

***Palliative care at the end of life
in Western Europe:
The Scandinavian Paradox***
(book chapter)

James M. Hoefler
Dickinson College

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Palliative Care at the End of Life in Western Europe: The Scandinavian Paradox

James M. Hoefler

Abstract

Tremendous strides have been made in the last two decades with regard to the quality of palliative care available to patients at the end of life. But progress has not been uniform, even among countries in the same region of the world. The objective of this chapter is to describe, in a comparative Western European context, the current status of end-of-life palliative care in four Scandinavian countries: Denmark, Norway, Sweden, and Finland. Despite their well earned reputations as liberal, progressive welfare states, these four Scandinavian countries tend to do less well than many of their Western European counterparts when it comes to end-of-life care policies and practices. Understanding the cultural and political forces that underlie this reality may help health care professionals and policy makers overcome the barriers that have impeded the development of palliative care policies in these four countries.

Key Words: Palliative care, terminal care, hospice, Denmark, Norway, Sweden, Finland, Scandinavia

1. Introduction

According to the World Health Organization (WHO), palliative care at the end of life – care concerned with the quality of life patients experience in their dying days – is one of the more important but neglected public health issues of our time.¹ WHO identifies needs for improvements both in (1) training and education for care givers and (2) symptom management for patients.

Advances in end-of-life care have been made in many countries in recent years. The UK has developed a solid reputation as a leader in end-of-life care, and other countries in central Western Europe (e.g., Ireland, Belgium, and Austria) have made important strides in this area as well. At the same time WHO notes that progress in adopting palliative care as a clinical priority has lagged elsewhere, even in many first-world countries. Data collected on palliative care policies and practices across Western Europe suggest that countries in Southern Europe (Spain, Italy, and Portugal) and Scandinavia (Denmark, Norway, Sweden, and Finland)

tend to register below (and often well below) the median on end-of-life care (see Figure 1).²

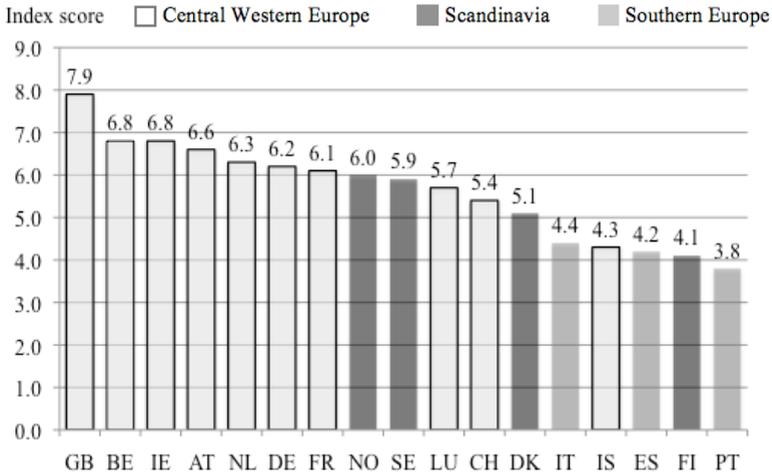


Figure 1: Index scores for *Quality of Death*

In Southern Europe, the religious influences of the Roman Catholic Church are surely an important part of the explanation for the current status of end-of-life care there. Catholic positions on health care at the end of life are best characterized as conservative by current standards of professional medical practice. The Church's stance on forgoing artificial nutrition and hydration (ANH) at the end of life is instructive. This practice is typically viewed as both ethically sound and clinically appropriate in the professional, secular palliative care community, but is viewed with considerable suspicion by the Catholic hierarchy. The same could be said for the use of palliative sedation to manage intractable symptoms at the end of life. Palliative sedation has become widely accepted as an end-of-life protocol within the palliative community, but the procedure is generally considered unacceptable by Church leaders.^{3 4 5 6}

Most citizens identify themselves as Catholics in Spain (94%), Italy (90%), and Portugal (85%), so it stands to reason that palliative care might lag in these countries given conservative church positions on end-of-life care. Even if many who identify themselves as Catholic are not regular church-goers, the moral positions of the church in end-of-life scenarios still shape, to a large degree, the kinds of care that are readily available in places where the Church is an important part of the societal fabric.

The medically and culturally conservative influence of the Catholic Church helps us understand the end-of-life care landscape in southern Europe, but Catholic

positions in this area have very little to do with what happens in northern Europe. There are very few Catholics in Scandinavia (see Figure 2). Indeed, religious influences of any kind are essentially non-existent in these predominantly secular countries.

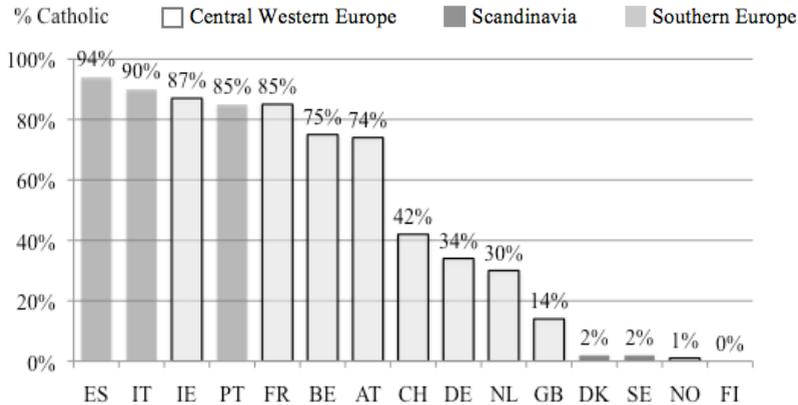


Figure 2: Percent of residents identifying as Catholic in Western Europe⁷

It is also the case that the welfare state in Spain, Italy, and Portugal is modest by Western European standards. This provides a second explanation for low end-of-life care rankings in southern Europe. For example, public health care spending rates in these three countries are among the lowest in Western Europe. Palliative care at the end of life is not particularly expensive, but low spending on health care in general means there is less to spend on any kind of care.

Here again, though, while welfare state spending helps explain why southern European countries might lag behind their continental neighbours in the quality of end-of-life care provided, health care spending does not help us understand much about the status of end-of-life care in Scandinavian countries. While health care spending per capita in Finland is not much higher than it is in Italy, and while health care spending is about average in Sweden, Denmark and Norway spend more on health care per capita than anywhere else in Western Europe (see Figure 3). More generally, while Finland spends a little less than the median amount on social welfare programs, Denmark, Norway, and Sweden all cluster at the high-spending end of the spectrum (see Figure 4).

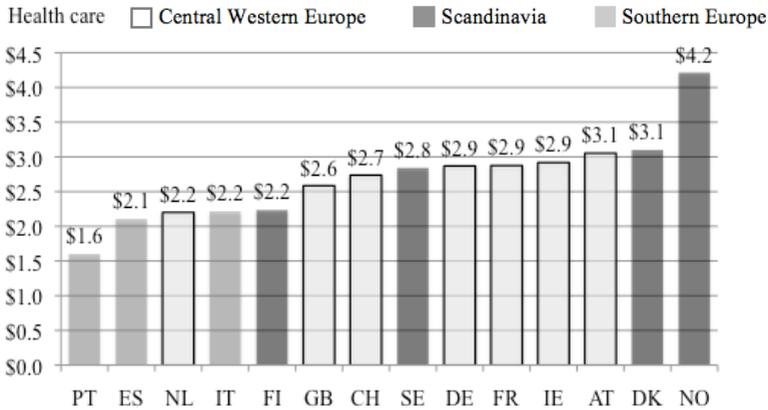


Figure 3: Per capita spending on health care

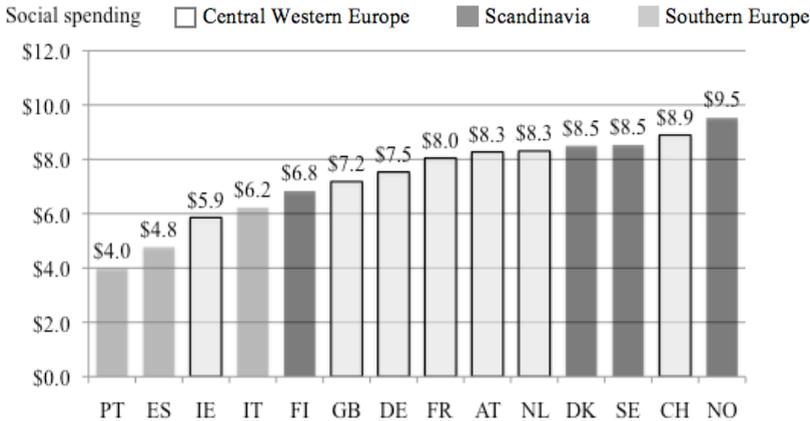


Figure 4: Per capita expenditures on social protections (PPP in \$1,000s USD)

This all presents us with something of a paradox: On the one hand, Spain, Italy, and Portugal lag behind when it comes to providing quality care at the end of life and it appears that conservative religious influences and relatively modest welfare state spending help explain this outcome. On the other hand, Denmark, Norway, Sweden, and Finland also have relatively poor scores on end-of-life care even though religious influences there are essentially nonexistent and welfare spending is generally robust. Clearly, other forces must be at work in Nordic Europe.

2. Methods

The data on palliative care in Western Europe assembled for this analysis were drawn from a survey of recently published comparative data on palliative care which was conducted within the European context. Particular attention was paid to published research on clinical practice, health care policy, and palliative care outcomes.

Studies included in this review were selected on the basis of the following criteria:

- Substantive relevance: all studies addressed specifically some dimension of palliative care;
- Methodological approach: emphasis was put on studies that exhibited comparative quantitative rigor;
- Geographic relevance: studies were limited to those dealing primarily with Western European countries;
- Temporal relevance: studies included had to have been published no later than 2005.

Overall, seventeen studies qualified using the above criteria. These seventeen works fell into four distinct areas of palliative care:

- Resource allocation^{8 9 10 11}
- Medical training^{12 13 14 15}
- Clinical practice^{16 17 18}
- Symptom management^{19 20 21 22 23 24}

3. Results

Despite their status as generally progressive welfare states, all the detailed evidence suggests that the Scandinavian countries lag behind other countries in Western Europe with regard to the provision of palliative care services at the end of life. A review of this evidence is followed by a discussion of the Scandinavian mindset – a state of mind which is generally optimistic, eschews exceptionalism, and is characterised by comparatively low levels of sympathy and relatively high levels of regime support. This mindset may help explain why these otherwise progressive countries tend to fall short in the provision of palliative care.

A. Palliative care and patient access

Quality palliative care at the end of life sometimes requires that care be provided by well-trained physicians who attend to their patients in residential hospices or in specialised hospital units devoted to palliative care. The Scandinavian countries do not rank very highly on either measure. Despite Norway's and Denmark's generous predispositions regarding the provision of health care services, these two countries tend to devote fewer resources to end-of-life care than many other countries on the continent.²⁵ With regard to overall "quality of death," Norway ranks eighth and Denmark ranks twelfth among the

seventeen countries of Western Europe that were rated.²⁶ When countries are rated on the general availability of end-of-life Sweden does fairly well, but Denmark, Finland, and Norway all sink to the bottom of the list (see Figure 5).

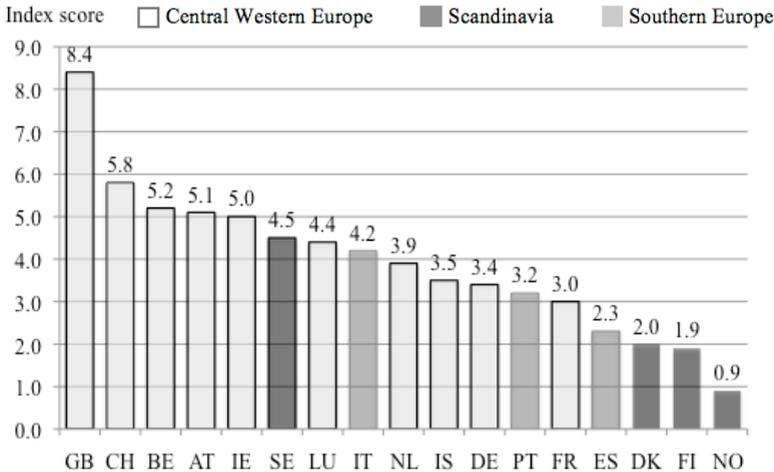


Figure 5: Index score for availability of end-of-life care services

In another study, Denmark ranked ninth (with only 17 palliative care beds per million population) and Finland ranked tenth (with 14 palliative care beds per million population) among the eleven countries surveyed (Norway and Sweden were not surveyed). Researchers found that there were nearly four times as many palliative care beds per capita in the United Kingdom as there were in either Denmark or Finland, and only Portugal ranked lower on this measure among the eleven countries studied.²⁷

B. Palliative care and physician skills

There are nearly twice as many doctors trained in palliative care per person in the United Kingdom as there are in Denmark or Finland. Once again, only Portugal ranked lower among the eleven countries surveyed.²⁸

Palliative care training also seems to be substandard in Scandinavian countries, and Denmark provides a good case study. While all UK medical schools require all students to take courses in palliative care, only 6% of Danish doctors report getting any undergraduate training in this area.^{29 30} Nearly half of the Danish physicians in one study reported receiving no palliative care education at all, and only about one-quarter reported receiving more than four days of training in a medical curriculum that currently spans 13.5 years.³¹

In some countries, the lack of formal training in palliative care is compensated for by participation in educational conferences and professional meetings with colleagues. Finland ranks first on the propensity of its doctors to participate in such endeavours and Sweden ranks a middling ninth. But Norway ranks fifteenth, and Denmark ranks last of the seventeen European countries studied.³²

Participation in continuing medical education (CME) programs is another way doctors can improve their skills after formal medical training has ended. Here again, there is a clear and divergent pattern among Scandinavian and non-Scandinavian countries. Continuing medical education is mandatory for doctors in most Western European (and in many eastern European) countries, but doctors in none of the Scandinavian countries are required to learn anything new after their formal medical training is completed.³³ It may come as no surprise, then, that patients in Scandinavian countries have less faith in their doctors than patients elsewhere in Europe when it comes to a physicians' ability to manage their pain (see Figure 6).

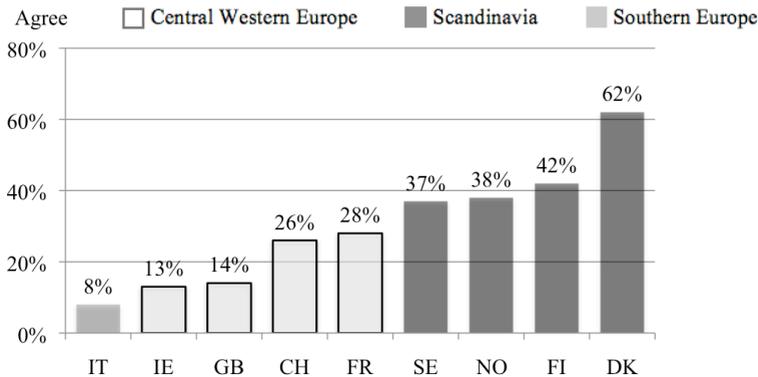


Figure 6: *My doctor does not know how to control my pain*

Scandinavian doctors also tend to be rated poorly on the “continuity of care” dimension of their clinical practice. Finland ranked relatively well (third) among seventeen countries studied when assessing the willingness of general practitioners (GP’s) to visit their patients after normal office hours, either in the patient’s home or in hospital.³⁴ But Sweden (ranked twelfth), Norway (ranked fifteenth), and Denmark (ranked seventeenth) all scored relatively poorly on this measure. When GP’s are hesitant to attend patients at home after hours or on the weekend, hospital admission may be the only alternative. And when hospital doctors unfamiliar with a dying patient are forced to take up a complicated case of end-of-life symptom management without assistance of the patient’s primary care physician, the continuity and quality of the patient’s care are almost sure to suffer.

C. Palliative care and the management of death

As Brown and Weeks argue elsewhere in this volume, Do Not Resuscitate (DNR) orders are important expressions of patient autonomy that can positively affect the quality of one's death if executed in a timely and thoughtful manner. Unfortunately, Denmark and Sweden, the only two Scandinavian countries studied in one recent six-country study, ranked relatively poorly in the percentage of patients who executed DNR orders at the end of life.³⁵ Denmark and Sweden also ranked relatively low with regard to forgoing other life-sustaining therapies at the end of life.^{36 37 38} Patients in Scandinavian countries also tend to suffer longer with chronic pain than patients elsewhere in Europe (See Figure 7).³⁹

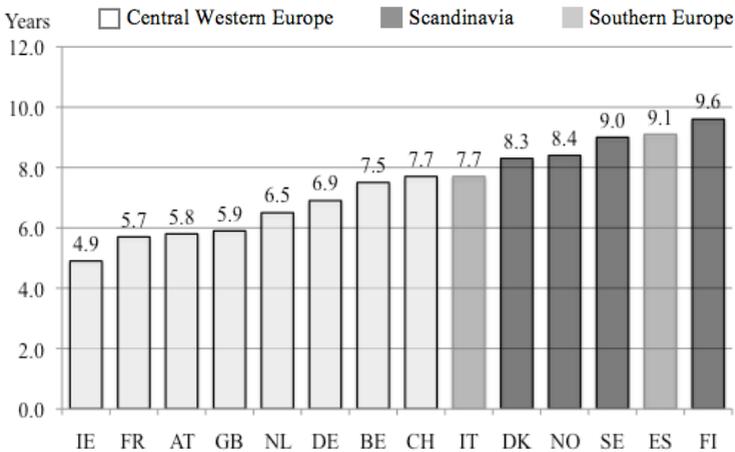


Figure 7: Duration of pain among chronic pain patients (years)

Denmark and Sweden also ranked last among seven countries studied in use of continuous deep sedation (CDS) at the end of life (Norway and Finland were not included in the study). CDS, a relatively new end-of-life protocol for addressing intractable end-of-life symptoms,⁴⁰ has been found to be very effective in those difficult cases where pain, dyspnea, agitation, and/or delirium cannot be palliated using traditional approaches. As many as 19% of patients in the British end-of-life patient population chose CDS in their final days. Even in medically conservative Italy, CDS rates are reported to be 9%. In Sweden and Denmark, the rates of CDS were reported to be 5% and 4% respectively.^{41 42 43 44}

In sum, the Scandinavian countries are quite generous when it comes to spending public resources to provide health care and other social benefits to its citizens. Given the general Scandinavian predisposition to spend generously on the most vulnerable members of their respective populations, and given the lack of any

conservative religious influences, it is something of a riddle that the Scandinavian countries would score so low on measures associated with caring for perhaps the most vulnerable citizens of all: patients in need of good palliative care at the end of life. The role of culture provides us with some insight as to why this is the case.

4. Discussion

As a group, Danes, Norwegians, Swedes, and Fins share similarities in history, ethnicity, language (excepting the Fins), and culture that set them apart from the rest of Western Europe. These commonalities combine to undergird a common Scandinavian mindset that has remained quite stable over time.

Individually, these four Nordic countries are among the most ethnically homogenous nations in the Western world.⁴⁵ They each lack the kind of religious, ethnic, and cultural diversity that tends to erode common cultural predispositions in states that have more diverse populations. In addition, these four countries are relatively small in population, and with the exception of Denmark, they are the most sparsely populated lands of Western Europe. Denmark, Norway, Sweden, and Finland have a combined population about half the population of Spain, sprinkled across a land mass twice as large. The ethnically homogeneous, sparsely populated countries of Scandinavia provide fertile ground for stable social norms that have roots deep enough to have a significant bearing on social policy.

A. Dispositional optimism

The first Scandinavian norm suggested by the data is a tendency toward *dispositional optimism*: a generally positive and fatalistic expectancy that one will experience good outcomes.⁴⁶ Consider the fact that:

- The residents of Scandinavian countries are annually reported to be among the happiest people in the world. A 2010 Gallup Poll ranked Denmark, Finland, Norway, and Sweden (in that order) in the top four spots in its most recent survey of the world's happiest countries. Indeed, all four Scandinavian countries typically make the top-ten list of other researchers who have studied *happiness* and *satisfaction* in countries around the world.⁴⁷ This is the case despite a northern European climate characterized much of the year by the kind of short, cool, rainy (Denmark) and snowy (Norway, Sweden, and Finland) days that most would consider less than optimal for engendering cheerfulness (see Figure 8).⁴⁸

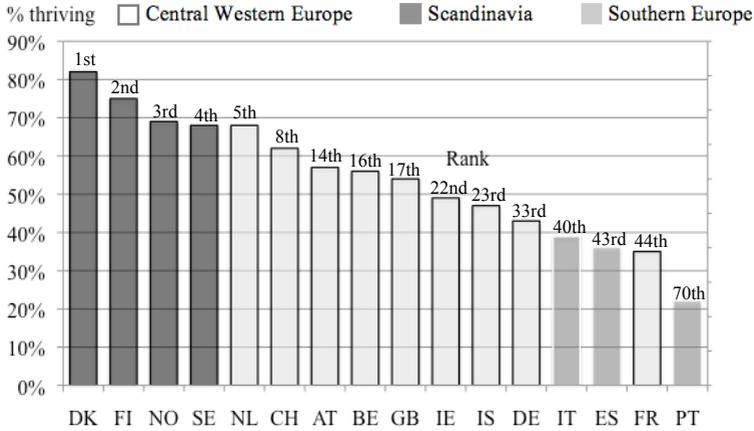


Figure 8: Percent of the population who report to be *thriving*

- Scandinavians specifically report being more satisfied with their health status than other Europeans, even though Scandinavians – Fins and Danes in particular – are likely to get sick and die sooner than residents of other countries in Western Europe.⁴⁹
- As Cooley notes elsewhere in this volume, death anxiety is prevalent in many cultures, and thinking about death often interferes with one’s ability to be happy. Here again, however, Scandinavians (with the exception of Norwegians) distinguish themselves from the mainstream, as they are more likely than residents of almost any other country in Western Europe to agree with the following statement: “Death is inevitable, it is pointless to worry about it.”⁵⁰

Medical treatment at the end of life is often futile and often only serves to exacerbate the patient’s suffering. This is why patients in many first-world countries decide, in consultation with their physicians, to forgo some or all life-sustaining treatments as death approaches. This transition from care that is focused on sustaining life to care that emphasizes aggressive symptom management is not yet typical or routine, however. Rather, it requires that physicians and patients express some level of dissatisfaction with currently predominant Western medical norms that focus on *cure* rather than *care*. Scandinavian countries rank low on measures associated with proactive management of the dying process and surely their dispositional optimism – the predisposition to be satisfied with *what is*, and not to agitate for what *might be* – is at least partly responsible.

The *Jante Law* is a second dimension of the Scandinavian mindset that may help explain its laggard status with regard to palliative care.⁵¹ Jante Law is a term used to describe an informal pattern of group behaviour observed in Scandinavian countries for centuries.⁵² The Jante Law emphasizes the collective good and conformity to group norms while discouraging anything that has the potential to disrupt social stability. Exceptional achievement and the acquisition of specialized knowledge, especially when that knowledge is provided by outsiders, both violate central tenants of the Jante Law.

The widely shared tendency to look disapprovingly on individual specialization and expertise may help explain resistance to advances in palliative medicine where specialized knowledge is often required in order to provide first-rate end-of-life care. Policy makers in other countries have employed a number of approaches to improving the delivery of palliative care. Designation of faculty chairs in palliative care and establishing specialist credentials for health professionals in palliative care are two such approaches.

Scandinavian countries have lagged behind on credentialing palliative care programs and specialists, it is argued here, because both these policy initiatives run counter to the Jantian principles. As Dahl (p. 103) notes in his essay on the nature of Scandinavians: “Suspicion toward anything extraordinary is everywhere,” and this appears to be one reason why all four Scandinavian countries have shied away from taking a leadership position here.⁵³

The low priority put on exceptional knowledge in Denmark may also be a reason why so few physicians in Denmark and Finland have volunteered to serve on international working groups of palliative care experts. Switzerland, a country with only slightly more residents than Denmark or Finland, has had nine medical professionals serve on international palliative care boards since palliative medicine emerged in the early 1990s as an important cause among health care professionals. Denmark and Finland have each only contributed one such expert to the international effort. Germany is the only other country in Western Europe to contribute so little to international initiatives, but Germany has a robust nationwide effort to advance the cause of palliative care for end-of-life patients within its borders. Denmark’s and Finland’s efforts here are weak, at best. Only two of thirteen countries surveyed had weaker palliative care movements.^{5 10}

It would be a mistake to overstate the role Jante plays in modern-day, increasingly cosmopolitan Scandinavian countries. At the same time, it would be wrong to discount entirely the role Jantian predispositions continue to play in Nordic Europe. Culture changes slowly, even in our increasingly globalized world, and maybe even slower in this sparsely populated, culturally homogeneous land where Jantian pride seems at work to inhibit advances in palliative care that are taking place elsewhere.⁵⁴

C. The empathy gap

A third reason why Scandinavian countries may be lagging their Western European neighbours in the area of palliative care may have something to do with the *empathy gap*: the comparatively low levels of empathy Scandinavians report feeling about assisting those most likely to need palliative care. Consider that:

- The four Scandinavian countries rank at the bottom of the list of countries included in the World Values Survey regarding their ‘identification with suffering’ as a motivation for doing volunteer work (see Figure 9);⁵⁵

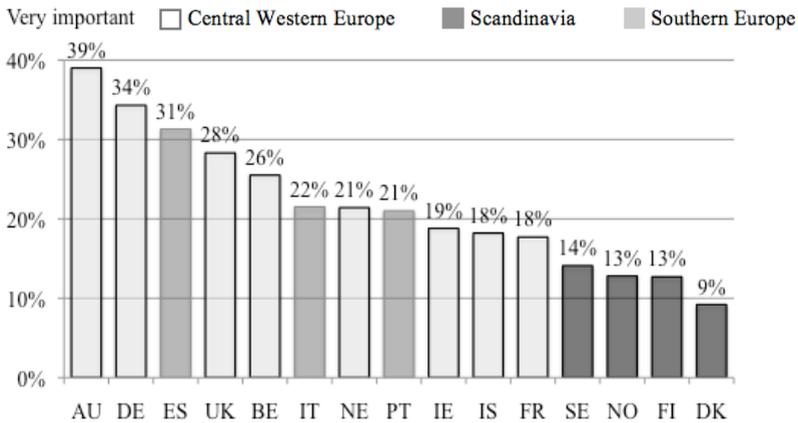


Figure 9: *How important is it to identify with those who are suffering?*

- A second World Values Survey question asked: *How important is the moral duty to assist the elderly?* Finland and Denmark (the only two Scandinavian countries included in the survey), scored relatively poorly here as well (see Figure 10).

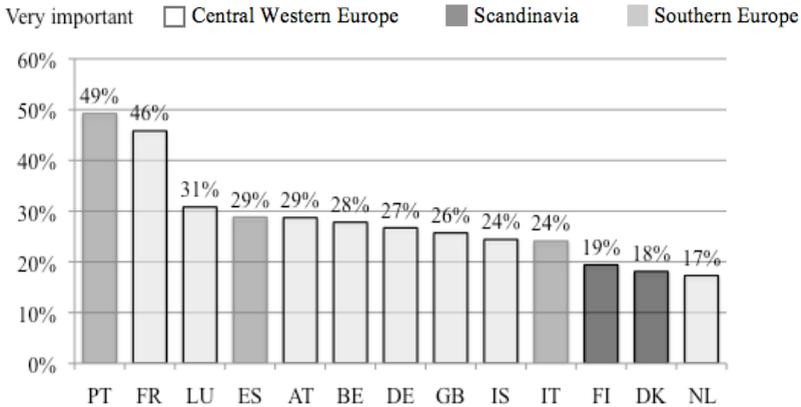


Figure 10: *How important is the moral duty to assist the elderly?*

Danish doctors, in particular, seem comparatively uninterested in managing pain and other symptoms of their end-of-life patients. Reports on physician attitudes about end-of-life care reveal that Danish doctors give this area of medicine a comparatively low priority. In Sweden, 23% of doctors report getting some training in palliative care at the undergraduate level and 60% of Swedish doctors report thinking that more undergraduate palliative care training should be provided. In Denmark, where only 6% of doctors report getting some training in palliative care at the undergraduate level, only 42% of doctors report thinking that more undergraduate palliative care training should be provided.⁵⁶

Comparative data on patient experiences with chronic pain – a common concern among end-of-life patients – also reinforce the notion that Scandinavian physicians are less than sympathetic in their clinical practice. In one recent study of chronic pain in Europe, Breivik, et al., reported that Danish and Norwegian doctors rated their patients' pain using the standard ten-point pain scale only six and five percent of the time, respectively. This placed these two countries twelfth and thirteenth, respectively, among the fourteen Western European countries studied. The same study placed Denmark and Norway twelfth and tenth respectively in the percentage of patients (74% and 69%) who said their doctors did not adequately control their pain – Sweden happened to score quite well on this measure with only 30% reporting uncontrolled pain.⁵⁷ The Breivik study also placed Denmark in last place (by a fair margin) with regard to physician willingness to prescribe medications to control symptoms in patients suffering with chronic pain (while Norway and Finland actually scored well on this measure; Sweden scored in the middle).⁵⁸

It may be presumptuous to suggest that Danish doctors in particular, or Scandinavians in general, tend to have comparatively low levels of concern for patients who require palliative care services. For example, it may be that reluctance of doctors to ask patients about their pain and to use strong medications can be attributed to a lack of training. It seems as likely as not, however, that lack of empathy is at least partly to blame given that Scandinavians, in general, report levels of empathy that are generally lower than elsewhere in Europe.

Finally on this point, it should be pointed out that the hospice movement is quite young in Scandinavia, and both professional and volunteer staff are still finding their way there. The development of hospice as a palliative care alternative for dying patients has strong roots in the not-for-profit sector where volunteer workers are still, in many respects, the lifeblood of the enterprise. Once again, there may not be enough evidence to suggest that hospice has taken a long time to take root in Scandinavia because volunteers are scarce and people there are generally just less empathetic regarding the elderly and those who are suffering.

It may also be true that volunteer efforts in palliative care are psychologically “squeezed out” by the welfare state. That is, the natural impulse to contribute time and resources to charitable causes has atrophied somewhat in Scandinavia where the breadth of the welfare state is so extensive that residents simply assume that if something should be done, the government will do it. Given the overall pattern of Scandinavian thinking charted above, however, it seems at least plausible that the *empathy gap*, whatever its cause, is at least partly responsible for the lag in the development of hospice in this part of the world.

D. Political legitimacy

Political legitimacy is the fourth dimension of the Scandinavian mindset that may help us understand the relatively weak state of palliative care in Nordic Europe. All countries have their internal critics and dissenters, and Scandinavian countries are no different in this regard. At the same time, residents of Scandinavian countries exhibit relatively high levels of confidence in their respective governments, in general, and in their respective health care systems in particular.⁵⁹ As such, they may be less willing to question or complain about the resource allocation decisions that have very clearly short-changed attention to palliative care in their countries.

The general approach Scandinavians seem to take about their governments and their policies is this: as long as all people are treated about the same, then no one has much reason to complain. This ‘passion for equity,’ as Dahl puts it,

[which] has been passed down from the nineteenth century and that helped shape the political system of today is certainly a fine thing – so long as it does not prevent new ideas, new institutions, and novel interests to emerge in the fabric of Nordic society.⁶⁰

The problem is that Nordic societies may be less willing or able to respond when new initiatives do come along, especially when those initiatives require advanced training and credentialing for some doctors, and specialized care for some patients. Development of the clinical specialist practice of palliative care is a fairly recent phenomenon in the practice of medicine. But with a few notable exceptions, there seem to be few activists, politicians, policy makers, or health care professionals willing to challenge the status quo by championing the cause of end-of-life care in Scandinavia. The general and comparatively high sense of satisfaction with government seen in Scandinavian countries may help explain the general lack of activism that has led to advances in palliative care elsewhere in Europe.

5. Conclusions

At first blush, the fledgling state of end-of-life care in Scandinavia is surprising given that countries in this region of Europe have the capacity (with relatively healthy economies and strong welfare state inclinations) to be leaders rather than followers in the area of palliative care. Scandinavian cultural predispositions seem helpful in explaining this paradox, where welfare states that are generally quite protective of vulnerable populations have end-of-life care policies and practices that are meagre at best. The improvements called for by WHO, both in training and education for health professionals and in symptom management for patients, may be difficult to realize in Scandinavian countries where strong and persistent cultural forces – dispositional optimism, the Jante Law, the empathy gap, and faith in government – all seem aligned to inhibit advances in this area.

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James M. Hoefler, Ph.D., is professor of political science at Dickinson College in Carlisle, PA, US. Professor Hoefler has written two books on end-of-life care in the United States and serves on the biomedical ethics committee at the Carlisle Regional Medical Center in Carlisle, PA.