

HOW TO MANAGE THE END OF LIFE. AN INTERNATIONAL PERSPECTIVE

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How to Manage the End of Life. An international perspective.

Sergio Perelman^{*} and Pierre Pestieau[†]

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Abstract

This paper aims to explore the diverse strategies employed by various countries in managing end-of-life care. It examines the interplay between the State, the marketplace, and the family in navigating this critical phase of the human lifecycle. The core argument presented advocates for a paradigm shift away from intensive medical interventions towards an increased emphasis on palliative care. This proposed transition holds significant potential benefits, including the reduction of social insurance costs, minimizing out-of-pocket expenditures for families, and alleviating unnecessary suffering for patients.

Keywords: end-of-life care, palliative care, aggressive medical intervention, healthcare costs

1. Introduction

Less than a century ago, the topic of pensions was seldom addressed. At that time, the average life expectancy was below 65 years, which meant fewer people lived long enough to require pension support. However, as life expectancy began to extend, pensions rapidly ascended the ladder of social policy priorities. This increase in longevity also led to a rise in age-related disabilities, shifting the focus towards addressing issues of dependency and the loss of autonomy, which necessitated long-term care solutions.

More recently, there has been a growing concern surrounding end-of-life issues, a term that carries considerable ambiguity. The question arises: when does the end of life truly begin? For a young adult tragically killed in a road accident, it occurs in an instant. In many countries, the end of life is considered to have begun when all hope for recovery has vanished. At this juncture, a distinct care regimen is initiated, often accompanied by exceptionally generous reimbursement policies.

There exist two prevalent definitions of the end of life: the first posits that it begins when there is no longer any hope of recovery, yet does not exclude the possibility of employing various aggressive treatments intended to extend life. The second, more restrictive definition,

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asserts that the end of life commences once a patient is admitted into a palliative care program or similar.

Notably, in some Anglo-Saxon countries, the terms 'end-of-life' (EOL) and 'palliative care' are frequently used synonymously, indicating a period when the nature of care significantly shifts. This phase underscores the vital role of family support and introduces new responsibilities for public authorities, both in financial and legal realms.

The approach to end-of-life care varies considerably across different countries. This article aims to explore and compare these varying practices worldwide, highlighting the complexities and diverse perspectives on managing the final stages of life.

2. Health care

The end-of-life period begins at the point at which there can be no further recovery or cure, and the only way out is death. During this period, there should be a change in the type of healthcare provided. Most healthcare systems and traditional medical approaches focus on curative interventions. While curative care aims to improve and prolong quality of life, not all illnesses are curable. Curative interventions for incurable diseases may not prolong life or improve its quality. What's more, they are often costly for individuals, their families and healthcare systems as a whole. These healthcare systems are focused on healing, and tend to keep patients alive, even at the cost of pain, suffering and a deterioration in their quality of life, regardless of the expected success of the care. Preparing or planning for death remains outside the normal care process, leaving people with terminal illnesses with limited opportunity to choose the level of medical intervention they prefer. So, instead of focusing on intensive procedures with little clinical benefit and no improvement in quality of life, some research is now concentrating on the "quality of death". This research compares the quality of palliative care in different countries.

The period preceding admission to palliative care is sometimes a time when family and doctors may be tempted, for different reasons, to prolong life, sometimes at the price of unbearable suffering for the patient and high costs for families. Many people, especially at advanced ages, wish to avoid therapeutic overkill. This is not always possible, for two reasons. Firstly, the dividing line between aggressive therapy and palliative care is not always clear. Secondly, some doctors, more so in a country like the United States than in Belgium or the Netherlands, take the Hippocratic oath to the letter. As a result, they are unwilling to resign themselves to their patient's death as long as there is hope of keeping him or her alive. It is in the name of this oath that they are reluctant, even opposed, to euthanizing their patient, even where this is perfectly legal and despite the patient's wishes.

3. The costs.

It is important to note that the costs of end-of-life care can be influenced by factors such as the availability of palliative care services, the prevalence of advance care planning and the

use of aggressive medical interventions. The United States often has higher end-of-life care costs than many other developed countries. This is partly due to the widespread use of aggressive medical interventions, a fee-for-service healthcare system and a cultural tendency to pursue life-prolonging treatments. In contrast, European countries such as the Netherlands and Belgium have well-established palliative care programs. In these countries, end-of-life care may focus more on improving patients' quality of life than on aggressive medical interventions. That said, there are variations between countries in terms of their stance on the issue of end-of-life care. The example of Canada is interesting. Here, the healthcare system is publicly funded, and it takes several months to get most medical appointments. However, as soon as a patient is declared to be EOL (end of life), these barriers come down. They have the right to unrestricted end-of-life care. This care can be provided on the premises of a palliative care home or at home. This contrast between limited access to health care before the end of life and unrestricted access after the patient is deemed to be at the end of life is found to a greater or lesser extent in most countries. The reasons for this difference in treatment are open to question. Could it be a way for the state to compensate individuals for their impending death? Even if the out-of-pocket expenses can be substantial, health care at the end of life is for the most part covered by social security. Clearly, the decision to enter palliative care remains the responsibility of the patient and his or her family. However, this decision has a definitive budgetary impact. A recent study¹ conducted in Canada shows that increased use of palliative care services should lead to a reduction in end-of-life costs.

4. The family

The quality of end-of-life care, whether at home or in an institution, often depends on the family circle. The family plays a decisive and, more often than not, positive role. Being surrounded by loved ones is comforting. The end of life is undoubtedly the time of life when people feel most vulnerable and fragile. To be able to count on the loving, selfless assistance of loved ones to protect them is essential, especially in the case of mental degeneration. The family can protect the individual from himself (falls, injuries...) or from others (abuse of weakness), but care must be taken not to go too far and to respect the patient's principle of self-determination. This means respecting their ability to decide for themselves, and to be free to make their own choices for as long as possible. Being old doesn't mean being incompetent or a sub-citizen, especially when you still have all your wits about you. And even with mental diseases such as Alzheimer's, it's perfectly possible to continue to make one's own choices up to an advanced stage.

Unfortunately, this is not guaranteed. Sometimes, for his own good, his loved ones deprive him of what little freedom he has left. He would so much have liked his suffering to have been shortened by a dignified euthanasia. This was refused by a reluctant family and an obtuse doctor taking advantage of his weakened state. Before that, when he still had a good part of his head, he was subjected to what could be called abusive altruism. His children put him in a shabby nursing home he didn't want, for his own good of course. Not too badly either, for their own good. Still, for his own good, they put him under guardianship, so that he no longer has any control over his income and assets. How do you avoid such hell? It's not

easy. Even more complicated than avoiding institutional abuse, or even cynical family abuse. In this case, the abuser is convinced of his right to do so. He behaves in this way for the good of the dependent person, who doesn't know what's good for him. Added to this is the fact that, in extreme cases, the legal system always sides with the family. It's clear that once set in motion, this infernal scenario cannot be stopped. So we need to prevent and anticipate. The best way to prevent this is undoubtedly to invest emotionally in the family. In Asian countries, for example, there has been a change in the way children are brought up. Parents are gradually abandoning the strict style of what is known as "tiger parenting"² for a style imbued with patience and love, which takes longer but ensures that they can count on their children in their old age in case of need.

That said, even with the best will in the world, it's not always possible to avoid such altruistic abuse, and it's important to take action long before it's too late. The situation varies widely from country to country. The proportion of elderly people who have a written plan designating a person who will make decisions about their treatment ranges from 67% in the USA and 62% in Canada to 16% in the Netherlands.³ These are elementary precautions which, in most cases, will be of no use, as the majority of end-of-life situations are, fortunately, more harmonious than those just described.

5. The law. Policies on euthanasia and assisted suicide.

Law concerning the end of life varies from country to country. Therapeutic overkill is never forbidden and sometimes implicitly encouraged in a number of countries. On the other hand, laws concerning end-of-life care and issues such as euthanasia or assisted dying vary considerably from country to country. Both the Netherlands and Belgium allow euthanasia under strict conditions, which must be based on the patient's explicit request and unbearable suffering. In Switzerland, assisted suicide is legal in certain circumstances. Organizations such as Dignitas and Exit offer assisted suicide services to people with terminal illnesses. In Canada, medical assistance in dying (MAD) is legal subject to specific eligibility criteria, including a serious and irremediable medical condition, and a distinction is made between active and passive euthanasia⁴. According to a recent survey⁵, active euthanasia is currently legal in only a minority of countries: Australia, Belgium, Canada, Colombia, Luxembourg, the Netherlands, New Zealand and Spain. Passive euthanasia, on the other hand, is authorized in Argentina, Chile, Finland, Germany, India, Ireland, Japan, Mexico, Portugal, South Korea, Sweden, Switzerland, the United Kingdom and several states in the United States. This list is rapidly evolving, as a growing number of countries are considering legalizing euthanasia. In France, assisted dying is still illegal, but debates and efforts are underway to change the law. It is worth noting that where it is authorized, assisted dying does not seem to be exploding, contrary to what its detractors predicted.

The possibility of access to euthanasia gives patients the security of knowing that they will not suffer excessively, even if they do not usually resort to it. It's hard not to think about suicide when discussing euthanasia. In most countries, suicide is most common among the elderly, although it is the leading cause of death among younger people. Needless to say,

these figures are underestimated for the elderly. Even if this cannot be measured, it is known that many elderly people die with the help of their GP. It should be noted that the possibility of euthanasia does not reduce the number of suicides.

Undoubtedly, the variations in end-of-life care across different countries can be attributed to cultural, religious, and societal distinctions. These differences manifest not only in legal perspectives regarding practices such as assisted suicide and euthanasia but also in the organization of palliative care services. The same national features explain differences in the way patient autonomy and self-determination in end-of-life care decisions are respected.

In several nations, including France, there is a noticeable disparity in the distribution of palliative care facilities across different regions. This uneven accessibility leads to unfortunate consequences in terms of equity, making it harder for certain populations to access these essential services. Furthermore, it is evident that disparities at the end of life are intensified among individuals with differing levels of resources, highlighting a broader issue of inequality in end-of-life care.

6. Japan and its old people

When it comes to old age, Japan is a country of records: extremely low fertility and one of the highest longevity rates in the world. As a result, Japan's current population of 128 million is set to shrink to 87 million in 2060 and 51 million in 2100. By 2100, the proportion of the population aged over 65 will be close to 40%. In addition, the country's public debt is abysmal and the effective retirement age is close to 70. Despite this advanced age, the country is experiencing major difficulties in financing its pay-as-you-go pension system. Younger generations have the impression of being the victims of a real holdup. In a country where euthanasia is not legal, this has given rise to some surprising reactions, with Yusuke Narita, a young economist and professor of economics at Yale University, tackling the question of how to cope with the burdens of a rapidly ageing Japanese society. In recent public appearances⁶, he has declared: "I have the impression that the only solution is quite clear. In the end, isn't it mass suicide and mass 'seppuku'⁷ of the elderly?" In reaction to this opinion movement, which fortunately remains in the minority, Japanese filmmaker Chie Hayakawa recently shot "Plan 75", a dystopian film depicting cheerful salesmen courting pensioners to submit to government-financed euthanasia. Her aim was to show just how far gerontophobia could go. In this respect, we need to distinguish between the current problem of financing pensions, which can be solved without resorting to such extremes, and the problem of primitive societies where resources were limited and where living too long prevented new births. These situations, which belong to the distant past, are reflected in Japanese folklore, in which families take their elderly parents to mountain tops or remote forest corners to let them die. This folklore gave rise to the 1958 film 'The Ballad of Narayama' and its 1983 eponymous remake, which, like 'Plan 75', won awards at Cannes. It's worth noting that just because we reject an extreme solution such as mass euthanasia, that

doesn't mean we shouldn't act. Fortunately, other levers exist: immigration, fertility and retirement age. Japan still needs to use them.

7. Patient participation

Determining the exact amount of costs incurred by patients for end-of-life treatments can be difficult, as it depends on a variety of factors, including the healthcare system, insurance coverage, individual treatment choices and the availability of support services. In addition, cultural and societal factors can influence the preferences and choices of patients and their families at the end of life. The overall cost of end-of-life treatments can vary considerably, depending on factors such as the country or region, the specific medical interventions required and the healthcare system in place. End-of-life treatments can include palliative care, medications, medical procedures and other supportive care. In many countries, end-of-life care is covered by health insurance or state-funded healthcare systems, which can help ease the financial burden on individuals and their families. However, out-of-pocket expenses may still arise for a variety of reasons, including co-payments, uncovered services and certain medications. In some regions where access to healthcare is limited or insurance coverage inadequate, individuals and families may bear a greater financial burden for end-of-life treatments. The result can be significant disparities in access to quality care, and financial strain for families who are already coping with the emotional challenges of end-of-life situations. It is essential to bear in mind that data on the overall costs of end-of-life treatments may not be readily available or accurately documented due to variations in healthcare systems, reporting practices and cultural differences. In most countries, the palliative care phase, whether at home or in an institution, is fully reimbursed by social security. However, before this phase, when families and patients are tempted to undergo interventions, whose sole aim is to prolong life by a few weeks, the out-of-pocket expenses can be considerable. In other words, the relentless pursuit of treatment leads to suffering and expense.

8. Where to die?

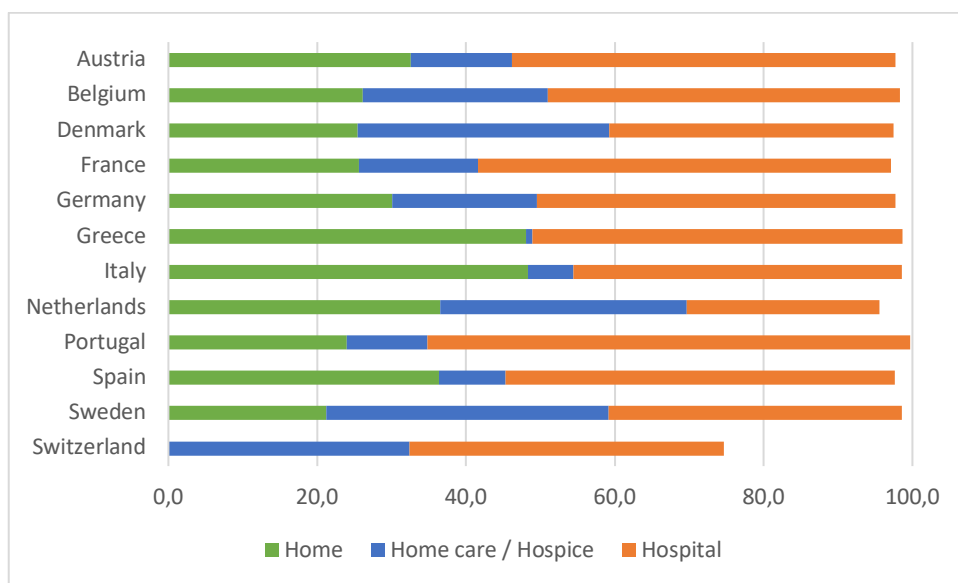
Using data from the European SHARE survey⁸, Otlovic et al.⁹ attempt to compare where people die in around twenty countries, i.e., at home, in a nursing home or in hospital, with the implication that the latter solution is the costliest for families. They show that the increased use of ambulatory long-term care facilities in countries with higher public spending on long-term care leads to a reduction in hospital admissions and an increase in the proportion of out-of-hospital deaths, compared with countries where end-of-life care is mainly privately financed, which tend to have underdeveloped and underused formal long-term care facilities. As a result, end-of-life care in privately-funded countries is more hospital-based. Focusing on Belgium, Gielen et al. (2010) show that life ending in hospitals is more expensive than in palliative care centers¹⁰

Figure 1 shows places of death in a sample of European countries using SHARE updated data. This figure shows that the fraction of people who are in a nursing home or hospice at

the time of death is particularly high in Sweden, Switzerland, the Netherlands and Denmark, which are known to have particularly high levels of public LTC insurance. In these same countries, the proportion of people dying in hospital is relatively low.¹¹

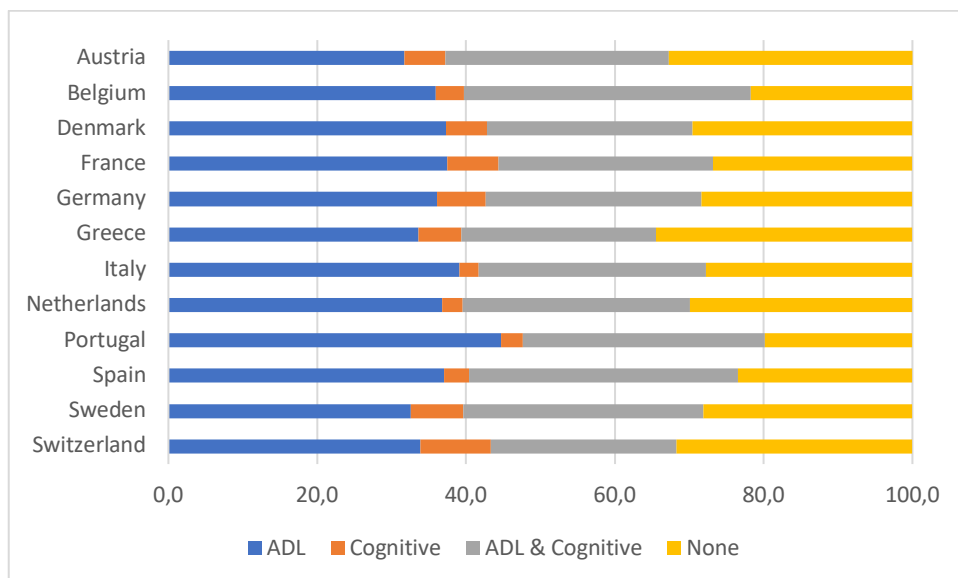
At the time of death, there are some people who suffer no dependency at all, and who are perfectly autonomous. However, they represent a minority, as Figure 2 shows. Portugal is the country where people have the most physical or cognitive problems, and Greece has the least, followed by Austria and Switzerland. In terms of disabilities, we distinguish between limitations in the exercise of daily activities (ADL) and cognitive dependencies, separate and combined.

Figure 1: Place of death in Europe (in %)



Source: SHARE Survey. Own calculations based on information reported by relatives of the deceased respondent (Waves 2 to 8, 2005 to 2020).

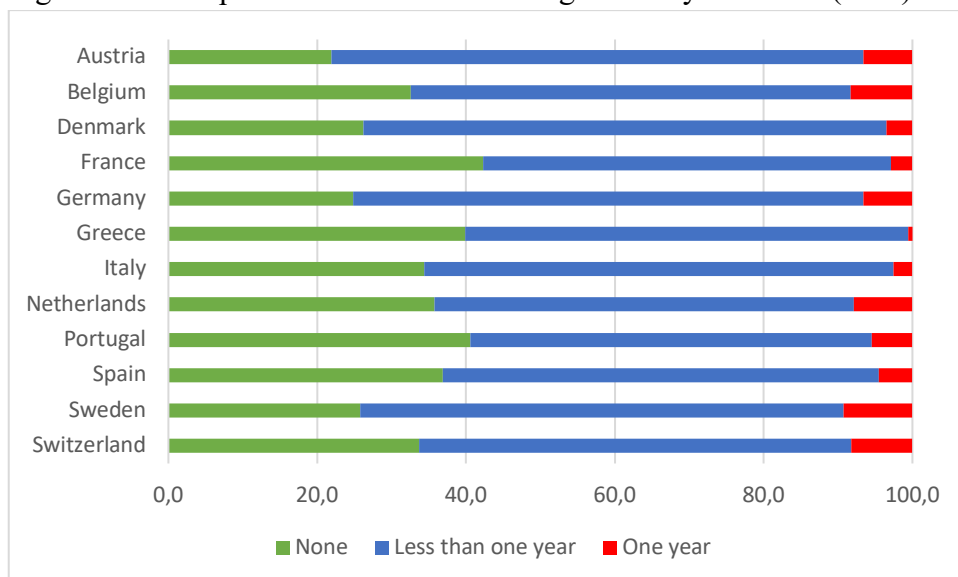
Figure 2: Type of dependency in the last year of life (in %).



Source: See Figure 1.

It is also interesting to compare countries according to the time spent by individuals in an institution of any kind in the last year of life. According to Figure 3, France is the country where most people spend the whole of their last year of life at home. More generally, this trend is found in southern European countries. To the contrary, in Sweden and generally northern European countries, people are the most likely to spend the last year of their lives in an institution.

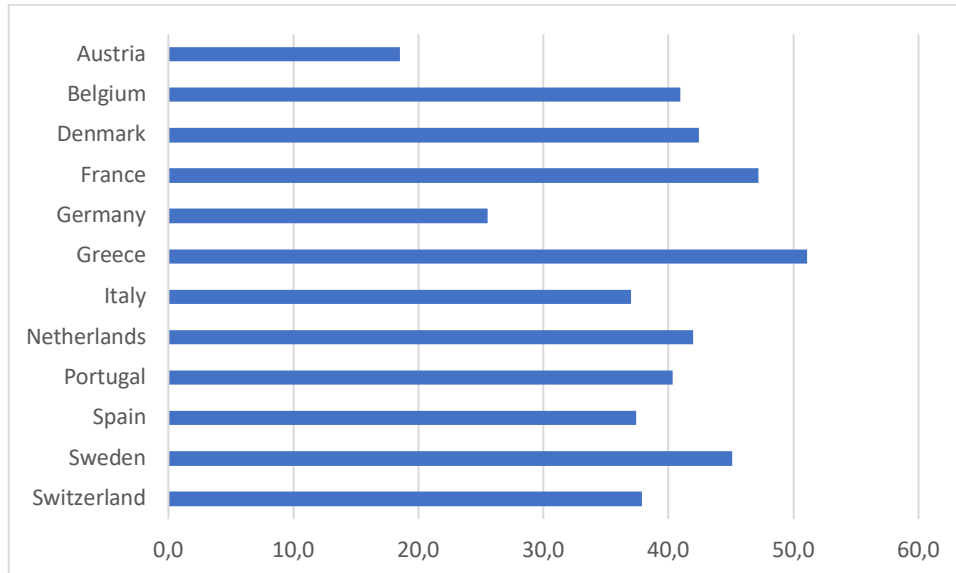
Figure 3: Time spent in an institution during the last year of life (in %)



Source: See Figure 1.

In Europe, the use of palliative care varies greatly from country to country. Figure 4 shows data for a sample of countries, with variations ranging from 18% in Austria to 52% in Greece for people dying over the age of 64. This figure includes palliative care received at home, in nursing home, in hospital and in specialized centers.

Figure 4: Share of people who used palliative care before dying (aged 65 or over)



Source: SHARE Survey, Waves 7 and 8 (2017 to 2020).

9. Conclusion

Among the various stages of life, the final phase stands out as the period when individuals experience heightened vulnerability, both physically and emotionally. As we navigate this concluding chapter, the desire for tranquility and peace becomes paramount. However, numerous factors can obstruct this pursuit. These include the possibility of encountering greed or lack of appreciation from relatives and friends, a medical community fixated on curing rather than comfort, insufficient social support, and legal systems that do not fully honor the dignity of dying individuals.

To address these concerns, it is imperative to establish a legislative and social support framework that respects and incorporates the wishes of patients regarding critical decisions. These decisions may involve management of assets, selecting a place to spend one's final days, choosing between palliative care and euthanasia, or opting out of aggressive medical interventions. Despite advancements in certain countries concerning these matters, there is still considerable work to be done to ensure everyone can end their life freely and with dignity.

In addition to the moral imperatives, there are practical considerations regarding health care costs, which are becoming increasingly burdensome for both the state and individual families. The agony associated with the end of life is, in many instances, profoundly distressing. The forthcoming years should see a significant shift towards enhancing investments in palliative care and reevaluating conventional treatment philosophies that often result in excessively aggressive interventions.

Such a paradigm shift promises threefold benefits: it would alleviate the financial strain on social security systems, reduce the economic burden on families during these challenging times, and mitigate unnecessary suffering. This reorientation towards patient-centric and dignity-affirming care at the end of life is not only a compassionate choice but also an economically and socially responsible one.

Appendix. Causes of death.

It is interesting to analyze the main causes of death, and especially to compare them for different age groups. Tables 1a and 1b illustrate what distinguishes the very old (80+) from the less old (50-79). While cancer and heart disease are equal as the main causes of death for the younger age group, this is not the case for the very old, for whom cardiovascular disease is clearly the leading cause of death. Among the very old, the "other" category takes on great importance, as it includes the many cases of death in old age.

Table 1a: Causes of death among the population aged 50 to 79 years old (in %)

Country	Cancer	Heart disease	Respiratory disease	Other
Austria	28.6	37.1	4.1	30.2
Belgium	44.8	27.9	5.7	21.6
Denmark	44.4	25.0	8.0	22.6
France	40.1	29.3	8.0	22.6
Germany	41.0	35.8	4.4	18.8
Greece	35.2	46.9	4.8	13.1
Italy	41.7	37.9	5.4	15.0
Netherlands	46.9	29.3	4.5	19.3
Portugal	38.6	25.9	3.0	32.5
Spain	32.3	34.3	8.6	24.8
Sweden	46.8	26.7	5.4	21.2
Switzerland	47.5	34.6	2.8	15.1
Mean	38.8	34.6	6.1	20.4

Source: SHARE Survey. Own calculations based on information reported by relatives of the deceased respondent (Waves 2 to 8, 2005 to 2020).

Table 1b: Causes of death among the population aged 80+ years old (in %)

Country	Cancer	Heart disease	Respiratory disease	Other
Austria	10.2	44.5	2.5	42.8
Belgium	17.5	30.3	5.7	46.6
Denmark	21.3	21.0	7.7	50.1
France	20.5	33.1	6.0	40.4
Germany	13.8	47.9	2.2	36.2
Greece	10.4	61.9	7.3	20.4
Italy	17.3	50.6	9.6	22.6
Netherlands	18.5	25.4	1.9	54.2
Portugal	13.9	31.1	7.7	47.4
Spain	15.7	40.1	12.3	32.0
Sweden	16.3	36.0	3.6	44.1
Switzerland	19.9	28.6	4.7	46.8
Mean	16.3	42.2	8.1	33.5

¹ Cost-effectiveness of palliative care (2022) <https://www.acsp.net/wp-content/uploads/2024/01/TWF-Cost-Effectiveness-Documents-de-travail-FR>

² Tiger parenting is a style of parenting that emphasizes academic achievement, life success, and discipline. Tiger parents are strict and stress the importance of school performance and career development, often by setting high expectations and withholding affection.

³ American Academy of Actuaries (2017), End-of-Life Care in an Aging World: A Global Perspective <https://www.actuary.org/endoflifecare#:~:text=Issues%20surrounding%20end%2Dof%2Dlife,economic%20burdens%20on%20future%20generations>

⁴ Active euthanasia: killing a patient by active means, for example, injecting a patient with a lethal dose of a drug. Sometimes called “aggressive” euthanasia. Passive euthanasia: intentionally letting a patient die by withholding artificial life support such as a ventilator or feeding tube.

⁵ World Population Review (2023) <https://worldpopulationreview.com/country-rankings/where-is-euthanasialegal>

⁶ <https://www.nytimes.com/2023/02/12/world/asia/japan-elderly-mass-suicide.html?searchResultPosition>

⁷ Seppuku is a form of taking one's own life that was considered honourable among the feudal Japanese samurai class.

⁸ The [Survey of Health, Ageing and Retirement in Europe \(SHARE\)](#) is a multidisciplinary and cross-national panel database of micro data on health, socio-economic status and social and family networks of more than 85,000 individuals (approximately 150,000 interviews) from 19 European countries (+Israel) aged 50 or over.

⁹ Orlovic, M., J. Marti et E. Mossialos (2017), Analysis Of End-Of-Life Care, Out-Of-Pocket Spending, And Place Of Death In 16 European Countries and Israel, Health Affairs, 36. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0166>

¹⁰ Gielen, Birgit, Anne Remacle, Raf Mertens, Patterns of health care use and expenditure during the last 6 months of life in Belgium: Differences between age categories in cancer and non-cancer patients, *Health Policy*, 97 (2010) 53–61

¹¹ Of course, age and cause of death—cancer, heart disease, respiratory problems or other—are related and can influence the place of death. Tables 1a and 1b in the Appendix illustrate these differences. As an example, cancer, which represents the leading cause of death, nearly 40%, among people aged between 50 and 79, is the cause of less than 20% of deaths among the 80+.