

Hendrik Jürges, Anne Laferrère and Adèle Lemoine

35 End of life and palliative care in Europe: An exploration of SHARE data

-
- ▶ The proportion of deceased that had needed help with pain, breathing or anxiety was 80 per cent, twice that of those deemed to need palliative care (41%)
 - ▶ Palliative care was less needed in Slovenia, Hungary, Austria, Poland, the Czech Republic and Germany. However, the need for help with pain, breathing and anxiety did not differ by country
 - ▶ Thirty-one per cent received adequate palliative care, or 75 per cent of those who needed it. Controlling for needs, a higher income increased palliative care reception
 - ▶ Care was less likely to be rated very good or excellent when palliative care was not available or when ailments were not properly addressed. Care was rated the highest in Austria, Greece, Switzerland, Spain, Croatia, Israel and the Czech Republic
-

35.1 Introduction

What is a good life? Is there a good death? The two questions sum up philosophy, literature and religion. As a more down to earth tool, the Survey on Health, Ageing and Retirement in Europe (SHARE) provides information on how Europeans and their families face old-age ailments. The survey also addresses death. A member of the family or a knowledgeable person is asked questions about the former respondent's last year of life. Inspired by Gawande (2014), questions about palliative care were added in Wave 7.

The 3 per cent who died in a hospice were assumed to have received palliative care (PC) there. For the others, the survey asked if they died in a PC unit and, if not, the following question: 'In the last four weeks of his/her life, did [Name of the deceased] have any hospice or palliative care?' A definition was provided: '*By hospice care we mean palliative care for terminally ill or seriously ill patients, delivered at home or in an institution. According to the WHO definition, palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*'. Note that the definition of palliative care was only provided after previous questions used the term or a synonym. For the 50 per cent

who died in a hospital, the question was ‘Was that in a *palliative care* or *inpatient hospice unit*?’, for the 9 per cent who died in a nursing home, the question was ‘Was that in an *inpatient hospice unit*?’ and for the 3 per cent who died in a residential home, it was ‘*Was the residential housing provided by hospice?*’ Until recently, in many European languages, a hospice meant a home for the sick or poor. Hence, that PC was overestimated is possible.

Fortunately, additional questions were asked, such as whether the deceased had suffered from pain, trouble breathing (dyspnoea), and anxiety, and how these ailments were dealt with. Leaving out those for whom no answer (2%) or a ‘don’t know’ answer (5%) was provided for PC or care provision, 2,998 observations remained. Of the deceased, 58 per cent had needed pain medication, 44 per cent had needed breathing assistance and 46 per cent had felt anxiety (all figures are unweighted). Pain relief in case of need was widespread (87%), as was help for breathing (89%). Anxiety seems to be somewhat less dealt with (82%). Receiving PC is expected to be synonymous with receiving help for these three ailments, if needed. However, there is a gap between both aspects.

Using a first definition of palliative care (dying in a hospice, in an inpatient hospice unit within a hospital or institution or having any hospice or PC in the last four weeks of life), the proportion receiving PC was surprisingly large, at 38 per cent (Table 1, col.4). For 59 per cent, PC was deemed not needed. The remainder is divided between when PC was not available (2%) and when it was too expensive (1%).

In 64 per cent of cases, all three needs were fulfilled, 20 per cent had none of the three ailments and 16 per cent had at least one of them unmet (Table 35.1, last line). Comparing PC reception and the satisfaction of the three needs leads to the creation of a stricter definition of palliative care, excluding from having had PC the 7 per cent for whom anxiety, pain or dyspnoea were not adequately cared for. The proportion of adequate palliative care provision plummets to 31 per cent and inadequate care increases to 10 per cent. In what follows, we analyse PC, adequate PC and whether the three needs (pain, dyspnoea, anxiety) were met.

35.2 Cross-national differences in palliative care

Needing and receiving PC depends on the cause of death. People who died from a long-term disease, such as cancer, represented a quarter of the deceased and nearly 40 per cent of those who had PC, and 58 per cent of those who died from cancer received PC. Significant differences in need for palliative care are observed among countries. Controlling for age and cause of death, countries

Table 35.1: Palliative care and the satisfaction of needed help with pain, breathing and anxiety.

	All 3 needs	At least one need	None of the 3	Total	Corrected definition
Declared...	were fulfilled (1)	was unfulfilled (2)	Needs (3)	(4)	(5)
... deceased had palliative care	27.1	7.1	3.5	37.7	37.7–7.1 =30.6
... palliative care was not available or too expensive	1.4	1.1	0.5	3.0	3.0
Quality of palliative care was poor					+7.1
... palliative care was not needed	35.0	8.0	16.3	59.3	59.3
Total	63.5	16.2	20.3	100.0	100.0

Note: In per cent. n = 2,998.

Source: SHARE Wave 7 release 0.

with the lowest needs were Slovenia, Hungary, Austria, Poland, the Czech Republic and Germany, where less than 30 per cent needed PC. The need for relief from pain, breathing and anxiety differed much less by country (Figure 35.1). When palliative care was deemed needed, only 7 per cent answered that it was not available or too expensive, but 29 per cent in Hungary did so.

To study access to care, we control for the need for care. We assume that the cause of death influences the need for PC or care and determines access only through this selection channel. Figure 35.2 presents the proportion receiving PC and that receiving adequate PC (excluding from adequate PC the cases for which pain, dyspnoea or anxiety were not taken care of) by country. Receiving adequate PC was more likely in Italy and Spain and less likely in Slovenia, Hungary or Israel.

Turning to the adequacy of care for pain, dyspnoea and anxiety, the best countries are again Italy and Spain but also Switzerland and Austria (Figure 35.3).

Conditional on needs, being married, the presence of children, relationship with proxy respondent, area of living, time spent with illness before death and the level of income or education could influence PC or care provision, either positively or negatively. We proceed with Heckman's two-step method. Table 35.2 presents the results. The first step estimates the need for PC (col. 1) and that of facing at least one of the three ailments (col. 4). Dying from cancer increases the

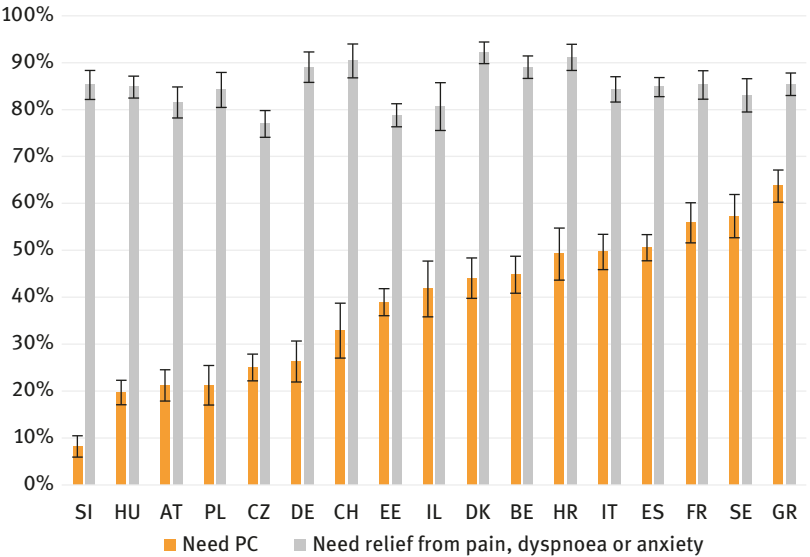


Figure 35.1: Need for palliative care or relief from pain, dyspnoea or anxiety by country.
Note: Adjusted for age and cause of death. Bars represent standard errors. $n = 2,998$.
Source: SHARE Wave 7 release 0.

probability of needing PC or help with pain, breathing or anxiety relative to other causes of death. Severe infections and respiratory diseases increase the probability of needing help for at least one of the three ailments, even relative to cancer. The positive relation between age of death and the need for PC supports the notion that the growing life expectancy might increase future needs for palliative care (Seale, 2000). Age is only significant at the 15 per cent level when the need for ailments relief is considered.

The second step (Table 35.2, col 2, 3, 5) estimates what affects receiving end-of-life care. The first specification (col. 2) uses the initial definition of PC, the second (col. 3) refers to the stricter definition of adequate PC and the third (col. 4) focuses on the proper relief of pain, anxiety and dyspnoea. Conditional on needs, dying older is positively related, while dying at home is negatively related, to receiving PC or adequate care. Sex has no effect. The presence of a spouse has no effect on receiving PC but positively affects the relief of pain, dyspnoea or anxiety. Being in the top income quartile facilitates receiving proper PC by 6 percentage points relative to those in the other income quartiles. Not being in the lowest level of education is positively correlated with adequate dealing with pain, dyspnoea or anxiety. Hence, a possible inequality in end-of-life care related to income and education, which may be linked to information about care.

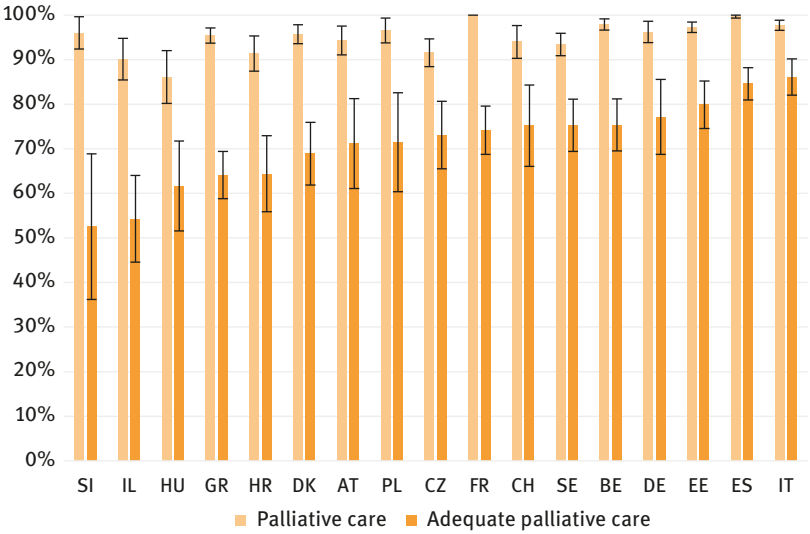


Figure 35.2: Quality of palliative care in case of need.

Note: Controlling for PC need. Adjusted for sex and age at death. Bars represent standard errors. n = 1,220 needing PC.

Source: SHARE Wave 7 release 0.

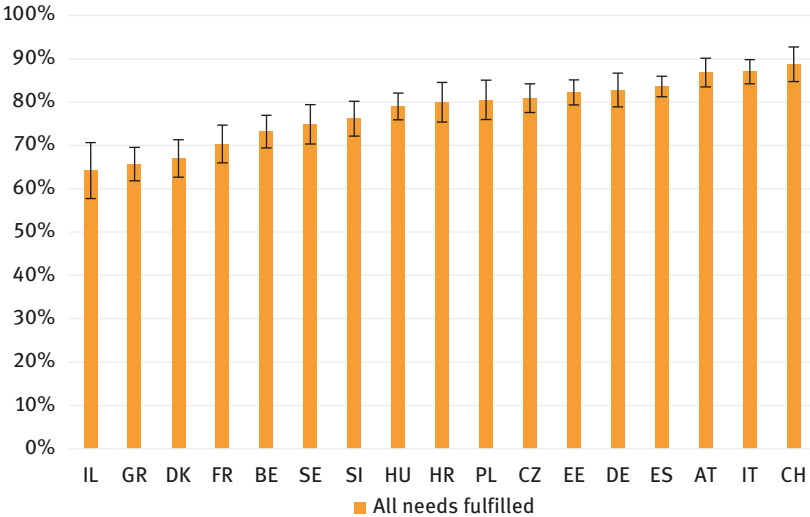


Figure 35.3: Relief from pain, dyspnoea or anxiety.

Note: Controlling for need for relief from pain, dyspnoea or anxiety. Adjusted for sex and age at death. Bars represent standard errors. n = 2,390 needing relief from at least one of the three ailments.

Source: SHARE Wave 7 release 0.

Table 35.2: Heckman probit: need for palliative care or relief from ailments, and determinants of PC, of adequate PC and of relief of ailments.

	(1) Need PC	(2) PC	(3) Adequate PC	(4) Need relief	(5) Met needs
Age at time of death	0.002**	0.002**	0.006***	0.001§	0.006***
Female	0.013	0.014	0.028	0.015	0.026
Cancer	ref			ref	
Heart attack	-0.342***			-0.181***	
Stroke	-0.160***			-0.173***	
Other cardiovascular disease	-0.190***			-0.145***	
Respiratory disease	-0.182***			0.046**	
Digestive system disease	-0.095*			-0.104**	
Infectious disease	-0.169***			0.047**	
Accident	-0.417***			-0.177*	
Degenerative disease	-0.143***			-0.193***	
Other	-0.126***			-0.159***	
Ill less than one month	-0.237***			-0.241***	
Ill more than one year	0.007			0.017	
Married		0.004	0.009		0.046**
No child		0.024	0.055		0.003
Income Q1		ref	ref		ref
Income Q2		-0.017	-0.051		-0.018
Income Q3		0.008	0.023		-0.006
Income Q4		0.026μ	0.063*		-0.014
Low education		ref	ref		ref
Mid education		0.005	0.040		0.052**
High education		0.034*	0.067§		0.090**
Big city		ref	ref		ref

Table 35.2 (continued)

	(1) Need PC	(2) PC	(3) Adequate PC	(4) Need relief	(5) Met needs
Outskirt of big city		0.001	−0.004		0.012
Large town		−0.034*	−0.041		0.014
Small town		−0.001	0.021		0.041§
Rural area		−0.031*	−0.004		0.051*
Area missing		−0.027	0.014		−0.007
Proxy non–relative		−0.031§	0.018		0.016
Nb years since death		0.002	−0.010		−0.012*
Died at home		−0.048**	−0.105**		−0.032*
N	2981	2981	2981	2981	2981

Note: Marginal effects. Other controls not shown: country dummies. *** $p < 0.01$, ** $p < 0.05$, * $p < 0.10$, § $p < 0.15$.

Source: SHARE Wave 7 release 0.

35.3 Determinants of care rating

The estimated probabilities of rating end-of-life care as very good or excellent are presented in Figure 35.4. Seventy-two per cent judged the care as excellent or very good, and this figure was 80 per cent or more in Austria, Israel, Switzerland, Greece, Croatia and Spain but 60 per cent or less in Hungary, Poland and Estonia. Clearly, having had inadequate care significantly reduces the rating to 58 per cent when PC was not available or too expensive, to approximately 67 per cent in the case of lack of pain relief, to 63 per cent in the case of lack of help with breathing and to 52 per cent when anxiety was not properly addressed. Having a spouse was favourable, as was dying at home. Having more income improved the care rating by 6 percentage points when income was higher than the median relative to the lowest quartile.

To summarize, receiving palliative care seems to be linked to care quality. The relief of pain or dyspnoea and, even more importantly, of anxiety helped people judge that care was excellent or very good. The links among anxiety, place of death and the rating of care should be further explored.

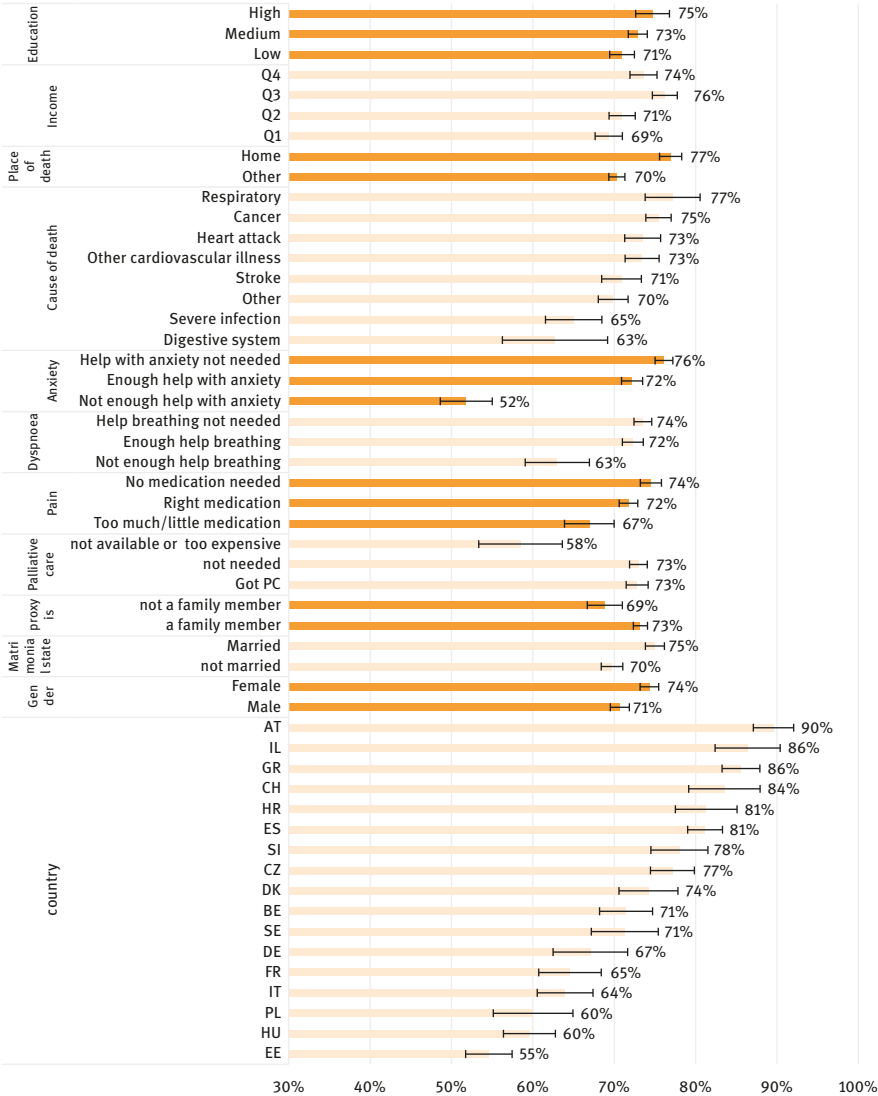


Figure 35.4: Estimated probabilities of rating care as excellent or very good.
Note: Logit model. Predictive margins. Bars are for standard errors. n = 2,892.
Source: SHARE Wave 7 release 0.

References

- Gawande, Atul (2014): Being Mortal. Illness, Medicine and What Matters in the End, Profile book, Wellcome Collection.
- Seale, C. (2000): “Changing patterns of death and dying”, *Social Science & Medicine* 51, 6, pp. 917–930.

