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Medical Practice Variations in End-of-Life Care

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Abstract

Across the world today, population aging is occurring at an unprecedented rate; the most rapidly growing are those aged 80 and over. This demographic trend highlights the growing demand of health care for the elderly and a corresponding need to examine international end-of-life care practices in order to inform the provision of best quality of care for this segment of the population. End-of-life care accounts for a substantial proportion of health care expenditures – up to 25 % of public healthcare funding – in many countries, although age per se may be a relatively minor determinant of costs of care at the end of life. End-of-life care as a distinct goal or practice of medicine is a relatively new concept. In the past century, the shift away from acute infectious diseases as the major cause of worldwide death, towards more complex chronic diseases, led increasingly to the development of palliative and hospice care. Currently there is wide global variation in capacity for such care, including location of death, availability of formal palliative and hospice care in both acute care settings and at home. There is also large variation in the roles of decision makers (patients, families, healthcare professionals) and the use of advance care planning and directives to inform such care, seemingly influenced by ethnicity, race and religion of individuals, and regions. Occasionally, this variation leads to conflict in decision making; very few countries have evolved formal resolution options that involve patients, families, healthcare providers, bioethicists, and legal or quasilegal bodies. Despite such variation, evidence suggests that care providers from various parts of the world encounter similar challenges in the provision of end-of-life care. Examining international variation in end-of-life care provides examples of differing levels of systems performance that can inform end-of-life care quality improvement initiatives for all systems.

Introduction

Across the world, population aging is occurring at an unprecedented rate (United Nations [2013](#)). As both mortality and fertility are continually decreasing in the vast majority of countries, the average age of the world's population is quickly rising (United Nations [2013](#)). Over the last 50 years, the number of elderly persons has tripled and it will more than triple again over the next 50 years (United Nations [2013](#)). Currently, the world's most rapidly growing age group is that aged 80 and over (United Nations [2013](#)). As a consequence, increasing proportions of the population are approaching end of life with chronic conditions. This demographic trend highlights the growing demand of health care for the elderly. Health care systems around the world must acknowledge this age shift, and refine policies and care strategies in preparation. A major component of care for the elderly is end-of-life care. With the rapidly increasing demand for such care, an analysis of end-of-life care practices around the world is warranted.

As the need for end-of-life care grows, both quality and costs of care are becoming exceedingly important. Several countries have recognized the impending economic challenge associated with health care for the elderly, and there is a growing body of international literature addressing the subject. Many studies have directly examined the health care expenditure implications of our aging population. An emerging theme is the relative importance of health care for the elderly, versus the number of people nearing death as key cost drivers for health care expenditure. Although there has been some controversy on this subject, most evidence suggests that a person's age has a minor impact on their healthcare expenditures compared to the major impact of proximity to death (Zweifel et al. [2001](#); Felder et al. [2010](#); Himsworth and Goldacre [1999](#); Polder et al. [2006](#)). Thus, an analysis of variations in end-of-life care practices and cost implications across the world should provide insight regarding the delivery of high quality care in a cost-effective manner – highly relevant in these times of rapidly increasing demand.

End-of-Life Care Services Around the World

End-of-life care as a distinct goal or practice of medicine is a relatively new concept. In the past century, the shift away from acute infectious diseases as the major cause of worldwide death, towards more complex chronic diseases, led increasingly to the development of palliative and hospice care. Historically, the main providers of end-of-life care were religious institutions, mainly for those with no family members and limited resources (Lutz [2011](#)). It wasn't until the mid-twentieth century that modern end-of-life care was conceptualized by the British physician, Cicely Saunders (Lutz [2011](#)). Dr. Saunders played a predominant role in forming the tenets which still govern hospice and palliative care, including (1) the use of analgesia and opioids for patients with physical pain; (2) the concept that pain is multifaceted and includes physical, spiritual and psychological discomfort; and (3) recognition of the needs of family and friends who provide care for the dying (Lutz [2011](#)). She is also credited with having developed the first modern hospice in the world, St Christopher's, in London, England in 1967 (Lutz [2011](#)). During the 1970s, political discussions in the United States (USA) sparked a change in end-of-life care, developing the discipline from a volunteer-led movement to a qualified medical specialty (Lutz [2011](#)). Soon after, the hospice movement gained worldwide acceptance and the development of hospice and palliative care services acted to shift end-of-life care away from the hospital environment where possible (Lutz [2011](#)).

In 2006 (and 2011), the International Observatory on End-of-Life Care (IOELC) and the Worldwide Palliative Care Alliance (WPCA), with support from Help the Hospices and the National Hospice and Palliative Care Organization, produced a report that measured the level of palliative care development in countries around the world (Clark and Wright [2007](#)). Data were compiled from various sources and were used to allocate every country in the world to one of the following six levels of palliative care development: (1) no known hospice-palliative care activity; (2) capacity building activity; (3a) isolated palliative care provision; (3b) generalized palliative care provision; (4a) countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision; and (4b) countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision (Lynch et al. [2013](#)). As one might expect, in 2011 there were few countries that had reached integration into mainstream service provision. However, worldwide availability of palliative care available worldwide has generally been increasing. In 2011, 136 of the world's 234 countries (58 %) have established at least one hospice-palliative care service, while only 20 countries (8.5 %) have achieved complete integration into mainstream health services, with an additional 25 countries (10.7 %) approaching this goal (Lynch et al. [2013](#)). Between 2006 and 2011, 21 countries (9 %), mostly in Africa and the Middle East, have initiated different forms of palliative care services (Lynch et al. [2013](#)). Although a large proportion of end-of-life care is still delivered in the hospital environment, this signifies the level of globally expanding diversity of services available. For a visual representation of the intensity of palliative care development around the world, the WPCA has mapped its measurements of palliative care development (Fig. [1](#)).

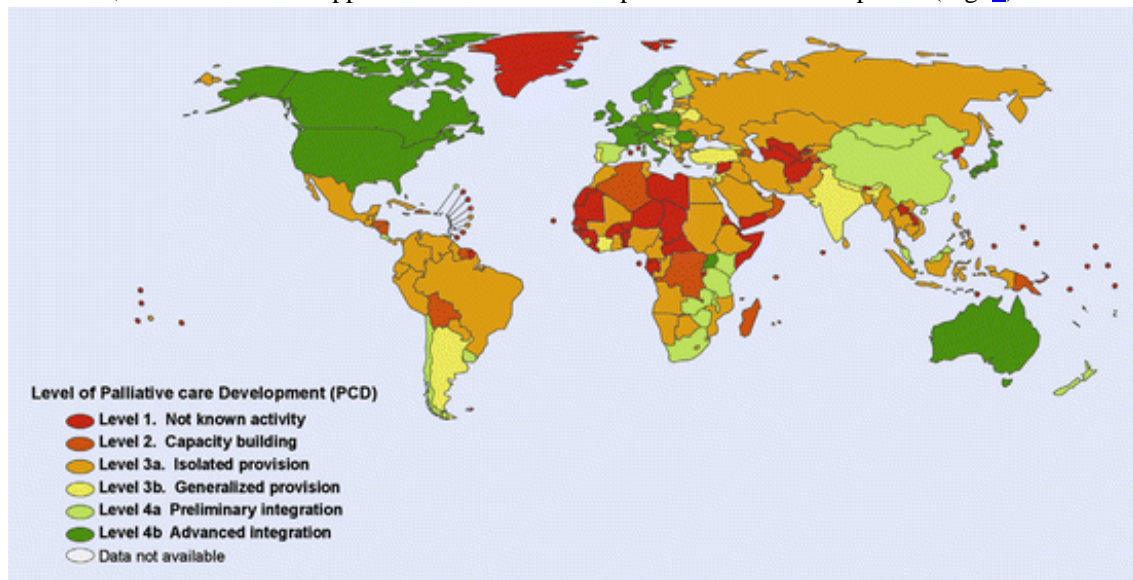


Fig. 1

International variation in palliative care development (Lynch et al. [2013](#))

End-of-Life Care in Hospitals

Variations in the Decision Making Process

Decisions regarding treatment at the end of life are inherently difficult, such as the choice to withhold life-sustaining therapy. The results of an international survey have revealed that patients, families, and palliative care experts around the world experience many common challenges in end-of-life decision making (Raijmakers et al. [2011](#)). Generally, there are many consistencies in the relative importance of factors directing end-of-life decision making, however the processes, which take these factors into consideration, vary considerably among countries. However, there appears to be substantial variation in expressed patient wishes of the preferred location of death (Raijmakers et al. [2011](#)). In Sweden, approximately 21 % of people die at home and this wish was least often ranked as important in end-of-life decision making, whereas in Argentina, where approximately 59 % of people die at home it is most often mentioned as an important consideration (Raijmakers et al. [2011](#)).

Advance Directives

Honoring the treatment preferences of patients is undoubtedly an important consideration in the provision of high quality patient centered care. The decision making process is made more difficult as many patients near the end of life, some critically ill, lack the capacity to make their own decisions. One strategy, which attempts to allow incapacitated patients to express their treatment preferences, is the use of advance directives (Lo and Steinbrook [2004](#)). Proponents of advanced directives argue that they may ease the burden of decision making on the family of the patient, and may serve as a foundation for physicians and families to begin discussions regarding the treatment of the patient at the end of life (Fassier et al. [2005](#)). Others argue that most advanced directives are not specific enough to provide definitive guidance and do not actually change end-of-life care plans (Lo and Steinbrook [2004](#)). Many other sources have documented a relatively instability in patients' preferences over time, changing according to age and different health states (Pardon et al. [2012](#); Fried et al. [2007](#)). There is relatively large international variation in the use of advance directives. Advance directives have been more popular in North America than in Europe, with the exception of the preferred priorities for care document that is used in England (Fassier et al. [2005](#); Gray [2011](#)). A survey of Italian Intensive Care Unit (ICU) physicians revealed that only 15 % had experience with advance directives, and only 30 % were familiar with the concept (Giannini et al. [2003](#)). In France, the willingness of patients to limit life-sustaining treatment was only known in 8 % of cases. In a Spanish study, no patients had written an advance directive and only 9 % discussed their preferences before being admitted to the ICU (Ferrand et al. [2001](#); Esteban et al. [2001](#)). Although there is some variability in the results of North American studies, the evidence suggests that the use of advance directives is rising, and one study from New York City reports that as many as 35 % of elderly people have completed an advance directive (Meier et al. [1996](#); Morrison and Meier [2004](#)). A recent Canadian study revealed 16 % of respondents were aware of the term advance care planning, 52 % acknowledged having had discussions with their family or friends, and 10 % had discussions with healthcare providers; however, only 20 % of the population had a written advance care plan (Heyland et al. [2013](#)). One potential explanation for this variability is the historical greater acceptance of a medical paternalism model of decision making in Europe compared to North America (Luce and Lemaire [2001](#)).

Who Makes the Decisions?

When decisions must be made for patients nearing the end of life who lack this capacity, there are varying views on who should be making such decisions. Approaches are difficult to generalize for

specific countries since there exists a high degree of variability among and within countries. In a European opinion survey on the decision to forego life-sustaining treatments, it was found that families were involved in 77 % of discussions (Vincent [1999](#)). There was a large variability in the responses however, where only 39 % of families were involved in Portugal, but 96 % of families were involved in The Netherlands (Vincent [1999](#)). In North America prior to the 1980s, families of the patients had little obligatory say in such decisions; however, in the past 30 years, autonomy has become increasingly important and recently it was found that 90 % of families partake in this decision making process (White and Curtis [2005](#); Pendergast et al. [1998](#)).

Over the last decade, many North American and European professional societies have agreed that sharing decisions among the health care team and the family is most likely to yield decisions that are in the patient's best interest and are most consistent with the wishes of the patient (Fassier et al. [2005](#)). In this model, the physician provides information on the different treatment options, and makes recommendations working together with the families and the patients themselves if possible (Emanuel and Emanuel [1992](#)). Although this shared decision making approach has been widely accepted in North America, many European physicians still consider decisions such as forgoing life-support to be the responsibility of the clinician (Fassier et al. [2005](#)). For example, surveys show that 61 % of Swedish intensive care specialists considered themselves solely responsible for life-support decisions and 42 % of Italian intensive care specialists rarely or never involved families in such decisions (Sjökvist et al. [1999](#); Giannini et al. [2003](#)). Although European physicians have been more reluctant to adopt this model in favor of traditional paternalism, the shared decision making process is gradually being accepted (Fassier et al. [2005](#)). For example, in recent studies from Spain, Belgium and France, end-of-life decisions were shared between the physicians and the families in 72 %, 91 %, and 100 % of cases respectively (Esteban et al. [2001](#); Holzapfel et al. [2002](#); Gajewska et al. [2004](#)). In their review of this topic, Fassier et al. ([2005](#)) have suggested that it may not only be traditional paternalism that is slowing the acceptance of shared decision making into European medical systems, but also family preference to have physicians make difficult decisions for them. A systematic summary of the literature indicated that for some diseases – such as lung cancer – more than 50 % of respondents preferred a passive role (Tariman et al. [2010](#)). For other cancers – such as breast cancer – the desire for a more active involvement in treatment decisions was higher and fewer than 37 % wanted a passive role. In a survey by Levinson et al. ([2005](#)), 96 % of patients preferred to be asked and given the opportunity to express their opinions, but more than 50 % wanted to leave the final decision to the physician. These examples point to the important conclusion that for many patients, shared decision making is not only about the course of treatment, but also about first consulting the patients about the desired level of involvement.

Conflict Resolution

A shared decision making model has been largely successful; however, it may provide increased opportunity for unresolved disagreement between the physician and the family. Conflicts occasionally occur in the intensive care unit setting regarding end-of-life treatment decisions – sometimes clinicians requesting more aggressive care than desired by patients or families, and sometimes families requesting treatment that physicians have deemed futile (White and Curtis [2005](#)). An international survey with respondents from the USA, Canada, South Africa, Europe, Asia and Australia showed that most clinicians around the world have few formal or binding medical futility laws or guidelines to direct their practice (Ball et al. [2010](#)). To assist with conflicts and difficult decisions, ethical consultation services have been suggested but are only occasionally used (Ball et al.

[2010](#)). Furthermore, survey respondents from Europe, Asia and Australia found that when they did use these bioethics services, they were believed to be unhelpful in conflict resolution, and while clinician respondents from the USA, Canada, and South Africa found such services to be slightly more helpful, they were still unsatisfied with this potential conflict prevention and resolution option (Ball et al. [2010](#)). The US and Canadian medical systems are heterogeneous but do have guidelines in place to address such conflicts (White and Curtis [2005](#)). A process-based approach is recommended by the American Medical Association that begins with communication with the patient or decision maker and if the conflict cannot be resolved, there is an option to transfer the patient to another care provider (White and Curtis [2005](#)). Many jurisdictions have evolved legal or quasilegal boards to assist in conflict resolution such as the Texas Advance Directives Act (Fine and Mayo [2003](#)) and the Ontario consent and Capacity Board (<http://www.ccboard.on.ca>). Recently, the Supreme Court of Canada has provided guidance that such boards, where they exist, are the preferable first recourse in helping to resolve such conflicts when patients or substitute decision makers request continued therapy when clinicians believe it to be no longer beneficial ([Supreme Court](#)).

End-of-Life Care Outside of the Hospital: Home and Hospice

When asked, a large proportion of people around the world indicate that they would prefer to die at home rather than in the hospital. In surveys, 71 % of elderly Americans indicated they would prefer to die at home, as did 50–70 % of English respondents (Gray [2011](#)). Similar preferences have been observed for many other countries including Canada, Germany, Italy, The Netherlands, and Spain (Wilson et al. [2002](#); Heyland et al. [2000](#); Gomes et al. [2012](#)). It follows that in the delivery of quality end-of-life care, an attempt might be made to honor these preferences. Providing alternatives to inpatient hospital care is undoubtedly an essential aspect of many end-of-life care models around the world; however, many countries fail to implement such systems on a large enough scale, and as a result many patients end up receiving end-of-life care and dying in hospitals for reasons other than medical necessity (Abel et al. [2009](#)). For example, although three-quarters of North Americans report preference for a home death, only 25 % of US deaths, and 10–20 % of Canadian deaths actually occur in the home (Gray [2011](#); CIHI Western Atlas 2007).

The United Kingdom (UK) has pioneered modern end-of-life care and is continuing to improve its quality by responding to people's preferences for home care by embracing a multifaceted model of end-of-life care involving community nursing services, residential care, and hospice care (Lutz [2011](#); Bardsley et al. [2010](#)). In 2008, the UK initiated a 10-year plan to improve end-of-life care (Gray [2011](#)). The principles of this strategy were built into a "care pathway" which aims to identify those who will likely die in the next 1–2 years, elicit their preferences regarding end-of-life care and then create a care plan integrating these preferences which often means minimizing time spent in hospitals (Gray [2011](#)). As a result, in 2012 it was reported that 42.4 % of decedents in England were dying at home or in a care home; a figure more aligned with the preference of the public than ever previously achieved (Department of Health [2012](#)). A recent cluster-randomized clinical trial of the Liverpool Care Pathway in Italy failed to demonstrate increased satisfaction with care; yet, the effect size may have been limited due to lack of penetration of intended palliative care services (Costantini et al. [2013](#)). Similar strategies have been implemented in Canada, such as the "End-Of-Life Care Strategy," which was implemented in Ontario between 2005 and 2008 (Seow et al. [2008](#)). One year after the implementation of this strategy, the number of end-of-life care clients increased drastically, and

qualitative analysis revealed that increased communication and collaborations have enhanced integration, consistency, and coordination of end-of-life care (Seow et al. [2008](#)). Other countries have been slow to develop community-based palliative care programs. Spain, for example does offer home-based palliative care programs, however many of these are privately funded which makes accessibility fragile and dependent upon ability to pay (Bruera and Sweeney [2002](#)). The slow development of publically funded community-based palliative care programs in Spain may be due to the general trend of decentralization of health services (Bruera and Sweeney [2002](#)). The situation appears similar in Argentina where publicly funded home care is only available in urban centers and is only privately funded elsewhere (Bruera and Sweeney [2002](#)). Differences in palliative care programs around the world have inspired the development of a “quality of death” index by the *Economist's* Intelligence Unit in 2010. This index was applied to 40 countries across the world and is comprised of numerous indicators pertaining to quality of end-of-life care, cost of end-of-life care, basic end-of-life healthcare environment and the availability of end-of-life care (Economist Intelligence Unit [2010](#)). The UK ranked first overall for quality of death, and first in both the subcategories of availability and quality of end-of-life care (Economist Intelligence Unit [2010](#)). Spain ranked 26th in the availability of end-of-life care, reflective of the scarcity of public resources allocated to community based end-of-life care (Economist Intelligence Unit [2010](#); Bruera and Sweeney [2002](#)). Canada and the USA are ranked highly in quality of end-of-life care at 5th and 7th, respectively; however they are still considerably behind the UK (Economist Intelligence Unit [2010](#)). Many countries end-of-life care plans might benefit from considering practices in the UK’s “care pathway” approach (Gray [2011](#)).

The Influence of Culture on End-of-Life Care

Cultural and religious norms influence many health care decisions made at the end of life. In one international survey, 96–100 % of physicians from North America, Europe, Asia, Australia and South Africa agreed that faith influences end-of-life care, while most denied that their own individual faith influenced their decisions (Ball et al. [2010](#)). However, a large European study found that times to therapy limitation and death, and discussion of decisions with patient families varied significantly based on physician and patient religious affiliation (Sprung et al. [2007](#)). Thus, it is also possible that the faith of individual physicians plays a role in their decisions and recommendations. In a systematic review of 6259 publications of patient and healthcare professional factors influencing end-of-life care, the authors found evidence that patient and clinician race, ethnicity, and nationality also appear to influence the technological intensity of end-of-life care. In general, Caucasian American (as compared to African American) patients and those in North America and Northern Europe may be less likely to desire intensive end-of-life care than others. Physicians of similar geoethnic origin to patients appear less likely to prescribe such therapy. Physicians with more clinical experience and those routinely working in the intensive care unit are less likely than other physicians to recommend technologically intense care for critically ill patients at the end-of-life (Frost et al. [CCM 2011](#)).

Communication between patients and their families about end-of-life care is commonly affected by religious and cultural variations. In Japan and China, for example, death is rarely openly discussed (Economist Intelligence Unit [2010](#)). Data from India and Argentina indicate talks about death may be avoided due to the common “protective motive” of families who want to shield the patient from receiving difficult diagnoses (Economist Intelligence Unit [2010](#); Bruera et al. [2000](#)). In North America, it is uncommon for diagnoses and prognoses to be withheld from patients, but a common hope for cure underlies prolonged curative, as opposed to palliative care plans, at the end of life

(Bruera et al. [2000](#)). Interestingly, unlike other countries, beneficiaries of Medicare in the USA only receive coverage for hospice care if they agree to forego treatments intended to cure (Scala-Foley et al. [2004](#)). It is no surprise that the idea of hospice care may be equated with giving up hope, since this association is engrained in the very structure of US Medicare.

Cost and Resource Variation

Total world health care expenditures are estimated at approximately six trillion USD ([WHO composition of Health Expenditures](#)). However, there is marked variation in global health care spending. The US spends the most, 2.6 trillion USD, or approximately 18 % of the gross domestic product (GDP), whereas median spending is approximately 10–12 % of GDP in Canada, Germany, Switzerland and France. In the USA, this equates to approximately 8000 USD annually *per capita*, in comparison to approximately 4000 USD annually *per capita* in other western nations. National expenditure on health care does not have a consistent relationship to overall health of a population. There is an association between life expectancy at birth and health care spending, but there is considerable variation in outcome for a given level of spending. The USA is an outlier, spending more *per capita* on healthcare than any other nation (Poisal et al. [2007](#)), yet not getting top ranking on many standard measures of health among Organization for Economic Cooperation and Development countries – 46th in average life-expectancy and 42nd in infant mortality (Schroeder [2007](#)). These data underscore that the determinants of health are often not the provision of reactive health care per se, but more broadly related to social circumstances, environmental exposure and behavioral patterns. There are also marked regional and socioeconomic variations in access and outcomes across the population within both developed and developing countries. In some parts of the developed world, most notably North America, access to care is far from universal – 45 million citizens, and millions more immigrants, lack any health insurance (Schroeder [2007](#)), and nearly 90 million lacked health insurance for at least 1 month during 2006–2007 (American College of Physicians [2008](#)).

Among various components of health care systems in developed countries, the provision of care at the end of life, often including aggressive diagnostic care, technology-assisted monitoring and treatment in intensive care units, is among the most expensive. In North America, intensive care consumes up to 1 % of the GDP (Halpern et al. [2004](#); Kelley et al. [2004](#)), and critical care services tend to dominate clinical expenditures in other western jurisdictions as well. More than 40 % of total health care spending is accounted for by those 65 and older in Canada, yet this age group accounts for less than 20 % of the total Canadian population (Wennberg et al. [2004](#)).

End-of-life care accounts for a substantial proportion of health care expenditures in many countries (United Nations [2013](#)). Countries whose population demographics follow the “baby boom” phenomenon will soon likely experience an additional increase in demand for end-of-life care as this generation become seniors. During these times of high demand, cost and resource use are becoming increasingly important outcomes and must be analyzed to ensure both quality and sustainability of health care systems. The consistently high proportion of funds spent on end-of-life care was noted in a review by Shugarman et al. ([2009](#)). Costs in the last year of life averaged 27–30 % of public expenditures of those over 65 in the USA, 26 % in The Netherlands, and 18–22 % in Switzerland (Shugarman et al. [2009](#)). A further consistency among many countries, including the USA, Canada and the Netherlands is that inpatient hospital care dominates end-of-life care spending (Shugarman et al. [2009](#)). However, in England it has been shown that with increasing age (after age 60) hospital costs at the end-of-life decline while social care costs (residential care, nursing home, home care, residential respite care, equipment and adaptations, day care meals) increase (Bardsley et al. [2010](#)).

Among English decedents over age 90, estimated social care costs exceed estimated hospital inpatient costs (Bardsley et al. [2010](#)). This may to a certain extent be a consequence of the English “care pathway” model which facilitates the use of social care services. An emerging theme is the direct effect of age on end-of-life care expenditures. In many countries, including the USA, Germany, Wales, and Canada, it has been observed that total costs associated with end-of-life care actually decrease with age (Shugarman et al. [2009](#); Brockmann [2002](#); Kardamanidis et al. [2007](#); Menec et al. [2007](#)). This may be interpreted as a tendency to lessen the intensity of treatment at advanced ages, however it may also be the result of a shift from inpatient to more community care – and possibly less complete cost ascertainment as more out-of-hospital costs are covered by out-of-pocket funding – at older ages (Shugarman et al. [2009](#)).

There is evidence that different payment systems influence end-of-life spending, and this has important financial and clinical implications. End-of-life spending decreases at very old age globally, but the decrease seems to be less in the USA than many other countries. For instance, register data from Norway show that an average 80 year old receives less than half the services of a 60 year old in the year they die (Melberg et al. [2012](#)). In the USA, the decline appears to be around 30 % (Lubitz and Prihoda [1984](#); Lubitz et al. [2003](#)). Part of the difference may be caused by the incentives inherent in the fee-for-service system which rewards the continued provision of services. In contrast, several European countries use a bundled one-time payment approach based on diagnosis, which provides an incentive to limit services. Both systems have challenges and the future growth of elderly populations is likely to increase these challenges. A pure fee-for-service system may be increasingly costly, while a diagnosis-based bundled payment may have difficulties with under-provision of care for elderly patients with multiple diagnosis and treatment needs. Policy answers to this dilemma include a focus on more integrated services and new payment mechanisms that emphasize performance related measures as opposed to payment based on volume.

Intra-country Variation

One consistent finding in end-of-life care has been of substantial variability – among and within countries – in the delivery of care (Dartmouth Medical School, Wennberg JE, Canadian Institute for Health Information Western Atlas, Block et al. ([2008](#))). When variability exists, it can be due to true differences in health needs of the population, but this almost certainly represents non-standard approaches to end-of-life and palliative care across regions. This may reflect uncertain best practices in end-of-life care, or worse yet, sub-optimal care according to World Health Organization goals. Using Medicare and other data, the Dartmouth Atlas has found that end-of-life care has strong geographic associations (i.e., where the patient happens to live), and not necessarily on the patient’s preferences or the power of care to extend life. For example, in 1995–1996, the likelihood of being an acute care hospital inpatient at the time of death varied by a factor of 2.8 (from under 20 % to nearly 50 %); being admitted to an intensive care unit at the time of death varied by a factor of 4.6 (from 6.3 % to nearly 30 % of all deaths); time spent in intensive care during their last 6 months of life varied substantially (from 20 % of patients spending 1 week or more to fewer than 4 %). Intensity of care in the last 6 months of life also varied remarkably as measured by the number of visits to physicians – variations of a factor of 5.6 (from an average of less than 9 to nearly 50). The number of physicians involved in patients’ care varied from 30 % of patients seeing 10 or more physicians during their last 6 months of life; whereas in other regions fewer than 3 % were treated by that many different physicians. The cost of this care during the last 6 months of life varied dramatically, from about \$6,200 to almost \$18,000 per decedent.

In 2007, the Canadian Institute for Health Information published a report on the use of health care at the end of life in four provinces in Western Canada (Canadian Institute for Health Information [2007](#)). The findings reported that over half of all western Canadians' deaths occur in hospitals (58 % or roughly 37,000 people). Hospital based palliative care comprised a component of end-of-life care for only 13–16 % of those dying, across the four provinces. The report identified patients with a “terminal illness trajectory” and found them to be much more likely to have died at home (11–17 %) or in a long-term care facility (16–27 % across provinces). Hospitalizations were common within 1 year of death – 62 % of decedents were hospitalized at least once, spending an average of 20.1 days in hospital. Decedents from smaller, rural or northern regional health authorities were more likely to have been hospitalized and to spend more days in hospital before death than decedents from larger, more urbanized areas, leading the authors to speculate that there may be increased availability of non-hospital based health services in larger urban centers compared to smaller communities in which these types of services would only be available at a local hospital.

Rationing of Resources

Irrespective of countries' funding schemes, if the demand for resources exceeds the supply, some form of rationing must take place. Accordingly, it is likely that health care rationing, or withholding some forms of treatment at the end-of-life, occurs in all countries (Truog et al. [2006](#)). In one study, perspectives from representative critical care physicians were sought in England, Italy, Spain, France, Argentina, Canada, and the USA (Evans et al. [2011](#)). A common theme was the lack of formal guidelines or legal policies regarding rationing for acute or critical care services near the end of life (Evans et al. [2011](#)). In most countries, rationing of health resources is an understandably sensitive political topic and as a result rationing tends to occur in a more informal manner (Evans et al. [2011](#)), sometimes practically delegated to the healthcare team who often operate with some degree of fixed resources, as opposed to open societal debate and formal governmental policy. Physicians commonly reported that the availability of ICU beds often factors in their decision of admitting a patient to the ICU (Evans et al. [2011](#)). The number of total ICU beds varies drastically among countries, ranging from 3.3 per 100,000 population in the UK to 24.0 per 100,000 in Germany (Wunsch et al. [2008](#)). As a result, in the UK 65 % of physicians believed that bed availability often limited ICU admission, where 55 % of German physicians and only 22 % of French physicians responded similarly (Vincent [1999](#)). In times of high demand attempts are made to accommodate increased need for intensive care. In Italy, an emergency care network exists to transfer patients to hospitals where ICU beds are available, while in Spain a similar system exists but ICU level services are also offered in emergency departments while scheduled surgeries may be restricted to temporarily create additional capacity (Evans et al. [2011](#)). In many developing countries, however, there may be little to no critical care beds to provide intensive care to patients, and sometimes scarce provision of opioid medications to alleviate pain and breathlessness at the end of life (Adhikari et al. [2010](#)).

Although clinical benefit is widely accepted as the most important criterion in medical decision making, in some countries resource limitation may play the dominant role for a large portion of the population who rely upon publically funded systems. In a survey of physicians across the world, respondents from resource constrained settings in Asia and South Africa believed that resource limitation influenced their end-of-life decisions for severely injured patients (Ball et al. [2010](#)). From the patient's perspective, out-of-pocket expenses can represent a significant barrier to accessing end-of-life care. Although public funding is often available for end-of-life care, out-of-pocket expenses are encountered to varying degrees in all countries (Economist Intelligence Unit [2010](#)). Out-of-pocket

expenses borne by the patient have been found to be lowest in Australia, The Netherlands, New Zealand, and Norway, while such costs in the UK, Canada, and the USA are substantially higher (Economist Intelligence Unit [2010](#)). In a survey of elderly people in the USA, when faced with a hypothetical end-of-life decision, respondents were more likely to recommend treatment covered by Medicare even if the chance of survival was low (Chao et al. [2008](#)). If the treatment would deplete the savings of the patient, most agreed that the patient should forego costly end-of-life treatments (Chao et al. [2008](#)).

In some countries, such as the UK, different types of treatment are explicitly rationed based on the cost per quality-adjusted life years gained. In other countries, the rationing is performed implicitly, and in the USA, there is an explicit reluctance towards the use of cost per quality-adjusted life-year thresholds as a rationing device. This may encourage additional spending at the end of life, but it is worth noting that even in the UK, end-of-life treatment is often not subjected to the same cost per benefit thresholds as other kinds of treatment. Due to short time gains for many end-of-life treatments, these therapies tend to be less economically attractive in comparison to others. Hence, the UK has introduced a different threshold for end-of-life treatments ([Boseley and Sparrow](#)).

Conclusions

Patients, and the healthcare systems of many countries, have acknowledged the value of high quality care at the end of life and the growing need for such services. However, end-of-life care around the world remains highly heterogeneous. A common theme evident in various parts of the world is a preference to receive end-of life care outside of the hospital environment. A great deal of progress is being made in the development of services which offer an alternative to in hospital death, especially in the UK, where care plans for patients are based upon elicited preferences and guide transitions among hospital, home, and hospice environments in a way that aims to maximize their comfort at end of life. Evidence suggests that care providers from various parts of the world encounter similar challenges in the provision of end-of-life care, and approaches to these challenges are variable between countries. The use of advance care directives, the delegation of responsibility for decision making and the resolution of conflicts between physicians and families are common points of contention. Approaches to these issues vary and are influenced by many factors including the structure of medical systems, religion, culture, and the necessity to operate within systems that have limited resources. However, the goal of maximizing comfort for patients at the end of life is held in common. Examining international variation in end-of-life care provides examples of higher and lesser performing systems that can inform end-of-life care quality improvement initiatives for all systems.

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