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Something's ironic in Denmark: An otherwise progressive welfare state lags well behind in care of patients at the end of life

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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 study is to describe, in a comparative context, the current status of end-of-life palliative care in Denmark using quantitative research published in the past five years. This study's conclusions, based on a synthesis of the research, suggest that despite its well earned reputation as a generally progressive welfare state, Denmark tends to trail well behind its European neighbors when it comes to end-of-life care. Understanding the cultural forces that underlie this reality may help Danish health care professionals and policy makers overcome the barriers that stand in the way of providing state-of-the-art medical care to patients who suffer at the end of life.

1. Introduction

According to the World Health Organization (WHO) palliative care at the end of life is one of the more important but neglected public health issues of our time [1]. WHO identifies needs for improvement in clinical practice, such as improved training and education of health professionals. WHO also identifies needs for improvements in patient outcomes, including better symptom management, with more attention paid to continuity of care.

While it is important to note that significant advances in end-of-life care have been made in some countries in recent years, WHO notes that progress has lagged in many places, including many countries in the first-world. For example, while the United Kingdom and the United States have developed solid reputations as leaders in palliative medicine, data collected on palliative care policies and practices around the world suggest that some countries – Portugal, Italy, and Denmark, for example – are currently trailing behind [2].

Portugal and Italy have the highest percentage of Catholics in Europe (92% and 90%, respectively) and Catholic positions on health care at the end of life are best characterized as conservative by current standards of professional practice. The Catholic stance on forgoing artificial nutrition and hydration (ANH) and use of palliative sedation to manage intractable symptoms at the end of life is instructive. These two practices are typically

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viewed as both ethically sound and clinically appropriate in the professional, secular palliative care community [3,4]. But both are viewed with considerable suspicion by the Catholic Church [5,6], and this may help explain why Portugal and Italy are lagging on palliative care developments. In addition, both Portugal and Italy are southern European countries with welfare policies that are modest by northern European standards. These two factors, taken together, may help explain why these nations rank where they do in end-of-life care. In Denmark, a generally secular northern European country with notably progressive welfare state policies, other cultural forces seem to be at work.

2. Denmark

Denmark's health care sector is shaped, regulated, and funded primarily by the national government. Implementation of health policy, set and funded at the national level, is decentralized to five local regions. These regions run the hospitals, manage the practice sector, and oversee local implementation in 98 individual municipalities. The local municipalities are responsible for providing home nursing, public health care, school health services, disease prevention programs, and rehabilitation services.

Denmark's system of health care is universal in that all Danes are covered and the vast majority of health services, including home nursing, rehabilitation services, necessary medical appliances, and medicines for those who are terminally ill, are provided free of charge The Danish government funds 84% of all health care expenditures with funds collected via a health care contribution tax (approximately 8% on taxable income) and supplemented by much smaller per capita taxes imposed by the local municipalities. Danish citizens pay directly for the remaining 16% of health care goods and services they receive (primarily pharmaceuticals and dentistry services).

All Danes have access to at least one designated general practitioner (GP). These GP's each have responsibility for approximately 1300 patients and serve as the point of first contact in most cases of non-emergency care. GP's also play the gate-keeper role, deciding when patients should be referred to a specialist or admitted to a hospital. Most GP's are self-employed, but reimbursement rates are set collectively by the physicians in annual negotiations with state and regional authorities [7].

3. 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 must have been published no later than 2005.

Overall, sixteen studies qualified using the above criteria. These 16 works fell into four distinct areas of palliative care:

- Resource allocation [8–11]
- Medical training [12–15]
- Clinical practice [16–18]
- Symptom management [19–23]

4. Results

Denmark ranks relatively low on nearly all measures of end-of-life care, despite having the financial capacity to spend more in this area, despite a general commitment to excellence in education, and despite a deep-seated and widely shared inclination toward policies that tend to advantage the most vulnerable members of its population. Comparative research on resource allocation, physician training, and clinical decision making suggests that Danes are less likely than other Europeans to have access to:

(1) palliative care beds in hospitals or hospices [24];
(2) doctors trained in end-of-life care [25], and;
(3) good continuity of care at the end of life [26].

The data also suggests that symptom management is substandard in Denmark. Danish patients suffering chronic pain are less likely to be prescribed pain medication and are more likely to experience pain than patients in most other western European countries [27].

4.1. Resource allocation

Denmark spends a greater percentage of its GDP on health care than any other country in Europe. And Denmark ranks second only to Switzerland in percentage of its overall national budget devoted to health care [28]. Denmark is also one of only five European Union countries to report a budget surplus in 2008 (3.6% of Gross National Income) [29]. Yet despite Denmark's generally sound financial footing and a predisposition to spend generously on health care, it devotes comparatively few resources to palliative care. Other countries in western Europe tend to be more generous with regard to end-of-life care even though they tend to spend less overall on health care, and even though many of them are experiencing significant budgetary shortfalls.

In Europe, only Finland and Portugal rank lower than Denmark in terms of the number of palliative care beds per capita made available to dying patients. Overall, only Finland ranks lower than Denmark with regard to palliative care services (e.g., palliative inpatient units, hospices, hospice support teams, and specialized palliative care teams) [24].

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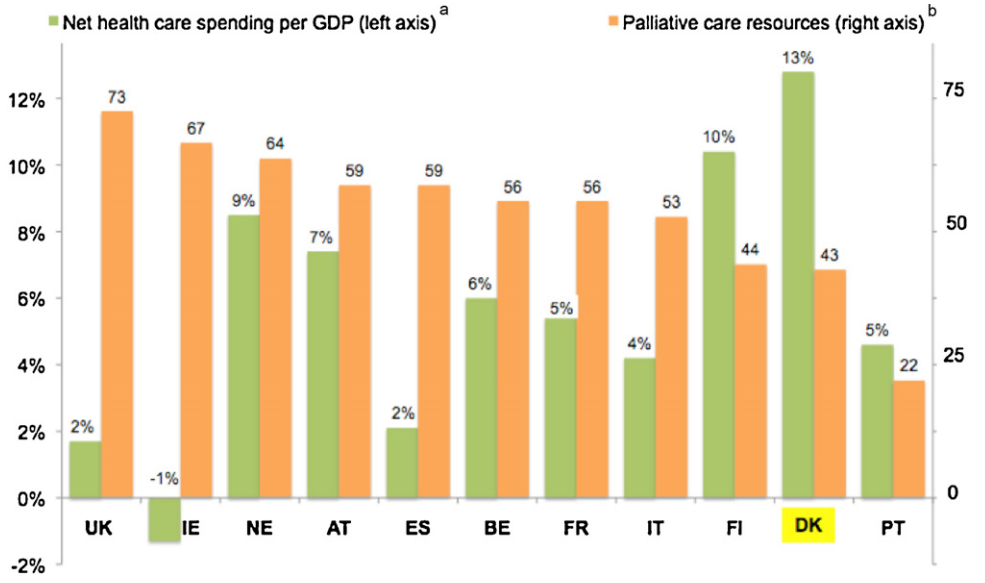

Fig. 1. (a) *Palliative care resource capacity* is a measure of a country's ability to devote more resources to palliative care. We assume here that countries being compared all have about the same per capita need for health care spending. Therefore, the more a country spends in per capita GDP on health care, the more likely it will be that there is potential to shift more resources to palliative care in that country. A few countries in western Europe, and Denmark is one of them, have also enjoyed budget surpluses in recent years. This surplus also creates the potential to spend more on palliative care. Conversely, if a country is running a budget deficit, this detracts from its ability to shift more resources to palliative care. We calculated *Palliative care resource capacity* by combining the total public health care spending per GDP in each country [1] then added (or subtracted) each country's national budget surplus (or deficit) per GDP (2008) [2]. At the low end, Ireland's public health care spending in 2008 represented 6% of GDP, which when combined with its budget deficit of 7% that year yielded a *net health care spending* figure of -1%. At the high end, Denmark's public health care spending represented 9% of its GDP in 2008, which combined with its budget surplus of 4% that year yielded a *net health care spending* figure of 13%. (b) *Palliative care resource* numbers come from the map of palliative care specific resources in Europe published by the European Association for Palliative Care (EAPC) [3].

Denmark also ranks near the bottom when it comes to the number of specially trained doctors who are available to address palliative care needs at the end of life [24]. In the United Kingdom, where palliative medicine has been recognized as a specialty since 1987, there are three times as many palliative care doctors and beds per person as there are in Denmark. In the United States, where palliative medicine has been recognized as a subspecialty since 1996, approximately 40% of patients are able to take advantage of specialized palliative care services in their dying days. In Denmark, where palliative medicine is not recognized either as a medical specialty or as a field of expertise, only about 4% of dying patients have access to specialist palliative care services. Denmark has the money and the predisposition to spend on health care in general, but it devotes comparatively little of its national resources to care at the end of life (see Fig. 1).

4.2. Medical training

According to the *Global Innovation Index Report 2009–2010* (2010), Denmark ranks at the very top of countries in Europe when it comes to (1) quality of the education system, (2) spending on education as a percentage of Gross National Income, and (3) predisposition to train professional staff after formal education is completed [30]. Medical training, in particular, is longer in Denmark than anywhere else in Europe [31]. In fact, Danish medical students spend nearly a year longer in undergraduate medical training than the typical medical student elsewhere in Europe. By the time Danish doctors complete specialist training, they will have spent nearly two years longer in their studies than physicians trained elsewhere on the continent.

Despite the general emphasis on educational quality, combined with the length of medical training in Denmark, Danish medical students receive comparatively little training in palliative care. Nearly half of the Danish physicians in one study reported receiving no palliative 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. While all UK medical schools require students to take courses in palliative care, only 6% of Danish doctors report receiving any undergraduate training in this area [32,33].

Reports on physician attitudes about training in end-of-life care reveal that Danish doctors give this area of medicine a comparatively low priority. The majority of Danish doctors do not think they need more training in palliative care and Danes are less likely to volunteer for service on international boards and committees devoted to improving end-of-life care.

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 [34].

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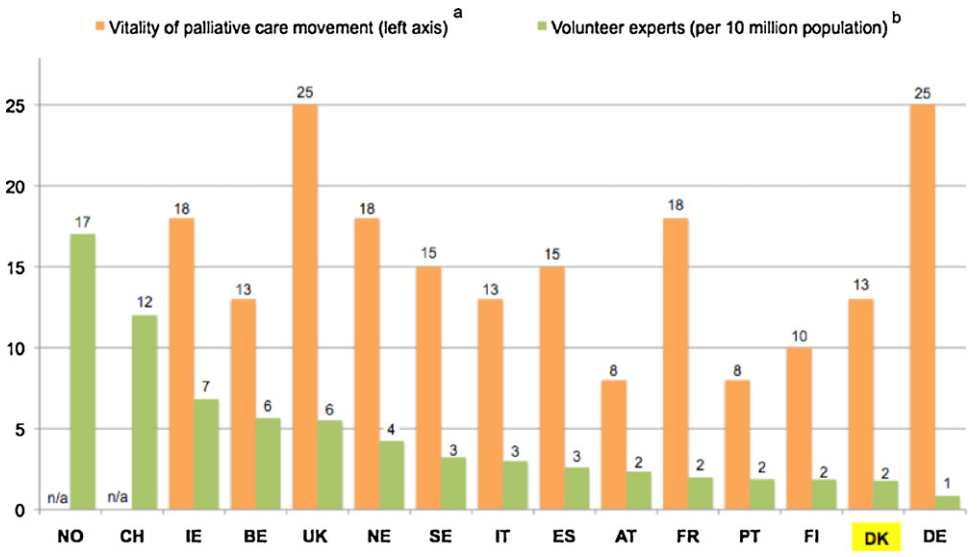

Fig. 2. (a) *Vitality of palliative care movement* scores come from the map of palliative care specific resources in Europe published by the European Association for Palliative Care (EAPC; no values were reported for Norway or Sweden) [4]. (b) *Volunteer experts* is a count (per 10 million residents) of palliative care experts who have volunteered to work toward improvements in palliative care in various international organizations (e.g., World Health Organization, Council of Europe, and European Association of Palliative Care).

In some countries, the lack of formal training in palliative care is compensated for by participation in educational conferences and professional meetings with colleagues. Denmark, however, ranks last among seventeen European countries studied with regard to the tendency of GP's to participate in such activities [35].

Participation in continuing medical education (CME) courses is another method of ensuring that physicians stay current with developments in clinical practice. CME courses can also help fill gaps in medical training. Over half of all western European countries now require that doctors take such courses [36]. But while Danish doctors are encouraged to participate in continuing medical education, Denmark remains one of the countries where continuing medical education is not required of its physicians.

The comparatively low priority palliative care has in Denmark is also reflected by the lack of Danish physicians serving on international working groups of palliative care experts devoted to advancing education and training in this area. Switzerland, a country with only slightly more residents than Denmark, has had nine medical professionals serve on international palliative care boards since palliative medicine emerged in the early 1990s as a cause among health care professionals. Norway, with fewer residents than Denmark, has had eight such representatives. Denmark has had only one.

Germany is the only other country in western Europe to contribute so little to international efforts in this area, but Germany has a robust nationwide effort to advance the cause of palliative care for end-of-life patients within its borders. Denmark's efforts here are comparatively weak, at best. Overall, Denmark scores in the lower third of countries surveyed with regard to the vitality of its palliative care movement [24]. Only three of thirteen countries surveyed scored lower (Italy, Finland, and Portugal; see Fig. 2).

4.3. Clinical practice

Clinical practice is another area where Denmark falls short with regard to palliative care. Danish GP's lag GP's in other countries in western Europe with regard to their willingness to visit patients after normal office hours, either in the patient's home or in hospital [37]. When a GP does not come to the home when called to address the intractable symptoms of a dying patient, hospital admission may be the only alternative. And when hospital doctors unfamiliar with the dying patient are forced to take up a complicated case of end-of-life symptom management, the continuity and quality of the patient's care typically suffers as a result (see Fig. 3).

Demark also seems to be out of step with other countries in western Europe with regard to the provision of invasive medical treatments such as cardio-pulmonary resuscitation and the provision of artificial nutrition and hydration at the end of life. These procedures are often futile for terminally ill patients and may only serve to exacerbate the patient's suffering. And there is little evidence to suggest that either procedure does much, if anything, to extend the life of the patient. This is why patients in many western countries decide, in consultation with their physicians, to forgo such treatments as death approaches.

Denmark ranks relatively low with regard to forgoing both interventions. It ranks fourth out of six European countries studied in the percentage of patients who execute Do Not Resuscitate (DNR) orders [38] and also ranks fourth out of six European countries studied with regard to forgoing ANH [39]. The fact that a comparatively low percentage of patients forgo resuscitation or ANH in Denmark could be interpreted to mean that Danish physicians work harder than elsewhere to save the lives of their terminally ill patients. It may also mean that Danish patients are comparatively more likely to suffer futile,

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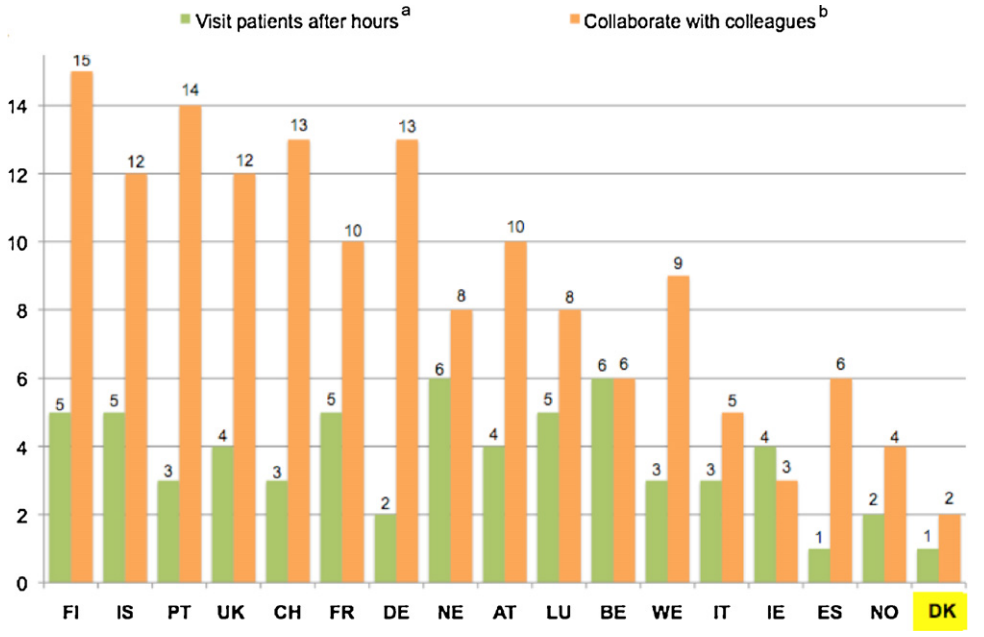

Fig. 3. (a) *Visit patient after hours* refers to GP's willingness to visit patients after hours (either at home, or in the hospital) [5]. (b) *Collaborate with colleagues* refers to GP willingness to participate in professional meetings with physician colleagues and other health care providers [6].

invasive attempts to extend their lives than elsewhere in Europe.

4.4. Symptom management

Denmark also ranks low (last among seven countries studied) in use of continuous deep sedation (CDS) at the end of life. CDS is a relatively new palliative care protocol which makes use of strong sedatives (usually benzodiazepines) to manage pain, dyspnea, agitation, and/or delirium that cannot be palliated using traditional approaches [40]. In the United Kingdom, a country with a reputation for providing progressive end-of-life care, it is reported that approximately 19% of patients in the end-of-life patient population chose CDS in their final days. Even in medically conservative Italy, CDS rates are reported to be 9%. In Denmark, the rate is 4% [41–44].

It could be that doctors are overusing this protocol in the UK and other countries where CDS rates are reported to be relatively high. It may also be true that some Danes suffer needlessly at the end of life because Danish doctors, short on training and education in palliative care, are not comfortable offering this relatively new procedure at the end of life when the situation warrants it as an option.

Comparative data on patient experiences with chronic pain – a common concern among end-of-life care patients – also reinforce other data which suggest that Denmark is behind in palliative care. In one recent study of chronic pain in Europe, Breivik et al., reported that Danish doctors rated their patients' pain using the standard ten-point pain scale only six percent of the time. This placed Denmark twelfth among the fourteen western European countries studied. The same study placed Denmark twelfth in percentage of patients (74%) who said their doctors did not adequately control their pain [45]. The Breivik study placed Denmark in last place (by a fair margin) with regard to the use of prescription medications to control symptoms in patients suffering with chronic pain [46] (Figs. 4 and 5).

5. Discussion

It is something of a riddle that Denmark, an otherwise progressive nation with notably liberal welfare state policies regarding the elderly and disabled [47], would score so low with regard to measures associated with caring for the most vulnerable citizens of all: patients in need of good palliative care at the end of life. Perhaps culture can help explain the seeming contradiction.

The Danes are annually reported to be among the happiest people in the world [48]. Danes also report being more satisfied with their health status than other Europeans, even though they are likely to get sick and die sooner than almost anywhere else in western Europe [49]. A predisposition to be satisfied is much to be admired in a people, but it may also foster in them a general sense of complacency. A tendency to be complacent about life in general, and health care in particular, can be especially insidious regarding end-of-life care, where so few people are ever in the process of dying at any given time, and when death ultimately silences the voices of those who might otherwise complain about the less-than-optimal care they may have received.

Janteloven (literally translated "*the Jante Law*") is another part of Danish cultural predispositions that may contribute to its low rankings in palliative care. Janteloven refers to an informal pattern of social behavior observed in Scandinavian countries for centuries. This informal code of

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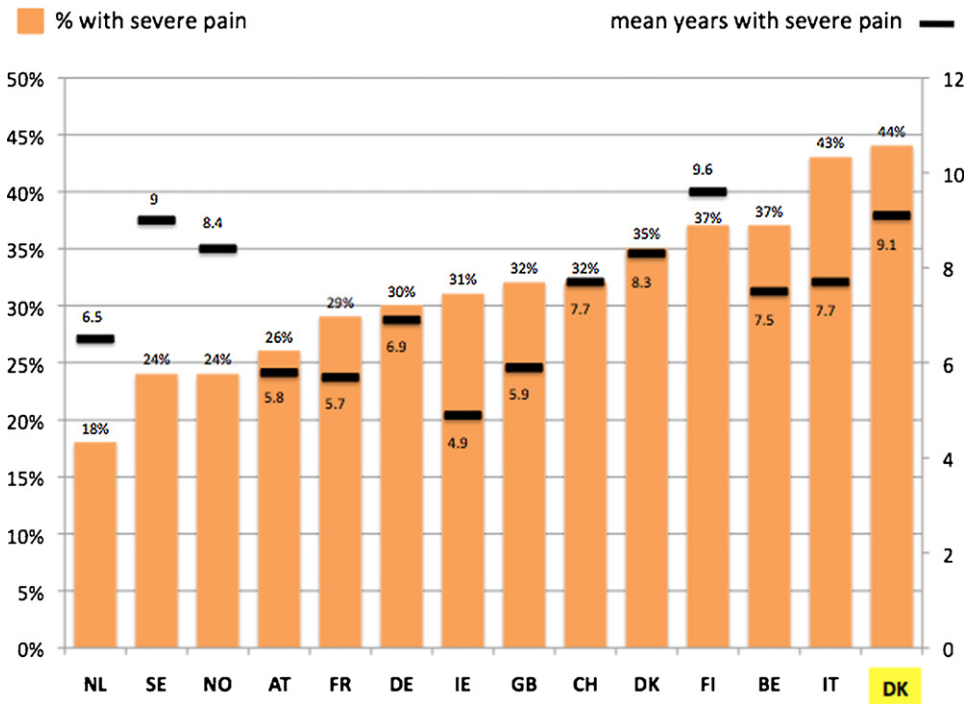

Fig. 4. Data for this chart are derived from a study of 46,394 chronic pain patients in western Europe and Israel, where chronic pain was defined as *pain lasting more than six months, having pain during the last month, several times during the last week, and last experienced pain having an intensity of 5 or more on a Numeric Rating Scale: 1 (no pain) to 10 (worst pain imaginable)* [7].

preferred conduct was first and most compellingly codified in a work published in 1933 by Danish-born novelist Aksel Sandemose [50].

Sandemose wrote about a small, fictional Danish town, Jante, and identified ten behavioral norms. Taken together, these norms tend to emphasize conformity while frowning on exceptional achievement and specialized knowledge, especially specialized knowledge gained from outsiders.

It would be a mistake to overstate the role Janteloven plays in modern, increasingly cosmopolitan Denmark. At the same time, it would be equally wrong to discount entirely the role Jantian predispositions play in Denmark

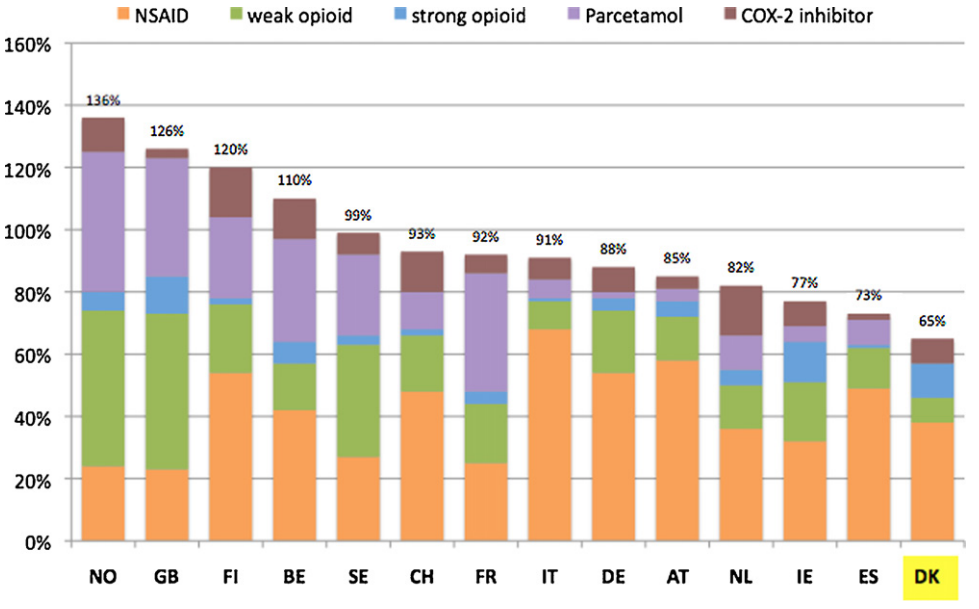

Fig. 5. This chart displays the current use of prescription pain medication by chronic pain patients. Many patients use more than one class of medication, which explains how four of the totals exceed 100% [8].

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today. Culture changes slowly, even in the increasingly globalized world, and maybe even slower in Denmark, which remains one of the most ethnically homogeneous nations in the western world.

Social stability in service of the collective good still appears to be a very important part of the socio-political fabric of Denmark. But while Jantian goals might be well-intentioned and even laudable in some contexts, a generally negative view toward individual specialization and expertise may be counterproductive when it comes to areas like palliative medicine where specialized knowledge is often required in order to provide first-rate care. The United Kingdom, a recognized leader in palliative care (1) awards a specialist credential in palliative care, (2) has a number of professors named as chairs of palliative care in their medical schools, and (3) just recently appointed its first subspecialist chair in pediatric palliative care. Meanwhile, Denmark has no nationally recognized certificate of palliative care and is yet to name its first faculty chair in this area of medicine (though one is purportedly to be named soon).

Creating chairs at medical schools for specialists in palliative care and awarding doctors (and nurses) special credentials (and commensurate status and compensation) for their training and experience in this area may be part of what needs to take place in Denmark, even if such policy initiatives run counter to Jantian impulses. Adopting clinical protocols from countries where palliative care is more advanced may also run counter to Jantian predispositions, but that too may be indicated.

N.F.S. Grundtvig's famous nineteenth century folksong about Denmark, familiar to every Danish school child, lauds the socially progressive principles of the Danish homeland as a place where *few have too much and fewer too little*. Clearly, and despite Grundtvig's lyrical rhetoric, there are many in modern Denmark who do have too little. They are the Danes who die each year with too little access to advanced, comprehensive palliative care delivered by knowledgeable, well-trained professionals.

6. Conclusions

The fledgling state of end-of-life care in Denmark is surprising given that Denmark has the capacity to be a leader rather than a laggard in this area. It appears that Danish policy makers and medical professionals will need to overcome strong socio-cultural predispositions if they are going to adequately address deficiencies in the quality and quantity of palliative care provided to patients at the end of life in Denmark.

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