

THE LAST YEAR OF LIFE IN EUROPE:
INITIAL FINDINGS FROM THE SHARE STUDY

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Abstract: This article provides an explorative overview of the life circumstances of older Europeans in their last year of life. Using information from 526 end-of-life interviews conducted as part of the 2006-07 Survey of Health, Ageing and Retirement in Europe (SHARE), we detect a high prevalence of disability in the last year of life, varying by socio-demographic characteristics and geographic region. The most important sources of help in the year prior to death are children and children-in-law, but non-family also plays a major role, particularly in Northern Europe. Two fifths of the decedents died outside of institutions, this fraction being larger in Southern than in Northern Europe. Most decedents divide their bequests almost equally between their children. Our findings draw an initial picture of older European's last year of life and show, how the research potential introduced in this paper might expand once future waves of SHARE become available.

Keywords: cross-national research; end-of-life research; quality of life

Introduction

Despite ‘broken limits to life expectancy’ (Oeppen & Vaupel, 2002) and evidence suggesting improvements in some dimensions of health in later life, including the immediate years prior to death (e.g., Liao et al., 2000; Parker & Thorslund 2007), the last year of life remains a particularly important and difficult period for the near-deceased themselves as well as for their families and health care professionals (see Romoren, 2003, for a comprehensive account). The year prior to death has been shown to be characterized by large increases in the propensity to experience significant cognitive and functional decline (e.g., Covinsky et al., 2003; Lunney et al., 2003), which constitutes a huge challenge to next-of-kin and professionals providing end-of-life care (e.g., Heyland et al., 2006; Imhof & Kaskie 2008; Lorenz et al., 2006), but also is an important cost factor for the medical system (e.g., Hogan et al., 2001; Rice & Fineman, 2004: 464f.). Thus, solid empirical knowledge about the last year of life is badly needed.

Over the past two decades, considerable evidence has been collected shedding light on various facets of older Americans’ last year of life, focusing on morbidity and disability in particular (see e.g., Bortz, 1990; Guralnik et al., 1991; Letzner et al., 1992 for early studies), but also investigating patterns of religious practice and belief (Idler et al., 2001), for example. The number of European studies investigating the life circumstances of near-deceased, however, is very limited yet (see e.g., Bickel, 1998; Kruse, 2006, for Germany; Cartwright, 1992; Hanratty et al., 2008, for Great Britain; Constantini et al., 2005, for Italy; Jakobsson et al., 2005, for Sweden). Moreover, to our knowledge no research taking a cross-national perspective has been conducted so far. This paper constitutes an important, though still preliminary, initial step to close this

gap. Based on unique data from the *Survey of Health, Ageing and Retirement in Europe* (SHARE), whose second wave in 2006-07 included an end-of-life (or “exit”) interview for first wave respondents who died since baseline data collection in 2004-05, we follow the lives of older people from 11 Continental European countries right until the time of their death.

The information available from the first round of SHARE exit interviews allows us, *first*, to describe patterns of ill health in the year prior to death, in particular with respect to limitations in performing activities of daily living (ADLs). *Second*, we will highlight the role of family and other persons in helping with these health-related limitations. *Third*, we will look at the place of death and how this is connected to prior health status and to the presence of family. *Fourth*, and finally, we will describe the distribution of the decedents’ bequests among family and others, discussing whether and how help the decedent received with ADLs might play a role therein.

The remainder of this article is structured as follows: the next section provides a detailed description of the data source on which this study is based. We then present our findings from the initial 2006-07 SHARE exit interviews. The final section concludes and provides an outlook on how the research potential introduced here is likely to expand with the availability of future rounds of SHARE end-of-life interviews.

Data

The analysis presented here is based on pre-release data from Wave 2 of the *Survey of Health, Ageing and Retirement in Europe* (SHARE), which was collected in 2006-07 (see Börsch-Supan et al., 2008, for a detailed description). The survey is modeled closely after the U.S. Health and Retirement Study (HRS) and it is the first European

dataset to combine extensive cross-national and longitudinal information on socioeconomic status, health, and family relationships of the elderly population. Wave 2 contains information on a representative sample of nearly 34,000 individuals aged 50 or older from 23,000 households in 14 countries, representing Europe's economic, social, institutional, and cultural diversity from Scandinavia to the Mediterranean. Eleven of these countries already participated in the 2004 SHARE baseline wave, contributing a total of 526 end-of-life interviews (for 282 men and 244 women). Because of this yet relatively small sample of decedents in the SHARE study, countries were grouped into broader regions (*Northern*: Sweden, Denmark, the Netherlands, *Western*: Belgium, France, Germany, Austria, Switzerland, *Southern*: Spain, Greece, Italy) to maintain sufficiently large numbers of observations for the analysis.

Exit interviews were conducted with so-called proxy respondents, mostly with relatives, but also with neighbors or friends (see Appendix for a detailed description) who provided information on the decedents' health, social well-being, and economic circumstances. Previous research showed that proxy respondents' assessments of physical health status, for example, exhibit a high level of reliability (e.g., Lawrence, 1995), thus making them not only an inevitable, but also trustworthy source of information for our study.

The average time between the decedent's death and the end of life interview was 14 months. Average age at death was 75.1 years among men and 80.7 years among women. One should bear in mind that what we will describe in the following as the life circumstances in the last year of life is likely to be a somewhat positively biased picture (see de Luca & Peracchi, 2005, and Schröder, 2008, for details on overall survey participation and attrition in SHARE). First, almost all of our respondents were sampled

from private households in 2004. With the currently available data we thus miss persons who already lived in nursing homes in 2004 by our initial sample design (Klevmarken et al., 2005; see Börsch-Supan et al., 2005: Chapter 2, for a detailed description of the SHARE baseline sample). Future waves of SHARE, however, will allow investigating end-of-life experiences in nursing homes along the lines of recent U.S. research (e.g., Allen et al., 2005; Munn et al. 2008; Wetle et al., 2005), as study participants moving into nursing homes will be tracked. Second, the fact that it was possible to find a person who was close enough to the first wave respondent and willing to share information about a recently deceased relative, neighbor or friend implies that we miss information on persons without close relatives or friends nearby. Overall, exit interviews have been realized in 60 percent of the cases of deceased respondents. Exit interviews are mostly missing for respondents who lived as singles. In cases where a member of the deceased's household could be contacted, exit interviews were conducted in 88 percent of the cases.

Results

Health and disability in the last year before death

We measure disability in the last year of life by the ability to perform activities of daily living (ADLs) without difficulty. We asked proxy respondents to name only such ADL difficulties, which lasted at least three months in the decedents last year before death. Building on the capacity to dress, walk across a room, bathe, eat and use the toilet, we distinguish three groups of decedents: ‘fully functional’ (no limitation), ‘moderately restricted’ (limitations in one to four ADLs), and ‘severely restricted’ (limitations in 5 ADLs).

Table 1 shows the percentage of fully functional, moderately restricted and severely restricted decedents by age at death, sex, education level, and country group. Overall, 39 percent of the deceased sample members are classified as having been fully functional in their last year of life, 37 percent are classified as moderately restricted and 24 percent are classified as severely restricted. These numbers vary significantly by age, sex, and country group. 49 percent of the decedents in the youngest age group (50-74) spent their last year of life fully functional and only 18 percent experienced severe restrictions for more than three months. In contrast, 32 percent of the decedents in the oldest age group (85+) were severely restricted during at least three months in their last year of life and only 28 percent were fully functional. Differences between the sexes are also notable. More women than men suffered from severe restrictions (33 vs. 17 percent), and less women than men were fully functional (31 vs. 46 percent). Part of this difference is due to the fact that women die at older ages. Our results for age at death and sex are in line with earlier studies from the U.S. (e.g., Guralnik et al., 1991; Liao et al., 2000).

We also find significant differences by level of education. The better educated have been shown to live longer (e.g., Huisman et al., 2004; Lleras-Muney, 2005) and earlier analyses using SHARE baseline data confirmed that they are healthier than the less educated (cf. Avendano et al., 2005; Jürges, forthcoming). Consistent with previous research investigating socio-economic differences in the health of near-deceased (cf. Cartwright 1992; Palmore & Burchett, 1997), our findings demonstrate that also in their last year of life, the better educated, i.e. those with at least completed secondary education (ISCED 3), are better off. 34 percent of the low educated, but 50 percent of the high educated spent their final year fully functional, whereas 28 percent of the low

educated and 17 percent of the high educated were severely restricted. Logistic regression analyses (details not shown here) confirm that educational differences remain significant even after controlling for age, sex, and cause of death.

Disability rates in the last year of life also differ across European regions (see Mackenbach et al., 2005, for an analysis of such differences in the full SHARE baseline sample). The lowest rates of disability were found in the Northern countries: 36 percent were disability-free and 17 percent were severely restricted. The largest rates of disability were found in the Southern countries, with 38 percent having been fully functional but 31 percent having been severely restricted. Again these differences remain statistically significant when cause of death is controlled for.

[Table 1 about here]

In order to understand how much of the disability we observe among the deceased SHARE respondents is actually due to a “terminal decline”, i.e. specific to the last year before death, it is useful to compare the increase in disability rates between Wave 1 and the last year before death with the increase in disability rates among those who survived and were re-interviewed in 2006. Table 2 shows the percentages of respondents in 2004 and 2006 (or in their last year of life, respectively) who were fully functional in 2004 and at the time of the re-interview, overall and by age group. In total, of those who survived and who were re-interviewed, 92 percent were fully functional in Wave 1 and 90 percent were fully functional in Wave 2. In contrast, of those who died between Waves 1 and 2, only 61 percent were fully functional in Wave 1 and 40 percent were fully functional in their last year of life. In other words, those who died between waves

were not only less functional on average in the first wave of SHARE, but they also experienced a much larger decline in their ability to perform ADLs.

Differences by age group (in 2004) are also substantial. Surviving respondents in the 50-74 age group experienced virtually no change in their functional status (although even the small decline we observe is statistically significant). Survivors in the older age groups experienced larger declines. Among those aged 75-84 and 85+, the percentage of respondents who were fully functional decreased by 6 percentage points and 8 percentage points, respectively. In contrast, among decedents, functional decline was largest in the youngest age group, both in absolute and relative terms, and smallest in the oldest age group, which is possibly due to some ceiling effect.

[Table 2 about here]]

Informal and formal help with activities of daily living

How did the decedents cope with the difficulties they experienced in their last year before death? More than 98 percent of the decedents who were moderately or severely restricted and for which end-of-life interviews were collected received help from family, neighbors and friends, or professional helpers. About half of them had one person who helped regularly, 30 percent were helped by two different persons, and 20 percent had at least three persons helping regularly (also see Bolin et al. 2008; Ogg & Renaut 2006, who provide detailed analyses of the provision of formal and informal care to elderly parents in SHARE's Wave 1).

Overall, the most important sources of help in the last year of life are children and children-in-law. 49 percent of all decedents received help from either sons or daughters

or children-in-law of either sex. Daughters (31 percent) and daughters-in-law (9 percent) are more often named as helpers than sons (20 percent) and sons-in-law (5 percent). The second most important sources of help with activities of daily living are spouses or partners (41 percent). Overall, 84 percent of the decedents received help from family members.

Non-family also plays an important role in caring for those who are in their last year before death. Overall, 46 percent of decedents who had problems with activities of daily living were helped regularly by friends, neighbors, volunteers, or – predominantly so – by professional helpers (39 percent; cf. Grabbe et al., 1995, for similar evidence from the U.S.).

Details on helpers, by country group, are shown in Table 3. The most striking difference can be found for the proportion of decedents who received help by professional helpers (see e.g., Broese van Groenou et al., 2006, for related evidence, which also suggests social class differences in elders' use of formal help). In the Northern countries, 70 percent of the decedents had help from professionals (cf. Larsson et al., 2008, for a detailed analysis). In Western Europe, these were 37 percent, and in Southern Europe only 18 percent received help from professionals. In contrast, children (in particular daughters and daughters-in-law) played a bigger role in Southern Europe: whereas 39 percent of the decedents in the South had help from a daughter and 26 percent received help from a son, only 23 percent and 17 percent, respectively, did in the North. In Northern Europe, daughters-in-law and other helpers are also less likely to be among those who help. Spouses, however, are somewhat more likely to help in the North, but they are most important in Western Europe.

[Table 3 about here]

Location of death

While many people state that they prefer to die in their own homes and not in hospitals or nursing homes, the majority does not die at their own home (cf. Beccaro et al. 2006; Bickel 1998). Table 4 shows the distribution of places of death of the SHARE decedents. We distinguish three categories of places: outside of institutions (which in most cases means at home), in hospitals or hospices, and in nursing homes. Overall, 39 percent of the decedents died outside of institutions, 47 percent deceased in a hospital or hospice and 14 percent died in a nursing home (cf. Brock et al., 1996, for a study on hospital and nursing home use during the last three months of life in the U.S.). Table 4 reveals a clear age gradient with respect to the propensity of dying in a nursing home. The probability is largest in the oldest age group and smallest in the youngest age group. The opposite trend is found for the likelihood of dying in a hospital or hospice: Whereas 58 percent of all decedents at ages 50-74 died in a hospital, only 39 percent of those aged 85 and over did. This is mostly due to the more acute causes of death at younger ages that are treated in hospitals. The probability of dying outside of institutions remains fairly constant across the entire age range (see Ahmad & O'Mahony, 2005, for a related study based on Welsh death certificates).

Whether decedents had close family (spouses or children) also plays some role in determining the location of death. Married decedents had a substantially lower chance of dying in a nursing home, but not higher chances of dying outside of institutions than those who were single, divorced, or widowed. Decedents with children had a lower chance of dying in a nursing home and a higher chance of dying outside of institutions.

Cross-country differences are again remarkable and in line with our earlier finding that in Southern Europe, family plays a bigger role in caring for people in their last year before death than in Northern Europe. In the South, 5 percent of the decedents died in a nursing home but 49 percent deceased outside of institutions, whereas in the North, the proportions of individuals who died in nursing homes and outside of institutions are about equally large (29 and 30 percent, respectively). Relative to the other groups of countries, dying in a hospital is most common in Western Europe.

[Table 4 about here]

Informal help and the decedents' bequest

In the SHARE end of life interview we also investigated who were the beneficiaries of the decedents' bequest (see Jürges, 2005, for an investigation of inheritances and bequest expectations in the SHARE baseline study). According to the proxy reporters, 10 percent of the decedents left no estate at all. If something was left and if the decedent was married, the spouse was named as a beneficiary in 82 percent of the cases (92 percent if the decedent had no children). Children – if present – were beneficiaries in 69 percent of the cases (89 percent if the decedent was not married at the time of his or her death). All other groups of potential heirs were mentioned rarely: siblings 10 percent, grandchildren 3 percent, and other relatives 6 percent. Less than 1 percent of the decedents left something to non-relatives or charities.

A recurrent theme in the sociological and economic analysis of intra-family relations is whether these relations are characterized by the altruism or reciprocity (or both). One example of reciprocity would be that those who have cared for the decedent

in the last year of life have a higher chance of being a beneficiary of the estate or of being the beneficiary of a life insurance (e.g., Brown 2006). Table 5 shows the percentage of decedents who left part of their estate to their spouse, a child, etc. depending on whether the spouse, child, etc. provided help with ADLs in the last year of life. Analytical samples are restricted to decedents who were not fully functional in their last year of life and who actually had relatives belonging to the respective group. Thus the percentages for spouses are computed for decedents who were married; the percentages for children are based on decedents who had children, and so on. Only the percentages for ‘other’ beneficiaries had to be treated differently, because the group of ‘other’ is not well-defined.

The results are surprisingly unambiguous. For each group of potential beneficiaries, help with ADLs increases the likelihood that someone of this group has actually received part of the estate. These results provide indirect evidence for the prevalence of reciprocity within and beyond the family. What we cannot infer from this result is that the deceased actually left something to specific individuals ‘because’ these individuals helped with ADLs. It is also possible that individuals helped ‘because’ they expected an inheritance and felt obliged to help, or that bequests and help were jointly determined by a particularly close relationship between the deceased and the helper (cf. Tomassini et al., 2003, for a related study on parental housing assistance and parent-child proximity in Italy). Of course, these alternative explanations can still be interpreted as reciprocal. More elaborate analyses – which are beyond the scope of the present study – would be needed to disentangle cause and effect. Moreover, part of the strong correlation between help and inheritance, especially for grandchildren and siblings, might simply be due to the fact that who helps and who inherits is also driven

by a ‘lack of alternatives’. If, say, the only living relative of the deceased was a sister, it might sound not too surprising that she has helped but also inherited from the decedent. However, when in this case the analysis is restricted to unmarried decedents without children, the pattern of reciprocity becomes even stronger. In this case, only 10 percent of the deceased left something to siblings if they had not helped with ADLs and 82 percent left something to siblings if they had provided help.

[Table 5 about here]]

In the SHARE end-of-life interview, yet another approach was followed to find out whether bequests are driven by altruism or reciprocity. Proxy respondents were asked whether the estate was divided about equally among the decedent’s children, or whether some children received more than others to make up for previous gifts, to give financial support, because they helped the deceased towards the end of his/her life, or for other reasons. Here we also find striking results. According to the information given by the proxy reporters, if children received anything, the estate was divided about equally in 88 percent of the cases. The remaining 12 percent were distributed equally across the remaining categories. Although this confirms earlier findings in the literature (e.g., Wilhelm 1996), it is somehow at odds with the results discussed in the preceding paragraph. Since it seems unlikely that all children provided about the same amount of care, reciprocity would predict a higher prevalence of unequal division (because of help given by some children) if there was any help given by the children. This, however, was not the case in our data.

Discussion

Based on an early release of data from ‘exit interviews’ conducted as part of the *Survey of Health, Ageing and Retirement in Europe* (Wave 2), this article provides initial insights into the life circumstances of older Europeans during their last year of life. Our key findings are:

- There is a high prevalence of disability in the year prior to death, with clear variation by gender and age.
- The most important sources of help in the last year of life are children and children-in-law, but non-family also plays a major role, particularly in Northern Europe.
- On average, two-fifths of the decedents died outside of institutions, but the proportion of decedents who died in a nursing home is much lower in Southern Europe than in the North.
- Most decedents leave bequests, which they divide almost equally between their children.

Future analyses of older Europeans’ last year of life are likely to uncover a plethora of important health, social, and economic issues, particularly if exit interviews are linked to more detailed information from preceding SHARE interviews with the decedents. Moreover, while the yet small number of observations precluded a fully-fledged investigation of cross-national differences in the life circumstances of the near-deceased, our somewhat rough distinction between three larger European regions (North, West, and South) already turned out to bear fruit, indicating how the research potential introduced in this article will expand once additional waves of SHARE – with greater numbers of exit interviews – become available.

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Appendix: Characteristics of proxy respondents

Tables A1 and A2 show some detail on the relationship of the respondents to the decedents. 40 percent of the proxy reporters were spouses and also 40 percent of the proxy reporters were children or children-in-law of the deceased. 11 percent were other family (siblings, nieces and nephews, grandchildren), and 9 percent were non-family

(neighbors, friends, social workers, nursing home and community officials). The proxy reporter's relationship with the deceased varies greatly by age at death and sex of decedent. For instance, for those who died at age 50 to 74, the surviving spouse answered the exit interview in nearly two-thirds of the cases, whereas children were proxy reporters in only 21 percent of the cases. For those who died at ages 85+, the percentages are nearly reversed. The numbers on respondent type by sex of decedent are in line with this result. For 57 percent of the deceased men but only for 20 percent of the deceased women, the surviving spouse informed us about the last year of life of the initial sample member. Again, the numbers are virtually reversed for children. They acted as proxy informant for 25 of the deceased men but 58 percent of the deceased women.

[Tables A1 & A2 about here]

It is worth noting that proxy respondents had very frequent contact with the decedent (see Hank, 2007, for a comprehensive analysis of contacts and proximity between parents and children in the SHARE baseline sample). Across all respondent types, 75 percent had daily contact with the deceased in the last year of his or her life. 14 percent had contact several times a week and only 11 percent had less frequent contact. Frequency of contact clearly varies by proxy reporter type (i.e. relationship to the deceased). Quite naturally, immediate family had the most frequent contact with the decedent. However, even among other relatives and non-relatives, more than 40 percent of the proxy reporters had daily contact.

Tables

Table 1: Disability rates (in percent) in the last year of life,
by age, sex, education, and country group (N=526)

	Severely restricted	Moderately restricted	Fully functional
Age 50-74	49	34	17
Age 75-84	37	36	26
Age 85+	28	41	32
Men	46	37	17
Women	31	36	33
Low Education	34	38	28
High Education	50	33	17
Northern	36	47	17
Western	42	35	23
Southern	38	31	31
Total	39	37	24

Source: SHARE, Wave 2 (pre-release), own calculations.

Table 2: Disability status in SHARE Waves 1 and 2 (last year of life, respectively),
by survivor status and age in Wave 1 (percentage of fully functional individuals)

	Fully functional in wave 1		Fully functional in wave 2/last year of life	
	survived	died	survived	died
Age 50-74	94	81	94	50
Age 75-84	83	59	77	39
Age 85+	61	34	52	24
Total	92	61	90	40

Source: SHARE, Wave 1 (Release 2.0.1) & Wave 2 (pre-release), own calculations.

Table 3: Help with ADLs received by decedents in their last year of life,
by type of caregiver and region (in percent)

	Northern European	Western European	Southern European	Total
Spouse	40	48	35	41
Son	17	16	26	20
Son-in-Law	2	7	4	5
Daughter	23	27	39	31
Daughter in Law	6	8	12	9
Other	21	24	29	25
Professional helper	70	38	18	39

Source: SHARE, Wave 2 (pre-release), own calculations.

Table 4: Place of death,
by age, sex, marital status, presence of children, and country group (in percent)

	Outside of institutions	Hospital	Nursing home
Age 50-74	37	58	5
Age 75-84	42	43	15
Age 85+	38	39	23
Men	40	53	7
Women	38	41	21
Unmarried	39	40	21
Married	39	54	6
Without child	34	45	21
With children	40	47	13
Northern	30	42	29
Western	36	53	11
Southern	49	46	5
Total	39	47	14

Source: SHARE, Wave 2 (pre-release), own calculations.

Table 5: Beneficiaries of the decedent's estate,
by group of beneficiary and help provided to decedent in the last year of life (in percent)

	Provided no help with ADL	Provided help with ADL
Spouse	44	79
Child	52	70
Sibling	6	67
Grandchild	2	27
Other	5	10

Source: SHARE, Wave 2 (pre-release), own calculations.

Table A1: Type of proxy reporter, by age and sex of decedent (in percent)

	Spouse	Child (in law)	Other relative	Non-relative
Age 50-74	64	21	8	7
Age 75-84	35	41	13	11
Age 85+	17	64	11	7
Male	57	25	9	9
Female	20	58	12	9
Total	40	40	11	9

Source: SHARE, Wave 2 (pre-release), own calculations.

Table A2: Frequency of contact in last year of life, by type of proxy reporter (in percent)

	Spouse	Child (in law)	Other relative	Non-relative	Total
Daily	96	68	47	41	75
Several times a week	0	20	20	41	14
Once a week or less	4	11	33	17	11

Source: SHARE, Wave 2 (pre-release), own calculations.

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