respondent's proxy starting from the second wave. Proxies are individuals close to the deceased, having daily contact with them, usually family members (80 per cent of proxies were spouses, children or children-in-law of the deceased).

The research sample contains data from the end-of-life interviews matched with the latest corresponding regular interviews. It consists of 2,751 individuals from 13 European countries interviewed either in the first or in the second wave of data collection prior to their death, which was reported in the end-of-life interviews of wave 2, 3, or 4. The average time between death and the last regular interview is 19 months, and it is shorter for those who died before the fourth wave. The end-of-life interviews inform about the last year of life whereas the regular interviews provide details about the previous year of life.

2.2. The Measures

Our analysis investigates limitations in daily living and the source of care in the last years of life. First, we compare the number of limitations in performing six ADLs (dressing, walking, bathing, eating, getting in or out of bed, and using the toilet) and four IADLs (preparing a hot meal, shopping, telephoning, and taking medication) in the last year of life with the respective number of such limitations in the previous year of life. With respect to ADLs, we group individuals with none, one to five, and all six difficulties into three categories: '0', '1-5', and '6', respectively. Similarly, we group individuals with none, one to three, and all four IADLs causing difficulties into three categories: '0', '1-3', and '4', respectively.

We then proceed to a comparative analysis of the relation to the care provider. Care includes assistance in performing all ADLs and IADLs. Care providers being family members of the decedents (*i.e.* spouse, children, or other relatives) are treated as kin, whereas all individuals from outside of the family (*i.e.* friends, neighbours, professionals, or volunteers) are treated as non-kin. Three types of sources of care are distinguished: 'only kin', 'only non-kin', and 'kin and non-kin', as in the study by Hank and Jürges [9]. Table **1** provides prevalence of the daily living limitations and sources of care in the last and in the previous year of life.

The multivariate analysis aims to investigate the region and cause-of-death effects in the last and the previous year of life on the daily living limitations and the source of care. Hank and Jürges [9] distinguish three regions of Europe corresponding to the variety of welfare state typologies [19]: Southern Europe (Greece, Italy, and Spain), Northern Europe (Denmark, the Netherlands, and Sweden), and Central Europe (Austria, Belgium, France, Germany, and Switzerland). We adapt this classification. We assign Poland to Southern Europe and the Czech Republic to the Northern Europe based on the descriptive statistics in key variables [20] rather than on the welfare states, because they are difficult to incorporate into the standard typology [21].

The proxies reported the main cause of death in the end-of-life interviews by selecting one of the following answers: cancer, a heart attack, a stroke, other cardiovascular-related illness such as heart failure or arrhythmia, respiratory disease, disease of the digestive system such as gastrointestinal ulcer or inflammatory bowel disease, severe infectious disease such as pneumonia, septicaemia or flu, accident, or other. We use this information to control for the cause of death.

We run ordered logit estimations of the numbers of limitations in ADLs and IADLs, respectively, and multinomial logit estimations of the source of care in the last and the previous year of life. We control for the region, cause of death, age, gender, and marital status in all estimated models.

3. RESULTS

3.1. Descriptive Statistics

The proportion of individuals receiving care in the last year of life (96%) is substantially greater than the respective proportion in the previous year of life (55%) (See Table **1**). It is not surprising as less than a half of the decedents (about 37%) had at least one ADL or IADL limitation in the previous year of life. In the last year of life, however, the percentage of respondents with at least one ADL or IADL limitation grows (to about 59%). Family members are usually the sole providers of care in the previous year of life (63% of all decedents), which also holds for the last year of life (54%). Non-kin care supplements kin care slightly more often in the last (30%) than in the previous year of life (27%). Only non-kin care is rare and more frequent in the last (16%) than in the previous year of life (10%). More sources of care are observed in the last year of life than in the previous one, which should be linked to an increase in demand for care. In summary, the last year of life differs significantly from the previous year of life with respect to daily living limitations and receipt of care.

Table 1: Limitations in Daily Living and Care in the Last and in the Previous Year of Life in Europe, 2004-2011

Attributes	Year of life	
	Last	Previous
	Percentages of decedents	
ADL limitations number: [a]		
0	42	63
1–5	38	31
6	20	6
IADL limitations number: [b]		
0	41	64
1–3	37	26
4	22	10
Care receipt [c]	96	55
Care providers: [d]		
Only kin	54	63
Only non-kin	16	10
Kin and non-kin	30	27
Sample size	2,222	2,222

Notes: ADLs: activities of daily living. IADLs: instrumental activities of daily living. [a] Pearson $chi2^2(4)=333^{**}$. [b] Pearson $chi2^2(4)=468^{**}$. [c] T-statistics t(1207) = –22**. [d] Pearson $chi2^2(4)=67^{**}$. ** *p*<0.01.

Source: SHARE waves 1–2 (Release 2.5.0), wave 3 (Release 1), and wave 4 (Release 1.1.1); authors' calculations.

3.2. Daily Living Limitations

Table **2** presents results of the ordered logit estimation of daily living limitations. The age increases the number of daily living limitations, but to a lesser extent in the last than in the previous year of life. Our findings confirm that women experience more difficulties with ADLs and IADLs at the end of life than men [22]. Being married reduces the number of IADLs causing trouble at the end of life and the number of such ADLs, but only in the previous year of life.

Individuals who died of cancer had substantially less daily living limitations in the previous year of life than individuals who died of any of the other diseases. Interestingly, this relation reverses in the last year of life: individuals dying of cancer suffer from substantially more limitations in ADLs and IADLs than individuals dying of any of the other diseases. Individuals who died in an accident or of a heart attack suffered the least of the functional limitations in the last year of life in comparison with individuals dying of cancer. In the previous year of life, however, those who died of a heart attack were more severely limited in performing ADLs and IADLs than individuals who died of cancer. Those who died of cancer did not differ from those who died in accidents with respect to ADLs or IADLs in the previous year of life.

Regional disparities occur within Europe as regards the functional status at the end of life, although they decline in the last year of life. We find no significant difference between Northern and Central Europe as regards the last year of life even though in terms of the previous year of life the regions are significantly different. Decedents in Northern Europe are less limited in daily living than decedents from Central Europe and even less than decedents from Southern Europe, thus confirming the results for the last year of life by Hank and Jürges [9].

3.3. Sources of Care

Table **3** presents results of the multinomial logit estimation of relation to care providers. Married individuals are less likely to receive care from the non-kin than the unmarried. Interestingly, women are less likely to receive care from the non-kin in the previous year of life than men, but the gender impact vanishes in the last year of life. Presumably, this finding reflects female role as a care-giver, not a care-receiver, which cannot be sustained in the last months of life due to health deterioration. In the last year of life the non-kin start to support the kin in giving care to married individuals and women.

Table 2: Ordered Logit Model for the Limitations in ADLs and IADLs in the Last and in the Previous Year of Life

Individual characteristics	ADLs				IADLs			
	Year of life				Year of life			
	Last		Previous		Last		Previous	
	Odds ratios (Robust standard errors)							
Age [e]	1.04**	(0.00)	1.06**	(0.01)	1.05**	(0.00)	1.07**	(0.01)
Female	1.22*	(0.10)	1.27*	(0.13)	1.33**	(0.10)	1.22*	(0.12)
Married	1.02	(0.08)	0.81*	(0.84)	0.80**	(0.07)	0.79*	(0.08)
Region: [e,f]								
Central	1.13	(0.10)	1.28*	(0.15)	1.07	(0.10)	1.35*	(0.16)
Southern	1.37**	(0.12)	1.70**	(0.19)	1.46**	(0.13)	1.58**	(0.18)
Cause of death:								
Heart attack [e,f]	0.35**	(0.04)	1.15	(0.19)	0.39**	(0.05)	1.50*	(0.25)
Stroke	0.83	(0.12)	1.73**	(0.31)	0.92	(0.13)	2.26*	(0.41)
Other card. dis.	0.64**	(0.08)	1.68**	(0.27)	0.73*	(0.10)	1.76**	(0.30)
Respiratory dis.	0.92	(0.15)	1.71*	(0.39)	0.80	(0.14)	2.33**	(0.53)
Digestive sys. dis.	0.56*	(0.14)	1.12	(0.35)	0.53*	(0.14)	0.80	(0.30)
Infectious dis.	0.95	(0.17)	2.44**	(0.54)	0.88	(0.17)	2.30**	(0.51)
Accident	0.26**	(0.13)	1.13	(0.36)	0.23**	(0.07)	0.99	(0.40)
Other	1.19	(0.08)	2.45**	(0.08)	1.38**	(0.15)	3.11**	(0.44)
Log likelihood	2,731		1,627		2,692		1,663	
Sample size	2,724		2,177		2,724		2,177	

Notes: ADLs: activities of daily living. IADLs: instrumental activities of daily living. Limitations in ADLs were measured in three categories: 0, 1–5, and 6. Limitations in IADLs were measured in three categories: 0, 1–3, and 4. Southern Europe: Greece, Italy, Poland, and Spain. Central Europe: Austria, Belgium, France, Germany, and Switzerland. Northern Europe: the Czech Republic, Denmark, the Netherlands, and Sweden. Dis.: disease. Card.: cardiovascular. Sys.: system. [e] Significant differences in odds ratios for IADLs between the last and the previous year of life at 1 per cent level. [f] Significant differences in odds ratios for ADLs between the last and the previous year of life at 1 percent level. * $p<0.05$, ** $p<0.01$. Reference group: unmarried men living in Northern Europe who died of cancer.

Source: SHARE waves 1–2 (Release 2.5.0), wave 3 (Release 1), and wave 4 (Release 1.1.1); authors' analysis.

Table 3: Multinomial Logit Model for the Care Provider in the Last and in the Previous Year of Life

Individual characteristics	Only kin care provider *versus...*							
	Only non-kin				Kin and non-kin			
	Year of life				Year of life			
	Last		Previous		Last		Previous	
	Odds ratios (Robust standard errors)							
Age [g]	1.02**	(0.01)	0.96**	(0.01)	1.01*	(0.01)	0.99	(0.01)
Female [h]	1.29	(0.21)	0.67	(0.17)	1.37*	(0.17)	0.71*	(0.12)
Married [h]	0.23**	(0.04)	0.26**	(0.07)	0.75*	(0.10)	0.37**	(0.07)
Region: [g]								
Central	0.48**	(0.09)	0.81	(0.22)	0.64**	(0.09)	0.63*	(0.12)
Southern	0.14**	(0.03)	0.29**	(0.09)	0.23**	(0.03)	0.42**	(0.08)
Cause of death:								
Heart attack	1.20	(0.38)	0.80	(0.29)	0.85	(0.19)	1.31	(0.35)
Stroke	2.04*	(0.63)	0.63	(0.28)	1.67*	(0.37)	1.28	(0.35)
Other card. dis.	1.82*	(0.54)	0.38*	(0.18)	1.17	(0.25)	0.77	(0.24)
Respiratory dis.	2.90**	(1.11)	0.66	(0.38)	1.39	(0.43)	0.95	(0.38)
Digestive sys. dis.	3.57*	(1.80)	0.64	(0.77)	1.16	(0.49)	0.90	(0.66)
Infectious dis.	1.36	(0.54)	0.54	(0.29)	1.51	(0.43)	0.75	(0.27)
Accident	10.47**	(7.57)	1.43	(1.28)	1.97	(1.34)	0.93	(0.67)
Other	1.86**	(0.43)	0.73	(0.26)	1.27	(0.21)	1.48	(0.35)
Log likelihood	1,484		-777		1,484		-777	
Sample size	1,696		960		1,696		960	

Notes: ADLs: activities of daily living. IADLs: instrumental activities of daily living. Limitations in ADLs were measured in three categories: 0, 1–5, and 6. Limitations in IADLs were measured in three categories: 0, 1–3, and 4. Southern Europe: Greece, Italy, Poland, and Spain. Central Europe: Austria, Belgium, France, Germany, and Switzerland. Northern Europe: the Czech Republic, Denmark, the Netherlands, and Sweden. Dis.: disease. Card.: cardiovascular. Sys.: system. [g] Significant differences in odds ratios versus only non-kin providers between the last and the previous year of life at 1 percent level. [h] Significant differences in odds ratios versus kin and non-kin providers between the last and the previous year of life at 1 percent level. * $p < 0.05$, ** $p < 0.01$. Reference group: unmarried men living in Northern Europe who died of cancer.

Source: SHARE waves 1–2 (Release 2.5.0), wave 3 (Release 1), and wave 4 (Release 1.1.1); authors' analysis.

Causes of death do not contribute much to the explanation of care provision in the previous year of life. In the last year of life only non-kin are significantly more likely than only kin to provide care to individuals dying of a stroke, other cardiovascular, respiratory or digestive system disease, as a result of an accident or from other cause. This might result from the public medical care, which is more likely to cover patients with the above-mentioned conditions.

Decedents in Northern Europe receive care from family members only significantly less often than individuals in Central and even less often than those in Southern Europe at the end of life. In particular, in the last year of life the non-kin are least likely to be the only source of care in Southern Europe, while being most likely to be so in Northern Europe. We find significant regional differences between the last and the previous year of life with respect to care provision by only kin versus by only non-kin.

4. DISCUSSION

Almost all decedents received care in the last year of life, which is a crucial change in comparison with the previous year of life. The set of individuals involved in care differs between the previous and the last year of life, as non-kin individuals provide care in the last year of life more often. A decline in care provision by the non-kin in the last year of life anticipated from the retreat from futile medical care was not observed.

Family members usually provide care at the end of life. In the last year of life, family members still meet the increased needs for care to a substantially greater extent than non-kin care providers. In our opinion, the inclusion of non-kin care providers does not indicate that family care providers reduce hours or involvement in care. The increased percentage of individuals receiving care from their family in the last year of life seems to result mainly from the substantial increase in the number of daily living limitations with respect to both ADLs and IADLs. Moreover, the decline in functional status possibly significantly broadens family responsibilities to assist in daily living. This in turn might lead to an increase in the number of relatives involved in care, or an increase in hours of care provided by family members, or both.

We find significant disparities between the European regions, especially between the Southern and the Northern Europe, with respect to the number of limitations in ADLs and IADLs, but they diminish in the last year of life. In addition, the regions differ deeply in the provision of care. Non-kin support to family members in the provision of care is very seldom in Southern and seldom in Central Europe, improving only slightly in the last year of life. However, in the Mediterranean countries, kin care involves fewer family members, who spend significantly more time on care, than in other European countries [23]. Possibly, in Southern Europe it is mostly family members within the household who provide care, whereas in Northern Europe it is mostly family members living in separate households who do so. We could expect that family members living together spend substantially more time on care than family members living in separate households. Regional disparities may be credited to the prevalence of familialistic policy regimes [24] and multi-generational households [25] in the Southern Europe.

Individuals who died of cancer were relatively least impaired in the previous and most so in the last year of life in comparison with individuals with other causes of death. The dynamics of cancer progression is responsible for this, as health usually declines rapidly for patients with lung, large bowel or ovary cancer. Presumably, limitations of the available medical treatment options for cancer contribute to the qualitative difference between individuals dying of cancer and individuals dying of other diseases.

The non-kin are most often the only care providers to individuals dying of a stroke, other cardiovascular, respiratory or digestive system diseases, in accidents and from other causes. We do not observe the same tendency in the case of a heart attack, infectious diseases or cancer, a medical condition associated with the largest decline in the functional status over the last years of life. Separate patterns of care receipt and functional status of individuals dying of cancer, which is increasingly the cause of deaths [26], deserve a more detailed analysis.

The limitations of this study do not affect its results. Missing end-of-life interviews are rare (3%) and usually occur when the proxies were unable or unwilling to share information about the deceased. The previous study by Hank and Jürges [9] found no evidence for bias due to the lack of relevant end-of-life interviews. Another source of a potentially more severe bias is the missing vital status of respondents who withdrew from the survey. This occurs where respondents participating in one wave cannot be contacted in the following waves. However, all individuals with unknown status are eligible for all future waves of SHARE until the end-of-life interviews are completed. Hopefully, the data releases to come will inform about their status. For the time being, the data from the end-of-life interviews are not representative for the whole population of diseased adults in Europe.

The regional differences indicate that universal solutions to the end-of-life problems may be hard to develop. The largest room for improvement in access to public or formal care is in Southern Europe. Professional care might be more efficient than the informal care most often received by adults with daily living limitations in Southern and also Central Europe. This might in part explain the relatively low functional status in Southern and Central Europe in the last year of life. However, if care provided by the kin and the non-kin are imperfect substitutes, the chances for improvement may be limited. A study by Motel-Klingebiel, Tesch-Roemer and von Kondratowitz [27] shows that informal care is not crowded out by care received from prosfessionals. But then it would be advantageous to enhance sharing care responsibilities between a larger number of family members, akin to Northern Europe. Perhaps public policies could address the inequality of engagement in end-of-life care within a family.

In sum, with this study we used a larger sample of SHARE decedents, including individuals residing in nursing homes. Our findings contribute the comparative components to the analysis of the end of life. Firstly, we observe the dynamics from the previous to the last year of life. Secondly, we observe significant cause of death-specific changes in daily living limitations and sources of care. Thirdly, we add IADLs to ADLs in the analysis of the functional status. We find that the last year of life differs significantly from the previous year of life, but the changes are region- and cause of death-specific. Further analysis should be conducted separately for specific cause of death and gender using a representative sample. Moreover, because the pace at which health declines depends on where the last 12 months of life were spent [28], places of residence in the last years of life are worth analysing once data providing information on all accommodation changes at the end of life become available.

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