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CREATING A SPACE FOR END OF LIFE: A LEAP-FROG OPPORTUNITY FOR DEVELOPING COUNTRIES FROM A HEALTH AND HUMAN RIGHTS PERSPECTIVE

MARTA KIKENA DE MATTO*

I. INTRODUCTION

Significant progress has been made since the mid-twentieth century furthering the right to health within the human rights framework, initially established by the International Bill of Human Rights,¹ which consists in relevant part of the Universal Declaration of Human Rights (UDHR)² and the International Covenant on Economic, Social and Cultural Rights (ICESCR).³ The right to health has been

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1. See *The International Bill of Human Rights: Fact Sheet No.2 (Rev. 1)*, U.N. OFFICE OF THE HIGH COMM'R FOR HUMAN RIGHTS (June 1996), available at <http://www.ohchr.org/Documents/Publications/FactSheet2Rev.1en.pdf>.

2. Universal Declaration of Human Rights, G.A. Res. 217 (III) A, U.N. Doc. A/RES/217/217(III) (Dec. 10, 1948).

3. G.A. Res. 2200A (XXI), 993 U.N.T.S. 3 (Jan. 3, 1976) [hereinafter ICESCR]. The United States has not ratified ICESCR. U.N. Treaty Collection, Multilateral Treaties Deposited with the Secretary-General, ICESCR Status as of Dec. 17, 2013, https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-3&chapter=4&lang=en. The third and final component, not relevant to this article, of the International Bill of Human Rights is the International Covenant on Civil and Political Rights (ICCPR). G.A. Res. 2200A (XXI), 999 U.N.T.S. 171 (Mar. 23, 1976) [hereinafter ICCPR]. See *The International Bill of Human Rights: Fact Sheet No.2*, *supra* note 1. The United States has ratified the ICCPR. U.N. Treaty Collection, Multilateral Treaties Deposited with the Secretary-General, ICCPR Status as of Dec. 17, 2013, https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-4&chapter=4&lang=en.

elaborated upon in the organic Constitution of the World Health Organization (WHO)⁴ and subsequent international conventions on the rights of women,⁵ children,⁶ persons with disabilities,⁷ and detainees in danger of torture,⁸ among others, which have emphasized the need to protect large, ubiquitously vulnerable and traditionally marginalized groups across states.⁹

Currently, however, there does not exist a comparable international convention providing guidance on end-of-life and palliative care to address the rights of a large and vulnerable group that all people alive today (and foreseeable generations) are increasingly likely to fall into—as persons who are terminally ill or dying.¹⁰ Until such a convention is established, countries must either actively address the issue or encounter an eventual system of no system that has arisen in developed countries. Considering that such multilateral treaties can take years or decades to be drafted and ratified by a substantial number of United Nations (U.N.) member states,¹¹ developing countries cannot afford to wait and miss an ephemeral opportunity to integrate a comprehensive end-of-life and palliative care approach within their greater health care systems.

As the U.N. body charged with overseeing international health, WHO defines the right to health as “the enjoyment of the *highest attainable* standard of health.”¹²

4. See World Health Organization, Constitution of the World Health Organization (Apr. 7, 1948), http://www.who.int/governance/eb/who_constitution_en.pdf.

5. U.N. Convention on the Elimination of All Forms of Discrimination Against Women, G.A. Res. 34/180, U.N. Doc. A/RES/34/180 (Sept. 3, 1981), <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm>.

6. U.N. Convention on the Rights of the Child, G.A. Res. 44/25, U.N. Doc. A/RES/44/25 (Sept. 2, 1990), <http://www.un.org/documents/ga/res/44/a44r025.htm>.

7. U.N. Convention on Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (May 3, 2008), <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> [hereinafter CRPD].

8. U.N. Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, G.A. Res. 39/46, U.N. Doc. A/RES/39/46 (June 26, 1987), http://www2.ohchr.org/english/bodies/cat/docs/GC/CAT-C-GC-3_en.pdf [hereinafter CAT].

9. See *supra* notes 4–8 and accompanying text.

10. See Jan Stjernswärd et al., *The Public Health Strategy for Palliative Care*, 33 J. PAIN & SYMPTOM MGMT. 486, 486–87 (2007) (noting that in the next fifty years, worldwide need for palliative care will “increase dramatically” due to ageing populations and the corresponding increase in multiple chronic diseases); see also, e.g., Richard Harding et al., *Generating an African Palliative Care Evidence Base: The Context, Need, Challenges, and Strategies*, 36 J. PAIN & SYMPTOM MGMT. 304, 305 (noting that “as people’s lifestyle, nutritional preferences, and nonsedentary work patterns on the continent change, Africa may experience an increase in the incidence of those chronically debilitating, life-limiting diseases characteristic of resource-abundant nations (e.g., stroke, diabetes, hypertension, and heart disease).”).

11. See *The International Bill of Human Rights: Fact Sheet No.2*, *supra* note 1. The conclusion of both ICESCR and ICCPR spanned three decades. *Id.* Both multilateral conventions arguably began to be drafted in 1945 with the proposal for a “Declaration on the Essential Rights of Man” and both were adopted by the U.N. General Assembly in 1966, but not ratified until 1976. *Id.*

12. Constitution of the World Health Organization, *supra* note 4, at 1.

Therefore, the challenges faced by developing, resource-constrained countries in end-of-life care are inherently different than those faced by developed, resource-abundant countries. Developing countries, by virtue of being in the nascent stages of establishing their health care systems and policies, are in a unique position to leap-frog over many current end-of-life care problems through a combination of learning from the mistakes as well as the successes of the developed world, while leveraging their own unique resources.¹³ Through a comprehensive public health strategy¹⁴ developing countries should create a “space for end-of-life”¹⁵ as a natural process by avoiding over-medicalization, over-institutionalization, and isolation of the dying and their families.¹⁶ Such a societal “space” does not necessarily equate with a “place,” because physical institutions such as hospices and nursing homes will “always be stigmatized” and isolated.¹⁷ Instead, within the societal space for dying, individuals and families should have time to experience the psychological, social, emotional, and spiritual resolution of a life.¹⁸

Freedom from pain and end-of-life care are not solely or even primarily medical issues, as they have been treated in the West; instead, they are and should be treated as a community and human rights issues.¹⁹ “Many countries with scarce medical facilities have at the same time avoided the institutionalization and professionalization of death, whilst also retaining strong cultural, ritual, community

13. See generally V. Gunasekaran & F.C. Harmantzis, 29 *TECH. IN SOC'Y* 23, 23 (2007) (discussing how developing countries, by using wireless communications technology, can not only “bridge the digital divide” but also possess an advantage over other “traditional wired infrastructures,” and thus can leap-frog over outdated telecommunications stages entrenched in the developed world).

14. See generally Stjernsward et al., *supra* note 10, at 486 (advocating a public health strategy for palliative care as the best and most cost-effective method to reach the general population).

15. Interview with Carla S. Alexander, M.D., Director of Palliative Care & Support, Inst. Human Virology, Univ. Md. Sch. Med., in Balt., Md. (May 22, 2013). Dr. Alexander is an “internationally recognized expert in the area of Palliative and End-of-Life Care. Board certified and a Fellow of the AAHPM, she has practiced hospice and palliative care since 1986 and is a founding member of the American Academy of Hospice and Palliative Medicine (AAHPM), serving as President in 2000. She has taught elements of Palliative and End-of-Life care related to HIV/AIDS throughout the U.S. and Caribbean, Canada, Africa, Eastern and Western Europe, Ukraine, South America and Asia.” Her field of research focuses on “methods for providing support to health professionals in resource-constrained settings, [the] importance of self-care for physicians and other members of interdisciplinary team, [and the] care and support needs of persons dually impacted by cancer and HIV.” Carla S. Alexander, M.D., UNIV. MD. SCH. MED., <http://medschool.umaryland.edu/facultyresearchprofile/viewprofile.aspx?id=2239> (last visited Dec. 17, 2013).

16. Interview with Carla S. Alexander, M.D., Director of Palliative Care & Support, Inst. Human Virology, Univ. Md. Sch. Med., in Balt., Md. (May 22, 2013). Dr. Alexander concurred that in the U.S., the natural processes of birth and death are inappropriately approached as pathologies in the medical field. *Id.*

17. *Id.*

18. *Id.*

19. *Id.*

and family support systems in end-of-life care—precisely those that have been lost, medicalized, or commercialized in the west.”²⁰

Developing countries, in cooperation with the international community and their domestic local communities, should respect, protect, and fulfill²¹ obligations to persons who are terminally ill or dying and safeguard their right to freedom from pain. Specifically, developing countries should respect persons who are terminally ill or dying by ensuring their access to palliative care and increasing the awareness of its availability.²² Additionally, developing countries should establish nondiscriminatory policies that make palliative care and drugs physically and financially accessible.²³ They must also protect persons who are terminally ill or dying by ensuring they receive care that is of good quality by properly training health care providers and volunteers and encouraging a multidisciplinary ethos to address the field’s multifaceted problems from the outset of a country’s national health approach.²⁴ Of equal importance, developing countries must protect their population from paternalistic prescriptions of outside influences, such as prematurely introducing the concept of advance directives that may directly clash with domestic cultures, and to comport measures with cultural acceptability to the greatest extent possible.²⁵ Finally, developing countries should fulfill their obligation to protect vulnerable persons at the end-of-life by taking active measures to implement a comprehensive end-of-life care strategy that is integrated into the overall health care system.

End-of-life care is as complex as it is controversial. Consequently, it is necessary to briefly outline the parameters this article will address within end-of-life and palliative care in developing countries. First, each developing country and region faces unique challenges and opportunities in end-of-life and palliative care and thus any approach that takes a broad view of such a discrete group risks overgeneralization; however, the potential benefits of a broad analysis in

20. Jan Stjernsward & David Clark, *Palliative Care Medicine – A Global Perspective*, in OXFORD TEXTBOOK OF PALLIATIVE MED. 1199, 1199 (D. Doyle et al. eds., 3d ed. 2003).

21. See Comm. on Econ., Soc. and Cultural Rights, *General Comment No. 14 (2000): The Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)*, ¶ 34-36, E/C.12/2000/4 (Aug. 11, 2000), available at <http://www.unhchr.ch/tbs/doc.nsf/%28symbol%29/E.C.12.2000.4.En> [hereinafter *General Comment No. 14*] (noting that the legal obligations of states party to ICESCR include the duty to respect the right to health by refraining from discrimination or other harmful practices, to protect such rights by proactively adopting legislation, and to fulfill such rights by developing a national health strategy as a roadmap for meaningful implementation).

22. See *id.* at ¶ 12. General Comment No. 14 provides a highly useful framework—examining availability, accessibility, quality, and acceptability (AAQA)—for analyzing the implementation of the right to health within human rights. *Id.* This article adopts the AAQA framework to analyze the implementation of a comprehensive public health strategy in developing countries encompassing end-of-life and palliative care. *Id.*; see also *infra* Part III.

23. See *infra* Part IV.

24. See *infra* Part V.

25. See *infra* Part VI.

addressing reoccurring patterns arguably outweigh the risks. Next, it must be acknowledged that much more empirical data will need to be gathered in the end-of-life care field, and that resource-strained countries should not let this core building block of a national health strategy fall by the wayside.²⁶ Moreover, in many developing countries, the concept of long-term treatment for chronic conditions, such as heart disease, as opposed to acute afflictions, such as a broken bone, may have to disseminate alongside the concept of end-of-life care; rather than being a disadvantage, this relative “blank slate” can allow for developing countries to avoid tracking end-of-life care over-medicalization. Similarly, this article will focus on the measures developing countries need to take to address the moderate to severe pain of persons who are terminally ill or dying from old age or diseases such as cancer and AIDS, because even developed countries are still struggling to reach the proper balance for pain therapy for acute, non-palliative care.²⁷ Issues surrounding euthanasia and physician-assisted suicide are not addressed because they are too controversial to include in an introductory end-of-life care framework and deserve separate treatment.²⁸

Finally, it must be recognized that human and health rights are “interdependent, indivisible, and interrelated”²⁹ and thus delivery of proper end-of-life care will necessarily intersect with core minimum health obligations and other human rights, such as the “rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement.”³⁰ Similarly, when referring to the steps that developing countries must take to create a comprehensive end-of-life care strategy, continual partnership with the international community and with domestic local communities will inherently be required.³¹

26. See Harding et al., *supra* note 10, at 305 (discussing that even in the poorest regions of Africa, empirical evidence gathering is crucial to determine how to best deliver end-of-life and palliative care because “practices and standard of care provision are underpinned by evidence rather than anecdote”).

27. See M.K. Kotecha & B.D. Sites, *Pain Policy and Abuse of Prescription Opioids in the USA: A Cautionary Tale for Europe*, 68 ANESTHESIA 1210, 1210–13 (2013) (discussing the steep rise of opioid prescription use in the United States and the need to rebalance their application to short-term and acute palliative care, rather than as default therapy for long-term, chronic pain).

28. Interview with Carla S. Alexander, *supra* note 15.

29. World Conference on Human Rights, June 14–25, 1993, *Vienna Declaration and Programme of Action*, ¶ 5, U.N. Doc. A/CONF/157/23 (July 12, 1993).

30. See *General Comment No. 14*, *supra* note 21, at ¶ 3.

31. See ICESCR, *supra* note 3, at art. II, ¶ 1. (“Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures”); see also *General Comment No. 14*, *supra* note 21, at ¶¶ 39, 42 (emphasizing the obligation of all States party to

Initially, this article will examine the human rights and international law based on UDHR, ICESCR, and WHO guidance for end-of-life and palliative care within the right to health.³² Next, the availability of end-of-life care will be addressed, with a focus on raising the awareness of the existence of the field among medical professionals and the general public.³³ The availability and access to pain medication in developing countries during end-of-life care is also discussed.³⁴ Particularly pertinent in addressing availability are Article 8 of the U.N. Convention on Rights of Persons with Disabilities (CRPD), the WHO Model List of Essential Medicines, the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT), and the 2013 Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.³⁵ In turn, end-of-life and palliative care accessibility—via nondiscrimination and physical access as well as affordability and information exchange—will be examined, incorporating provisions from CRPD and the International Guidelines on HIV/AIDS and Human Rights and underscoring the importance of streamlining end-of-life and palliative care into the country's primary health care system.³⁶ Subsequently, analysis will center on the importance to deliver good quality of care by training medical professionals and integrating local community in national end-of-life care through trained volunteers and family caretakers.³⁷ Cultural acceptability and nuance will be considered in implementing end-of-life care policy, recognizing that Western notions of autonomy should not be assumed to be an automatic fit.³⁸ Finally, this article will conduct a case study of the Indian state of Kerala's integrated end-of-life care approach, which has won international recognition,³⁹ and advocate for the Maryland Medical Orders for Life-Sustaining Treatment (MOLST) form as a model of simplicity for developing countries embarking on considerations of end-of-life care planning.⁴⁰

II. HUMAN RIGHTS FRAMEWORK

Under customary international law (CIL) and as members of the U.N., developing countries have a responsibility to respect, protect, and fulfill the right to be free from unnecessary pain and to create a space for the conclusion of one's life

ICESCR to support domestically and through international cooperation other States' pursuit of the right to health to the extent feasible).

32. *See infra* Part II.

33. *See infra* Part III.

34. *See infra* Part IV.

35. *See infra* Part III.

36. *See infra* Part IV.

37. *See infra* Part V.

38. *See infra* Part VI.

39. *See infra* Part VII.

40. *See infra* Part VIII.

that honors inherent human dignity.⁴¹ Indeed, there is “a moral responsibility to give those who leave life—elderly people, those terminally ill, those dying slowly of AIDS and cancer—the same care and attention that we give to those who enter life.”⁴² This moral responsibility was initially addressed by the international community beginning with the Universal Declaration of Human Rights in 1948, which states “[e]veryone has the right to a standard of living adequate for the health of himself and his family, including food, clothing, housing and medical care and necessary social services.”⁴³ Although only a declaration and not a treaty, the UDHR serves as the foundation for ICESCR, the multilateral treaty with the force of law that most significantly elaborates on the right to health.⁴⁴ Any country that is an ICESCR treaty member, regardless of its level of development, must comport with Article 12, which promulgates the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health,” and requires signatories to take steps to “achieve the full realization of this right,” including those necessary for the “creation of conditions which would assure to all medical service and medical attention in the event of sickness.”⁴⁵

End-of-life and palliative care is an unavoidable and integral part of an adequate standard of living, falling squarely within the UDHR’s right to medical care, housing (in terms of long-term care), and necessary social services, since a comprehensive, community-inclusive, multidisciplinary approach has been found to be the most effective.⁴⁶ Under Article 12 of ICESCR, members of developing countries cannot ignore the elderly and terminally ill within their borders and are instead required to take active steps within their means for the “creation of conditions which would assure” end-of-life and palliative care systems.⁴⁷ Indeed, the inception of the International Bill of Human Rights was rooted in a special emphasis to protect vulnerable groups and individuals.⁴⁸ Thus, ignoring or retracting care at the moment when people are sick, in pain, and at the end of life—precisely when they become vulnerable—would run counter to the foundational ethos of human rights.

41. See *General Comment No. 14*, *supra* note 21, at ¶¶ 34–43; see also *supra* notes 21–25 and accompanying text.

42. Stjernsward & Clark, *supra* note 20, at 1199.

43. Universal Declaration of Human Rights, *supra* note 2, at art. XXV, ¶ 1.

44. See ICESCR, *supra* note 3, at pmb., art.12.

45. *Id.* at art. 12.

46. See Stjernsward et al., *supra* note 10, at 486–87, 491 (emphasizing the importance of community involvement for the establishment of a palliative care system “from the people, for the people, by the people.”); see also discussion *infra* Part VII.

47. See ICESCR, *supra* note 3, at art. 12.

48. See *The International Bill of Human Rights: Fact Sheet No.2*, *supra* note 1 (noting that the Universal Declaration of Human Rights and the covenants comprising the International Bill of Human Rights are a “yardstick by which to measure . . . international human rights standards everywhere on earth . . . without distinctions of any kind such as race, colour, sex, language, religion, political or other opinions”).

Developing countries that are not party to ICESCR, such as South Africa, Cuba, and Palau,⁴⁹ may still be bound to follow ICESCR provisions and provide end-of-life and palliative care systems under CIL. CIL contains two components: an objective component of a large majority of states following a uniform practice and a subjective component that a state is following a practice pursuant to a sense of obligation, rather than as a courtesy.⁵⁰ Currently, 161 countries are party to ICESCR,⁵¹ providing compelling evidence that a large majority of states have committed to following the basic medical care provisions addressed in Article 12 for end-of-life and palliative care.⁵² While accession to a treaty is the strongest possible evidence that member countries are acting pursuant to a legal obligation, repeated practice by a state also serves in this regard.⁵³ By allowing the delivery of international health care aid within their borders, developing countries, even without proactively establishing national health care systems, are potentially cementing health care obligations through practice. Thus, a cogent argument exists that the principles embodied in ICESCR, particularly in Article 12, have solidified as CIL and thus must be followed by all states.

Governments attempting to comport with the right to health may at times be frustrated with the rich-world perspective taken by international bodies, particularly the World Health Organization (WHO). WHO sets a high standard for palliative care by defining it as, “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁵⁴ The emphasis on prevention, early identification, and impeccable treatment appears to stem from assumptions about abundant-rich countries rather than taking into account the resource constraints of developing

49. See ICESCR, *supra* note 3.

50. See PETER MALANCZUK, AKEHURST’S MODERN INTRODUCTION TO INTERNATIONAL LAW 39 (7th ed. 1997). For example, diplomatic immunity is generally regarded as customary international law because most states practice it out of a sense of legal obligation, whereas extending car service to foreign diplomats to visit heads of state would not rise to the level of customary international law, because, although most states arguably practice it, they do so as a courtesy.

51. See ICESCR, *supra* note 3.

52. From a total of 193 U.N. member states, 161, or almost 85%, are parties to ICESCR. *United Nations Member States: Growth in United Nations Membership, 1945-Present*, <http://www.un.org/en/members/growth.shtml#2000> (last visited Dec. 18, 2013). See ICESCR, *supra* note 3, at art. 12.

53. See MALANCZUK, *supra* note 50, at 36–39 (proposing that although conventions and treaties embody express international law, the “main evidence” of customary law is in “the actual practice of states”).

54. WHO *Definition of Palliative Care*, U.N. WORLD HEALTH ORG., <http://www.who.int/cancer/palliative/definition/en/> (last visited Dec. 18, 2013).

countries.⁵⁵ For example, due to infrastructure, monetary, and technological constraints, developing countries' populations currently tend to seek care in more advanced stages of disease.⁵⁶ However, the definition goes on to elaborate in a manner more in keeping with the highest attainable standard of health for many developing countries, by noting that palliative care "affirms life and regards dying as a normal process . . . offers a support system to help patients live as actively as possible until death . . . [and] uses a team approach to address the needs of patients and their families."⁵⁷ Therefore, even if developing countries cannot comply with WHO's "impeccable" delivery of end-of-life and palliative care,⁵⁸ they should not regard progressive steps taken in this area as futile.

In the event that a developing country can successfully argue that it is not bound by the international right to health, addressing end-of-life care voluntarily, rather than out of a sense of international obligation, is clearly in the country's best economic, political, and social interests. Within one lifetime "there will be a dramatic sixfold increase in older people in the developing world, from 0.2 billion to 1.2 billion."⁵⁹ In addition, by 2020 the rates of cancer, cardiovascular disease, and diabetes will almost double worldwide.⁶⁰ If developing countries can take only one lesson from the West in end-of-life care, it should be that development brings such complex medical, social, and technological challenges in the field that a comprehensive national strategy must be undertaken in order to avoid irrational results, inefficient costs, and unnecessary harm.⁶¹ Finally, and most importantly for

55. See Stjernsward & Clark, *supra* note 20, at 1199 (pointing out that the definition of palliative care may be so ambiguous as to lead to the misunderstanding that over-medicalization is compulsory in offering end-of-life and palliative care).

56. See Stjernsward et al., *supra* note 10, at 487 ("Unfortunately, although the knowledge and experience to control pain and diminish suffering exist, the tragedy for most of the world's population is that palliative care is not available to them. In fact, the greatest need is in developing countries, where 45 million of the deaths occur and health care resources are the scarcest").

57. See *WHO Definition of Palliative Care*, *supra* note 54. The complete definition of palliative care elaborates that it:

provides relief from pain and other distressing symptoms; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help the family cope during the patients illness and in their own bereavement; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Id.

58. *Id.*

59. Stjernsward & Clark, *supra* note 20, at 1200. This increase does not account for those who will arrive at the end of life prematurely through non-communicable and chronic diseases.

60. See Stjernsward & Clark, *supra* note 20, at 1200 (noting that noncommunicable diseases will rise from 27% to 43% of the global disease burden).

61. See *The Cost of Dying: Patients' Last Two Months of Life Cost Medicare \$50 Billion Last Year; Is There a Better Way?*, CBSNEWS (Nov. 19, 2009), http://www.cbsnews.com/8301-18560_162-5711689.html?pageNum=4 [hereinafter *The Cost of Dying*]. As one American

resource-deprived countries, lack of end-of-life and palliative care leads to “improper use of scarce resources meant for curative therapy and also blockage of hospital beds” as, in the absence of end-of-life care guidance, most patients who do receive care are drawn to unnecessarily expensive treatments, inappropriate hospitalizations, and futile miracle cures.⁶²

ICESCR’s Articles 12 provision that every person is entitled to the highest attainable standard of health takes into account “both the individual’s biological and socio-economic preconditions and a State’s available resources.”⁶³ Indeed,

good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health. Thus, genetic factors, individual susceptibility to ill health and the adoption of unhealthy or risky lifestyles may play an important role with respect to an individual’s health. Consequently, the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health.⁶⁴

In the developing world, the alignment between the highest attainable level of health and end-of-life care is particularly salient because preventative and curative treatments are often nonexistent or lagging, thus leading to more interaction with medical services by people in terminal states and severe pain.⁶⁵ The case of cancer is illustrative. In theory, one third of the cancer cases worldwide are preventable and another third are curable if detected early and standard treatments exist.⁶⁶ The last third is not curable but freedom from pain and associated symptoms is possible in end stages.⁶⁷ However, in the developing world, where even basic cancer screenings and treatments are often not yet available,⁶⁸ most cancer cases are found at the incurable stage, thus heightening the need for the relatively simple measures needed for pain relief and palliative care vis-à-vis developed countries.⁶⁹ In developing countries, the highest attainable

physician working in the end-of-life field stated about the current lack of system in the U.S. and whether a national strategy equated with rationing, “We ration now. We just don't ration rationally.” *Id.*

62. Suresh Kumar, *Models of Delivering Palliative and End-of-Life Care in India*, 7 SUPPORTIVE & PALLIATIVE CARE 216, 218 (2013).

63. See *General Comment No. 14*, *supra* note 21, at ¶ 9.

64. *Id.*

65. See *supra* notes 55–57 and accompanying text.

66. See Stjernsward & Clark, *supra* note 20, at 1200.

67. *Id.*

68. *Id.*

69. *Id.*

standard of health is available, accessible, quality, and acceptable end-of-life and palliative care.⁷⁰

III. AVAILABILITY

End-of-life and palliative care must be available as a medical and societal response to dying, which for most developing countries translates into creating an awareness of the field itself among health care providers and the general population, as well as reforming overly burdensome drug laws.

A. Awareness

In the U.S., a country that is a leader in medical advancement, training for medical professionals in end-of-life and palliative care was almost nonexistent during the 1970s and 80s.⁷¹ Indeed, palliative medicine was only approved as a subspecialty by the American Board of Medical Specialties in 2006 and by the Centers for Medicare & Medicaid Services in 2008.⁷² Today, health care providers in developing countries must be trained with the idea that relieving pain and enabling patients to experience a “good death” is just as valuable as curing a patient.⁷³

However, end-of-life care is not solely nor primarily a medical issue.⁷⁴ Before policy changes can be implemented, awareness must be raised among the general public that dying is a process that takes time and that isolating the dying person along with his or her family and caregivers, although a natural response, can make the process unnecessarily difficult and frightening.⁷⁵ “Normally, human beings surround and help others in a crisis . . . but in death the instinct in most cultures is to withdraw.”⁷⁶ This instinct can be overcome, however, to parallel the attitude shift within one generation towards persons with disabilities, as evidenced

70. See *supra* notes 61–70 and accompanying text. See *General Comment No. 14, supra* note 21, ¶ 12.

71. See Patricia Patrizi et al., *Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Guarantees Built the Field*, ROBERT WOOD JOHNSON RETROSPECTIVE SERIES 1, 1 (Mar. 2011), <http://www.rwjf.org/content/dam/farm/reports/reports/2011/rwjf69582>.

72. *Id.* at 5 (noting that subsequently the field has experienced steady growth and that in 2008 “nearly one-third of hospitals (1,300 or 31 percent) nationally reported having palliative care programs”).

73. Interview with Virginia Rowthorn, J.D., Managing Director, Law & Health Care Program, Univ. Md. Sch. Law, Co-Director, Univ. Balt. Md. Global Health Interprofessional Council, in Balt., Md. (May 13, 2013).

74. Interview with Carla S. Alexander, *supra* note 15.

75. *Id.* Isolation should be avoided unless, of course, an easily communicable disease is the cause of impending death or the dying person expressly wishes to be alone. *Id.*

76. *Id.*

by domestic legislation such as the 1990 Americans with Disabilities Act⁷⁷ and international agreements such as the CRPD.⁷⁸

The CRPD is particularly relevant to the discussion of end-of-life and palliative care and its Article 8 can be paralleled with respect to the general content and specific measures.⁷⁹ The following provides a sample of how CRPD can be adapted to end-of-life care, with changes italicized. Developing countries should

raise awareness throughout society, including the family level, regarding *persons who are terminally ill or dying* and to foster respect for the right and dignity of *such persons*, combat stereotypes, prejudices and harmful practices relating to *persons who are terminally ill or dying*, including those based on sex and age *in all areas of end-of-life and palliative care*, and promote awareness of the capabilities and contributions of *persons who are terminally ill or dying*. Measures to this end include initiating and maintaining effective public awareness campaigns designed to: i) nurture receptiveness to *persons who are terminally ill or dying and their right to avoid pain*, ii) promote positive perceptions and greater social awareness towards *persons who are terminally ill or dying*, and iii) promote the recognition of the skills, merits and abilities of *persons who are terminally ill or dying* and of their contributions to the workplace and the labour market.⁸⁰

Additionally, developing countries should be

fostering at all levels of the education system, including in all children from an early age, an attitude of respect for *persons who are terminally ill or dying*, encouraging all organs of the media to portray *persons who are terminally ill or dying in a manner consistent with their inherent dignity*, and promoting awareness-training programs regarding *persons who are terminally ill or dying and the need to create a space for dying by providing sufficient health and community services while avoiding over-medicalization, over-institutionalization and isolation*.⁸¹

77. See Katharina Burns & Gary Gordon, *Analyzing the Impact of Disability Legislation in Canada and the United States*, 20 J. DISABILITY POL'Y STUDIES 205, 214, 216 (2010) (finding that, within twenty years, uniform federal disability legislation in the United States has led to favorable outcomes for person with disabilities, including creating "a foundation for change in attitude [regarding] accessibility, housing, and transportation," and that Canada would do well to adopt a similar uniform system to replace its current disability legislation patchwork across individual provinces).

78. See CRPD, *supra* note 7, at art. 1.

79. *Id.* at art. 8.

80. *Id.*

81. *Id.*

While direct person-to-person communication and education has been found to be the most powerful tool in informing the general public about this sensitive topic, media campaigns (particularly via television and radio to reach illiterate populations) that address how almost everyone and their family members can benefit from a cohesive end-of-life and palliative care strategy will be crucial.⁸² The United Kingdom and France have incorporated end-of-life education into school curricula, a step that many developing countries could follow in establishing their nascent primary school systems.⁸³ This curricula could be tailored to the specific ailments and issues facing a region, such as the impact of HIV/AIDS in African countries.⁸⁴ Raising awareness among developing countries' health care professionals as well as lay populations that end-of-life care is an issue that will eventually touch every individual and family is a crucial first step to garner support for further action, such as ensuring the availability of pain medication.

B. Pain Medicine Availability

Worldwide the need for pain medicine availability is staggering. Approximately eighty-three percent of the world's population, or 5.5 billion people in about 150 countries, today have inadequate or no access to controlled pain medications.⁸⁵ Of that, tens of millions of people each year, including terminal cancer and end-stage HIV/AIDS patients who are generally able to retain contemporaneous capacity, experience moderate to severe pain without recourse to relief.⁸⁶ The developing world, despite having ninety-five percent of all new HIV transmissions and half of all cancer patients, accounts for only six percent of worldwide morphine use.⁸⁷

To combat such disheartening statistics, policies ensuring pain medicine availability are a crucial early step that developing countries must take to establish a comprehensive approach to end-of-life and palliative care.⁸⁸ Countries that have no drug and pain medicine policies in place must enact legislation that balances proper control and availability. Countries that have overly burdensome drug policies must work to reform their drug policies to ensure that pain medicine is available, accessible, and affordable to the majority of the population.⁸⁹

82. Stjernsward & Clark, *supra* note 20, at 1216.

83. *Id.*

84. *Id.*

85. Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Human Rights Council, ¶¶ 51, 53 U.N. Doc. A/HRC/22/53 (Feb. 1, 2013) (by Juan E. Mendez) [hereinafter Report of the Special Rapporteur on Torture].

86. *Id.* ¶ 51.

87. *Id.* ¶ 52.

88. See Stjernsward & Clark, *supra* note 20, at 1210–11 (noting that improvements must be made across the pain medication availability spectrum, from “administration of drugs” to “prescribing, distributing, [and] dispensing.”).

89. *Id.* at 1213.

Developing countries should take active steps to establish essential medicines guidelines that incorporate from the outset the requirements for availability of pain medications. According to the WHO Model List of Essential Medicines, morphine (and in particular, standard release morphine tablets) should receive special attention as a core medicine that is “efficacious, safe and cost-effective” for palliative care and thus required in a basic health care system.⁹⁰ Additionally, a critical role of governments should be to guard against commercial pressures to adopt solely brand specific and expensive morphine and other pain-relieving drugs; generic morphine and other drugs should, at minimum, be widely available as an alternative.⁹¹

Buttressing states’ obligation to ensure appropriate pain medicine availability, the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) holds that freedom from torture or cruel treatment⁹² is “one of the few absolute and non-derogable human rights, a matter of *jus cogens*, a peremptory norm of customary international law.”⁹³ Denial of pain relief, although not solely intended to cause harm as in the traditional understanding of torture, may amount to cruel and inhuman treatment if “the suffering is severe and meets a minimum threshold . . . , the State is, or should be, aware of the suffering, . . . and when the Government fail[s] to take all reasonable steps to protect individuals’ physical and mental integrity.”⁹⁴ A compelling argument can be made that countries that are not in the process of implementing the WHO Model List of Essential Medicines to the degree that resources permit are not taking “all reasonable steps”.⁹⁵ For instance, many people who are terminally ill, particularly those with cancer and AIDS, experience pain that would meet that high threshold,⁹⁶ and in today’s interconnected world, leaders of most countries are, or should be, aware of the suffering that can come at the end of life. Thus, by failing to make adequate arrangements for coordinating their national health and drug policies, a developing country may be violating one of international law’s peremptory norms

90. U.N. World Health Organization, *WHO Model List of Essential Medicines*, 17–18 (Mar. 2011), available at http://whqlibdoc.who.int/hq/2011/a95053_eng.pdf.

91. See Stjernsward & Clark, *supra* note 20, at 1214 (discussing how “in many countries with health expenditure of less than U.S. \$10 per capita per year, 1 month’s supply of drugs promoted or offered by the many large multinational companies may cost between U.S. \$60 and 180”).

92. See CAT, *supra* note 8, at Annex (recognizing that because human rights “derive from the inherent dignity of the human person . . . no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment”).

93. See Report of the Special Rapporteur on Torture, *supra* note 83, at 20.

94. *Id.* at 13.

95. *Id.*; see *supra* text accompanying note 88.

96. See World Health Organization Pain & Palliative Care Communications Program, *The Urgency of Pain Control in Adults with HIV/AIDS*, 19 CANCER PAIN RELEASE (2006), <http://www.whocancerpain.wisc.edu/?q=node/78> (noting that in the advanced stages of AIDS, pain is common, affecting approximately half to three-fourths of all patients and that “pain in HIV disease has many similarities with cancer pain”).

by permitting patients in the final stages of life to needlessly experience pain—either directly through outright bans on pain medications⁹⁷ or indirectly through onerous regulations that create burdens for both prescribers and suppliers.⁹⁸

Furthermore, a report by the U.N. Human Rights Council links poor treatment in health care to widely accepted anti-torture conventions and norms.⁹⁹ The 2013 U.N. Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment notes that although inexpensive and effective medications exist, they are still “virtually unavailable in more than 150 countries.”¹⁰⁰ In reference to morphine, the report lists a number of unnecessary obstacles that developing countries should be cognizant to reform, including “overly restrictive drug control regulations and, more frequently, misinterpretation of otherwise appropriate regulations; deficiency in drug supply management; inadequate infrastructure; lack of prioritization of palliative care; ingrained prejudices about using opioids for medical purposes; and the absence of pain management policies or guidelines for practitioners.”¹⁰¹ Simply put, persons who are terminally ill or dying should not needlessly suffer when safe, effective, and relatively inexpensive pain therapies are arbitrarily placed behind a legislative wall.

Of course, developing countries should take care to avoid tipping the scales in the other direction and opening a deluge of prescription opioid pain medication that has currently reached epidemic proportions in the United States.¹⁰² Developing countries can overcome the saturation of opioid medication and addiction that

97. HUMAN RIGHTS WATCH, “PLEASE DO NOT MAKE US SUFFER ANY MORE . . .”: ACCESS TO PAIN TREATMENT AS A HUMAN RIGHT, 26–33 (2009), available at http://www.hrw.org/sites/default/files/reports/health0309webwcover_1.pdf (listing numerous examples of countries placing “unnecessarily strict” regulations or bans on reasonable access to pain medicine). China, for example, only allows certain jurisdictionally-placed hospitals to prescribe opioids, potentially forcing people to arbitrarily travel long distances for pain relief. *Id.* Honduras and Malawi do not allow for dispensation of morphine for longer than three consecutive days. *Id.* “[I]n Mongolia, Peru, Honduras, Kyrgyzstan and a state in India only palliative care specialists and oncologists are authorized to prescribe oral morphine.” *Id.*

98. *Id.* Examples of countries’ onerous regulations indirectly inhibiting access to pain medication includes Kenya, where oral morphine is only dispensed in hospitals and is therefore widely unavailable and Guatemala, where “every prescription must be authorized through an ink seal and a signature,” which are issued only by a central narcotics office. *Id.* In India, for example, although any physician can prescribe pain medicine, “pharmacies do not stock it because the licensing system is so complex and the penalties for errors are so stringent.” THE ECONOMIST INTELLIGENCE UNIT, THE QUALITY OF DEATH: RANKING END-OF-LIFE CARE ACROSS THE WORLD, 7, 28 (2010), available at http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf.

99. See Report of the Special Rapporteur on Torture, *supra* note 85, at 4.

100. *Id.* at 12.

101. *Id.* at 12–13.

102. See Kotecha & Sites, *supra* note 27, at 1212 (noting that the increase in opioid prescription in the United States in the last decade has been “nothing short of astounding,” with Americans, while comprising only five percent of the world’s population, now consuming eighty percent its opioids and ninety-nine percent of its hydrocodone).

many Western countries are now experiencing by integrating from the outset the following checks and balances as part of their pain medicine policy. In conjunction with a broader national health care strategy, developing countries should incorporate guidelines limiting long-term opioid therapy mainly to those who are terminally ill and dying, for the purpose of easing pain from diseases such as cancer and AIDS.¹⁰³ Long-term use of opioids for acute or non-palliative care should generally be avoided because of its highly addictive potential and associated significant morbidity and mortality rates coupled with the paucity of evidence on the efficacy of long-term opioid therapy for chronic, non-palliative care.¹⁰⁴ Finally, developing countries should be wary of the intersection of the pharmaceutical industry's opioid drug marketing and the conflicts of interest that can arise "with sponsorship and/or compensation by the pharmaceutical industry of leading societies, clinicians and regulatory bodies involved with pain advocacy."¹⁰⁵ In light of the developing world's staggering need for pain medicine, particularly morphine, good domestic governance as well as international peremptory norms dictate that developing countries must enact legislation that balances proper control and availability or actively revise any legislation that is unduly burdensome.

IV. ACCESSIBILITY

It is not sufficient that end-of-life and palliative care is only available to the richer echelons of society. In order to comport with the right to health, end-of-life and palliative care should be accessible to all of the population. Thus, in establishing their public health strategy, developing countries must ensure that end-of-life and palliative care are nondiscriminatory, physically accessible, affordable, and allow for information exchange.¹⁰⁶

A. *Nondiscrimination and Physical Accessibility*

The CRPD and the work of the Joint U.N. Programme on HIV and AIDS (UNAIDS), particularly the International Guidelines on HIV/AIDS and Human Rights, are helpful in providing guidance to developing countries on ensuring that end-of-life and palliative care are both nondiscriminatory and physically accessible.¹⁰⁷ Similar to the ICESCR analysis above, developing countries that

103. *Id.* at 1213.

104. *See id.* at 1213 (noting that in the United States, where long-term prescription opioid use has spiked in the last decade, "for every one death . . . there are 10 treatment admissions for abuse, 32 emergency room visits for misuse or abuse, 130 people who are dependent, and 825 who use the drugs recreationally").

105. *Id.* at 1212.

106. *See supra* notes 21–24 and accompanying text.

107. *See CRPD, supra* note 7, at art. 1; *see also UNAIDS Strategy 2011-2015*, UNAIDS, <http://www.unaids.org/en/aboutunaids/unaidstrategygoalsby2015/> (last visited Dec. 19, 2013). Second International Consultation on HIV/AIDS and Human Rights, Geneva, Switz., Sept. 23-25, 1996, Third International Consultation on HIV/AIDS and Human Rights, Geneva, Switz., July 25-

have acceded to CRPD are bound to carry out its principles; those that have not are arguably bound by customary international law. In any case, streamlining policies for persons with disabilities with policies geared towards those who are terminally ill or dying is in a country's best economic, political, and social interests.¹⁰⁸

The CRPD is particularly salient to the comprehensive national public health strategy that must be undertaken to effectively address end-of-life and palliative care in developing countries. In contrast to previous conventions on disability, the CRPD “embraces a social model of disability, concentrating the disability experience not in individual deficiency, but in the socially constructed environment and barriers.”¹⁰⁹ Developing countries should continually refer to the CRPD and measures undertaken for its execution in establishing end-of-life and palliative care in its national health strategy, paying particular attention to the principle that it is not the person at the end of his or her life that is the problem, but rather the socially constructed lack of a space for dying.

The terminally ill and dying are considered persons with disabilities in most cases, thus falling under the protection of CRPD. The CRPD defines persons with disabilities as having “long term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”¹¹⁰ Sometimes death occurs quickly without any infirmity prior; however, with medical advances, prolonged states of sickness before death have and will continue to become more commonplace in developing countries.¹¹¹ For months or years prior to death, patients can experience some or all of the impairments—mental, intellectual, and sensory—that can fundamentally incapacitate their effective decision making,¹¹² rendering them arguably more vulnerable than others who are still physically and mentally capable of voicing their preferences. The case for including the terminally ill and dying under CRPD protection is further supported by the fact that the preamble recognizes that “disability is an evolving concept.”¹¹³

26, 2002, *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version* 13, 17–19 (2006), <http://www.ohchr.org/Documents/Issues/HIV/ConsolidatedGuidelinesHIV.pdf>.

108. See discussion *supra* Part II.

109. Janet Lord et al., *Lessons from the Experience of U.N. Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance*, 38 J. L. MED. & ETHICS 564, 564 (2010).

110. CRPD, *supra* note 7, at art. 1.

111. See Stjernsward et al., *supra* note 10, at 487 (observing that “of the 58 million people dying annually (45 million in developing countries, 13 million in developed countries), it is estimated that at least 60% (35 million) will have a prolonged advanced illness.”); Stjernsward & Clark, *supra* note 20, at 1200–01.

112. See THE CAMBRIDGE HANDBOOK OF AGE AND AGEING 63, 121, 170 (Malcom L. Johnson et al. eds., 2005) (elaborating upon the mental, sensory, and physical deterioration that is characteristic of old age).

113. See CRPD, *supra* note 7, at pmb1. (elaborating that “disability results from the interaction between person with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,” therefore, the existence of

In order to assure that the terminally ill and dying are “entitled without any discrimination to the equal protection and equal benefit of the law,”¹¹⁴ developing countries should provide these individuals with reasonable accommodations.¹¹⁵ Reasonable accommodation is defined as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.”¹¹⁶ In practice, difficult choices will undoubtedly arise for countries with limited resources, such as whether reasonable accommodation means diverting scarce medical resources to preventative care for the healthy to palliative care for the dying. Such quandaries are never fully resolved, as can be seen from the ongoing national health care debates in developed countries;¹¹⁷ however, if from the outset developing countries proactively address end-of-life resource allocation through a public health strategy, then discrimination will likely decrease as health care professionals and volunteers have uniform guidance and are forced to make less ad hoc decisions in stressful, emergency circumstances.

The CRPD likewise provides guidance on ensuring that the terminally ill and dying have actual, physical access to “transportation, to information and communication . . . and to other facilities and services open or provided to the public, both in urban and in rural areas.”¹¹⁸ Clearly, universal physical access to end-of-life and palliative care cannot be achieved all at once, as developing countries must first address larger issues such as poverty, education, and infrastructure. But by erecting hospitals and other care centers with the intention to accommodate this population in mind (such as making the facilities wheelchair accessible from their initial construction), developing countries will be able to reasonably accommodate persons who are terminally ill and dying.¹¹⁹ By taking a proactive approach, developing countries can avoid regrettable and unnecessary barriers, as was represented by the ironic situation in the development of the CRPD, when U.N. conference rooms were inaccessible to persons in wheelchairs.¹²⁰

attitudinal and environmental barriers that are preventing the terminally ill and dying from receiving proper end-of-life and palliative care provides further support that they should come under the protection of CRPD).

114. *Id.* at art. 5, ¶ 1.

115. *Id.* at art. 5.3, ¶ 3.

116. *Id.* at art. 2.

117. See *The Quality of Death: Ranking End-of-Life Care Across the World*, ECONOMIST INTELLIGENCE UNIT, ECONOMIST, 2010, at 5–7 (discussing how in “Western societies death has become medicalised and curative procedures are often prioritized [sic] ahead of palliative care,” as reflected in the United States, where state-funded curative and palliative care are mutually exclusive).

118. CRPD, *supra* note 7, at art. 9.

119. See Lord et al., *supra* note 109, at 567.

120. *Id.*

A critical juncture within accessibility arises where HIV/AIDS and end-of-life care intersect. Unlike other chronic diseases that are on the rise globally (cancer and cardiovascular disease),¹²¹ HIV/AIDS is communicable and evokes a unique potential for discrimination.¹²² The UNAIDS International Guidelines on HIV/AIDS and Human Rights is a tool that should be incorporated from the outset of a developing country's national health and end-of-life care strategy in order to extend human rights to the terminally ill and dying, to avoid discrimination, and to reduce transmission rates.¹²³ "Public health interests do not conflict with human rights. On the contrary, it has been recognized that when human rights are protected, fewer people become infected and those living with HIV and their families can better cope with HIV and AIDS."¹²⁴ The UNAIDS Guidelines are also exceptionally useful in providing states with concrete steps that they can take to properly address the care of HIV/AIDS patients—many steps overlap or can be adapted to extend to other persons who are terminally ill or dying. For example, Guideline 1 within the HIV/AIDS prism echoes the need in end-of-life care for national framework that is "coordinated, participatory, transparent and accountable."¹²⁵ Guideline 7—that states should support legal services that inform those affected by HIV about their rights—could be extended to others who are terminally ill or dying.¹²⁶ Finally, Guideline 8 states that, even within the already vulnerable group of the terminally ill and dying, states and their domestic and international partners should always bear in mind the special social challenges facing women, children, minorities, migrants, and other marginalized subgroups.¹²⁷

B. Affordability and Information Exchange

In order to be affordable and allows for information exchange, end-of-life and palliative care should be part of the primary health care system in developing countries. In light of the prevalence of patients presenting at the end stages of diseases, developing countries should from the outset regard curative care and palliative care as complementary, not mutually exclusive.¹²⁸ Conceptually, up to three levels of health care can exist within a country, although overlap and interaction can make the distinctions difficult in practice:

121. See *The Quality of Death: Ranking End-of-Life Care Across the World*, *supra* note 117, at 9 (noting that globally, more and more people are living for decades with symptoms of heart disease instead of dying from heart attacks).

122. See International Guidelines on HIV/AIDS and Human Rights, *supra* note 105, at 5 (pointing to a cycle of discrimination where poverty leads to vulnerability to HIV infection, which in turn can prompt further discrimination and human rights violations).

123. See *id.* at 4–5.

124. *Id.* at 16.

125. *Id.* at 17.

126. *Id.* at 18.

127. *Id.* at 19.

128. Stjernsward & Clark, *supra* note 20, at 1211.

primary health care typically deals with common and relatively minor illnesses and is provided by health professionals and/or generally trained doctors working within the community at relatively low cost; *secondary health care* is provided in centres, usually hospitals, and typically deals with relatively common minor or serious illnesses that cannot be managed at community level, using specialty-trained health professionals and doctors, special equipment and sometimes in-patient care at comparatively higher cost; *tertiary health care* is provided in relatively few centres, typically dealing with small numbers of minor or serious illnesses requiring specialty-trained health professionals and doctors and special equipment, and is often relatively expensive.¹²⁹

Simply put, by definition most poorer people in poorer countries cannot gain access to or afford secondary care at “comparatively higher cost” or tertiary care that is “relatively expensive.”¹³⁰ As a result of the over-medicalization and over-institutionalization of the natural process of dying in the West,¹³¹ end-of-life and palliative care falls mainly within the secondary to tertiary health care levels, as evidenced by the fact that most people die in a hospital or other medical institution despite the wishes of the majority of the population to die at home.¹³² This result stems in part from how end-of-life and palliative care was structured from its inception as separate from and on the margins of the overall health care delivery system. Modern hospice and palliative care, characterized by the combination of clinical care, education, and research, is generally regarded as originating in the U.K. in the 1960s.¹³³ Subsequently structured inpatient hospice care within Western Europe spread on a notable level to Belgium, Sweden, Spain, Germany, Netherlands, and Italy.¹³⁴ Out of these seven countries, only Spain presented evidence of a strategic approach to palliative care using an integrated public health model, with the effect that end-of-life and hospice care remain on the periphery of

129. *General Comment No. 14*, *supra* note 21, at n.9.

130. *Id.*

131. *The Cost of Dying*, *supra* note 61 (reporting that a physician expert in end-of-life care explained that “modern medicine has become so good at keeping the terminally ill alive by treating the complications of underlying disease that the inevitable process of dying has become much harder and is often prolonged unnecessarily” and that “denial of death at some point becomes a delusion, and we start acting in ways that make no sense whatsoever.”); Interview with Carla S. Alexander, *supra* note 15; *see also supra* note 118.

132. *See The Cost of Dying*, *supra* note 61 (noting that the “vast majority of Americans say they want to die at home, but 75 percent die in a hospital or a nursing home”); *see also* Claire Henry, *Too Many People are Dying in Hospital Against Their Wishes*, *GUARDIAN* (Aug. 11, 2010), <http://www.guardian.co.U.K./society/joepublic/2010/aug/11/dying-end-of-life-choices-home-hospital> (indicating that although the majority of people in England would prefer to die at home, 58% still die in a hospital).

133. Stjernsward & Clark, *supra* note 20, at 1202, 1205.

134. *Id.* at 1205.

most health care systems.¹³⁵ In the U.S., as a result of over-medicalization and over-institutionalization, the dying process is “unnecessarily painful and isolating [with] too many patients dying in hospitals and nursing homes—in pain—rather than at home with their families.”¹³⁶

Developing countries should avoid structuring their health care systems in a manner that incentivizes ongoing hospitalization, as is currently the case in the U.S. Monitored home care can be just as sufficient as ongoing hospitalization in terms of quality outcomes, if not more so if one accounts for the probability of hospital-acquired infections.¹³⁷ As will be discussed, in Kerala, India, professional-led, volunteer-based “home care units have revolutionized the health care system [by helping] to provide target-specific care with greater understanding of the circumstances,” whereas institutional palliative care tends to overlook the underlying physical, emotional, and spiritual needs of patient and his or her family.¹³⁸ Such an approach is not only more compassionate, but also more efficient and flexible. Developing countries should incorporate end-of-life and palliative care into their primary care health care level because it is often the only level that either exists within poorer countries or can reach the majority of the population.

V. QUALITY

As far as possible within the highest attainable standard of health, end-of-life and palliative care should be “scientifically and medically appropriate and of good quality.”¹³⁹ WHO lists a number of examples, including unexpired drugs, potable water, and adequate sanitation;¹⁴⁰ however, most crucial among these is skilled medical personnel and volunteers because “excellent individuals make excellent organizations, foundations, associations, and countries.”¹⁴¹

A. *Medical Professionals*

Training of medical professionals, including physicians, nurses, and pharmacists, must occur on two levels. First, end-of-life and palliative care must

135. *Id.* at 1207.

136. *Id.* at 1203.

137. See *The Cost of Dying*, *supra* note 61 (noting that in the U.S., because primary care physicians do not have the time due to their patient load expectations to see if an individual patient is properly responding to certain treatments or medications outside of the hospital, the “easiest thing for everybody up the stream is to admit you to the hospital,” leading to numerous unnecessary tests and procedures which can lead to an outcome worse than death—dying slowly while suffering).

138. Kumar, *supra* note 62, at 221; see also *infra* Part VII, for a discussion on India’s experience with including palliative care in its primary health care system.

139. See *General Comment No. 14*, *supra* note 21, at ¶ 12.

140. *Id.*

141. See Stjernsward & Clark, *supra* note 20, at 1218.

be integrated into the basic medical school curricula within developing countries. In the West the most crucial step in incorporating end-of-life and palliative care into medical school curricula was to test relevant material on licensing exams, which did not occur for the most part until the late twentieth century.¹⁴² For example, in the U.S., the National Board of Medical Examiners' decision to increase end-of-life material tested in medical licensing exams in 1998 "turned out to be a critical lever" in setting in motion key changes.¹⁴³ These changes included the addition of end-of-life material in medical textbooks and medical schools expressly teaching on the topic.¹⁴⁴ Indeed, a report on end-of-life care in Maryland echoes the importance of these key changes, noting that medical students will not study a topic seriously unless it is tested.¹⁴⁵ Thus, from the outset of creating their medical licensing exams, developing countries must incorporate end-of-life and palliative care as a discrete subject matter.

The second level of medical training must address medical personnel who are already practicing but probably have not encountered formal end-of-life and palliative care education. Continuing education trainings must be short, interactive, and readily adaptable to each developing country's or region's resources and needs. Two U.S.-based programs, the Education in Palliative and End-of-life Care Program (EPEC)¹⁴⁶ for physicians and the End-of-life Nursing Education Consortium (ELNEC),¹⁴⁷ deserve specific mention as one of the most targeted didactic courses in this area. Both EPEC and ELNEC offer intensive and interactive two-day courses, that address topics such as pain management, communicating bad news, withdrawing and withholding treatment, and psychosocial issues.¹⁴⁸ The trainings can be adapted to specialties and specific end-of-life circumstances, as has been done for oncology, emergency medicine, and geriatrics.¹⁴⁹ An EPEC program has already been created in India.¹⁵⁰

142. See Patrizi et al., *supra* note 71, at 13.

143. *Id.*

144. *Id.*

145. MD. ATTORNEY GEN. COUNSEL FOR HEALTH DECISIONS POLICY, WORKGROUP REPORT ON HOSPICE CARE, PALLIATIVE CARE & END OF LIFE COUNSELING: EXECUTIVE SUMMARY OF WORKGROUP'S CONCLUSIONS & RECOMMENDATIONS, 16 (2009), available at <http://www.oag.state.md.us/Healthpol/> & http://www.oag.state.md.us/Healthpol/Hospice_and_Palliative_Care_Workgroup_Report.pdf.

146. EDUC. IN PALLIATIVE AND END-OF-LIFE CARE PROGRAM (EPEC), <http://www.epec.net/> (last visited Dec. 19, 2013).

147. *End-of-life Nursing Educ. Consortium (ELNEC)*, AM. ASSOC. OF COLLS. OF NURSING, <http://www.aacn.nche.edu/el nec> (last visited Dec. 19, 2013).

148. See Stjernsward & Clark, *supra* note 20, at 1217; see also *EPEC Curricula*, EDUC. IN PALLIATIVE AND END-OF-LIFE CARE PROGRAM (EPEC), http://www.epec.net/epec_core.php?curid=1 (last visited Dec. 19, 2013); *ELNEC Core*, AM. ASSOC. OF COLLS. OF NURSING, <http://www.aacn.nche.edu/el nec/about/el nec-core> (last visited Dec. 19, 2013).

149. *EPEC Curricula*, *supra* note 148.

150. *Id.*

B. *Trained Volunteer and Family Caretakers*

In developing countries, particularly in rural areas where a majority of the population do not have regular, timely, or sometimes any access to physicians, “empowerment of family members and volunteers in palliative care will be the most realistic approach for meaningful coverage.”¹⁵¹ Volunteer and family caretakers should be trained to take the lead in communities to create a space for dying that is not isolating.¹⁵² Training can range from informing volunteers of the importance of basic companionship to providing assistance at local outpatient clinics with basic but indispensable administrative tasks.¹⁵³ Indeed, “personal care and services, social support and companionship, and applied medical care can often be done better by empowered family members and volunteers than, for example a nurse who is only available occasionally.”¹⁵⁴ One innovative strategy may be for governments to establish formal systems of compensation for family members who undertake the heavy physical, social, financial, and emotional burden of caring for terminally ill and dying family members.¹⁵⁵ In these relatively new and potentially experimental areas, the international community, led by WHO, can be particularly active.¹⁵⁶

By including volunteers and family caretakers in the national end-of-life strategy from the outset, developing countries can harness a resource that has been relatively lost in the West—familiarity with the natural dying process.¹⁵⁷ As previously discussed, a disproportionate amount of people in the West die in institutions, contrary to the wishes of most to die at home.¹⁵⁸ Developing countries can avoid over-medicalization and over-institutionalization by identifying and training those individuals who have formal or informal experience with the process of dying, therefore avoiding isolation of the dying and their families during one of life’s most difficult moments.

151. Stjernsward & Clark, *supra* note 20, at 1216.

152. Interview with Carla S. Alexander, *supra* note 15; Stjernsward & Clark, *supra* note 20, at 1216; *see* Kumar, *supra* note 62, at 219–20 (emphasizing that in Kerala, India, a model of palliative care, the “main strategy . . . has been to encourage local people to address the social needs of patients and families, train community volunteers to offer emotional support” as well as to establish home care and tap into a network of doctors and nurses).

153. Kumar, *supra* note 62, at 219.

154. Stjernsward & Clark, *supra* note 20, at 1216.

155. *Id.* at 1212.

156. *See supra* note 30 and accompanying text (discussing the importance of local communities partnering with the international community in creating comprehensive end-of-life care systems).

157. Interview with Carla S. Alexander, *supra* note 15 (discussing how developing countries can harness a resource that has been relatively lost in the West—familiarity with the natural dying process); Interview with Virginia, *supra* note 73 (discussing how the medical residents in Malawi were familiar with each stage of the death process, from when a patient has a couple days to live to the last hours and final breath).

158. *See supra* note 133 and accompanying text.

VI. ACCEPTABILITY

In establishing a comprehensive end-of-life care approach in developing countries, the medical and societal ethics surrounding end-of-life in the West cannot automatically be incorporated as the ethics for all populations in all countries, particularly those lacking in resources.¹⁵⁹ Three authors from the developing world observed that

decision making in palliative care in [Asia, Southern Europe, Africa and the Middle East] is far removed from the ideal of autonomy, informed consent and individualism described in the classic textbooks on medical ethics. Rather, paternalism and respect for authority (loyalty), whether based on position or power, remain prime driving forces.¹⁶⁰

Perceived communal beneficence, rather than that of the individual, is weighed first in much of the developing world.¹⁶¹ The authors concluded that the Western approach of encouraging patient autonomy by presenting options but leaving a final choice to the patient is often viewed with suspicion and tends to elicit “far more confusion than appreciation.”¹⁶²

It is ironic to say that Western paternalism can result from not taking local patterns of paternalism into account. However, the main emphasis should be on achieving a broader, two-way understanding of local nuances while educating medical professionals and the general public about the benefits of end-of-life and palliative care. In implementing end-of-life and palliative care in developing countries, WHO recommends addressing the following topics to learn about local attitudes and beliefs, facilitate exchange of knowledge, and establish best practices from the outset:¹⁶³

159. Stjernsward & Clark, *supra* note 20, at 1207.

160. L.F. Ng et al., *Autonomy for Whom? A Perspective from the Orient*, 14 PALLIATIVE MED. 163, 163 (2000).

161. *Id.*

162. *Id.* at 164. For example, in applying the CRPD’s Article 12, which requires states to safeguard for persons with disabilities “legal capacity [that] respect [their] rights, will and preferences . . . free of conflict of interest and undue influence,” medical professionals and volunteers will likely have to be prepared to balance more input from family in end-of-life care of patients in developing countries than in the more individual-centered West. *See* CRPD, *supra* note 7, art. 12.

163. Stjernsward & Clark, *supra* note 20, at 1216 tbl.19. These considerations provide a starting point for taking local culture and norms into account and are not exhaustive.

TABLE 1:
WHO CHECKLIST TO RECOGNIZE AND RESPECT LOCAL CULTURE IN
END-OF-LIFE AND PALLIATIVE CARE

| <i>Attitudes, Values, Beliefs</i> | <i>Knowledge</i> | <i>Practice/Skills</i> |
|---|---|--|
| The philosophy and ethics of palliative care. | Principles of effective communication. | Practice of learned knowledge in the classroom. |
| Personal attitudes towards the disease (cancer, HIV/AIDS, terminal patients), pain, dying, death and bereavement. | Pathophysiology of the common symptoms. | Use of role play. |
| Illness as a state with physical, social, psychosocial, and spiritual dimensions. | Assessment and management of pain and other symptoms. | Discussion of real case-histories. |
| Team work multiprofessional. | Psychological and spiritual needs of seriously ill and dying patients and family. | Goal setting in physical, psychological, social, and spiritual dimensions. |
| The family as the unit of care. | Treatment of emotional and spiritual distress. | Development of family trees and of a family care plan. |
| | Availability of community resources to assist patients and families. | Monitoring of pain and symptom management. |
| | Physiological and psychological responses to bereavement. | |

One U.S.-based physician who specializes in end-of-life and palliative care in developing countries recounted a professional experience that is illustrative of the need to maintain local culture in perspective.¹⁶⁴ While working in a hospital in Zambia, she encountered a male in his early thirties, ill with HIV and pulmonary tuberculosis, waiting outside the hospital with precipitously worsening respiration.¹⁶⁵ She described how the intensive care physician went outside of the hospital to view this man, and refused to admit him into the intensive care unit (ICU) as a

164. Interview with Carla S. Alexander, *supra* note 15.

165. *Id.*

patient.¹⁶⁶ In contrast to the West, where hospital and medical professionals would generally do everything in their power to save him, the doctor in Zambia “had no problem saying no,” because there were only five beds in this ICU and he had to save them for “people who could get better.”¹⁶⁷

Although anecdotes such as this one cannot stand in the place of empirically-ascertained knowledge, it is representative of the very limited resources that exist on the ground, and the resulting difficult choices that must be made on a daily basis in most developing countries. Enacting a comprehensive national public health strategy that from the outset creates and retains a social space for dying can help developing countries bridge the gap between such limited resources and the normative conditions prescribed by health and human rights, ultimately reducing unnecessary suffering and elevating human dignity.

VII. KERALA, INDIA

India is fitting to examine because it is undergoing the challenges facing many developing countries—a rise in chronic non-communicable diseases, an aging population, fast-paced development yet still high rates of rural population, and regional diversity.¹⁶⁸ One of its states in particular, Kerala, has been recognized for its excellent provision of end-of-life and palliative care and should serve as a model to other developing countries as well.¹⁶⁹ Kerala is the only state in India that provides end-of-life and palliative care via a comprehensive public health system with community participation.¹⁷⁰ Today, although Kerala has only three percent of India’s population, the state accounts for over ninety percent of all palliative care programs in India.¹⁷¹ The historical development of end-of-life and palliative care in Kerala demonstrates the top-down importance of local leadership, national government, intergovernmental organizations (IGOs) and nongovernmental organizations (NGOs) all working in partnership.¹⁷² Equally important, however, in maintaining the program’s sustainability have been the bottom-up efforts of the local community and volunteers.¹⁷³ India’s first step in specifically addressing palliative care was in 1986, when a hospice in Mumbai was established.¹⁷⁴ In 1994, working in consultation with WHO and the national

166. *Id.*

167. *Id.*

168. *See* Kumar, note 62, at 216 (noting the “steady rise” of India’s elderly population, that noncommunicable diseases make up over half of all death, and that seven out of ten Indians still live in rural settings).

169. *Id.* at 217.

170. *Id.*

171. *Id.* at 218.

172. *Id.* at 217–19.

173. *Id.* at 218, 220–21.

174. *Id.* at 217.

government, the Indian Association of Palliative Care was formed.¹⁷⁵ End-of-life and palliative care efforts in Kerala began with civic society, mainly led by physicians and social workers; however, such an approach reached a very limited amount of the population.¹⁷⁶ In an effort to create greater participation in the community, in 1999 four NGOs launched a community-based initiative called the Neighborhood Network in Palliative Care (NNPC), which now covers most of Kerala.¹⁷⁷ Although resources were stretched further, to become even more sustainable, local governments involved themselves in the program after a media campaign by Kerala's leading newspaper.¹⁷⁸

In 2008, Kerala's government took the critical step of officially declaring palliative care as part of primary health care.¹⁷⁹ In 2010, WHO designated Kerala's Institute of Palliative Medicine as the "first WHO-collaborating center in palliative care in low income and middle-income countries."¹⁸⁰ The latest efforts in palliative care in Kerala have focused on reaching as many of the needy as possible, particularly through efforts enabling home-based care, which would generally be prohibitively costly without a trained volunteer cadre.¹⁸¹

In Kerala the key step in making end-of-life and palliative care widely available and accessible was the inclusion and subsequent enthusiasm of the community, manifested primarily through volunteers who have the following basic but critical responsibilities:¹⁸²

**TABLE 2:
KEY VOLUNTEER SERVICES FOR END-OF-LIFE AND PALLIATIVE CARE IN
KERALA, INDIA**

Help identifying need and initiating and running palliative care units in their locality
 Visit patients at home (both with the home care unit and on their own)
 Help at the outpatient clinic (keeping the patients comfortable, talking to them, helping with clerking and so on)
 Do administrative work (including clerical work and account keeping)
 Raise funds for the unit
 Mobilize support for the patients from the various governmental and nongovernmental agencies
 [Offer] regular nurse-led home care visits, supplemented by visits by trained nurses and doctors

175. *Id.*

176. *Id.* at 218.

177. *Id.* at 217–19.

178. *Id.* at 220.

179. *Id.* at 217.

180. *Id.*

181. *Id.* at 220.

182. *Id.* at 219.

[Provide] professional home care units includ[ing] medical consultations, medicines, procedures like tapping of ascetic fluids and wound care

Volunteers provide other services as well, such as food for starving families, support for poor children's education, transportation to and from health facilities, trained psychosocial support, linking patients with social and religious organizations and governmental benefits to which they may be entitled.¹⁸³

Kerala also benefits greatly from medical professional training from local and, although more scarce, national training programs.¹⁸⁴ In Mumbai, there are postgraduate degree courses in palliative care, albeit only at one hospital.¹⁸⁵ For physicians in Kerala and other parts of India, there are fellowships, distance learning education, and a two-month certificate course.¹⁸⁶ For nurses, similar trainings exist tied to nursing credentials.¹⁸⁷ For both physicians and nurses, Kerala and India should adopt the EPEC and ELNEC two-day intensive courses so that more professionals would gain exposure to the issue.¹⁸⁸ Overall, "the combination of economic, social, psychological and medical approaches has ensured all-round care of the patients and support to their families, thereby increasing the quality of life and quality of death."¹⁸⁹

VIII. MARYLAND MOLST FORM

Looking to the future, once developing countries are in the process of or have established a comprehensive national public health strategy that integrates end-of-life and palliative care, they can use the resulting societal space for dying to begin discussion surrounding higher level end-of-life planning. To avoid the discomfort and confusion bred by end-of-life planning and the multitudinous variations on advance directives in the West, developing countries can learn from what approaches have worked. Simplicity for patients and ease of access by medical professionals to patients' end-of-life plans in an emergency are crucial in creating trust that a patient's and family's wishes will be carried out.¹⁹⁰

The Maryland Medical Orders for Life-Sustaining Treatment (MOLST) form is an effective approach that provides simplicity, ease of access, and

183. *Id.* at 219–20.

184. *Id.* at 218–20.

185. *Id.* at 218.

186. *Id.*

187. *Id.*

188. *See supra* text accompanying notes 147–51.

189. *See* Kumar, *supra* note 62, at 221.

190. Interview with Carla S. Alexander, *supra* note 15; *see Maryland MOLST Order Form, MD. ORDERS FOR LIFE-SUSTAINING TREATMENT*, http://marylandmolst.org/pages/molst_form.htm (last visited Dec. 20, 2013).

concreteness.¹⁹¹ Added as a reform part of Maryland's Health Care Decision Act in 2011,¹⁹² MOLST is a two-page form that is a legal order signed by a physician or nurse after discussion with the patient that must be honored across the continuum of care, even if the patient's physician is not on staff.¹⁹³ The content of MOLST "[c]onsolidates important information . . . standardizes definitions, reminds patients and providers of available treatment options, and increases the likelihood that a patient's wishes regarding life-sustaining treatments are honored throughout the health care system."¹⁹⁴ Unlike most advance directives, which can be made decades before any onset of disease or symptoms and often suffer from a lack of concreteness, MOLST is aimed at creating a medically specific end-of-life care plan when patients are ill with a specific ailment or are frail, expressly taking into account that as people's health changes, their wishes may change as new issues and treatments arise.¹⁹⁵ Also unlike most advance directives, MOLST is flexible, portable, and easily changed or updated.¹⁹⁶

When asked whether in practice MOLST is helpful to practitioners, Dr. Carla Alexander, who specializes in end-of-life care at University of Maryland School of Medicine, indicated that MOLST is "very important," particularly for patients with HIV/AIDS and cancer.¹⁹⁷ Because the form is not an advance directive but rather a clear order, it must be followed unless overridden by a rigorous process, thus heightening the probability that a patient's wishes are not ignored.¹⁹⁸ Although most developing countries have a way to go before concepts of informed consent, individual control, and autonomy are introduced,¹⁹⁹ as health and human rights continue to elevate the importance of each individual person, at some point developing countries will likely have to confront such issues. MOLST's portability, simplicity, and flexibility should be retained, actively synthesizing input from medical professionals, family members, and other key players like trained community volunteers, even if the content of the form varies in different

191. See *Maryland MOLST Order Form*, *supra* note 190 (emphasizing the ease of the MOLST form in terms of portability, standardization of definitions, and concrete reminders about the specific treatment options available to individual patients).

192. See MD. CODE ANN., HEALTH-GEN. § 5-600 (LexisNexis 2007).

193. See *Maryland MOLST Order Form*, *supra* note 190.

194. *Id.*

195. See *How Do I Plan for My Health Care?*, MD. MOLST: MED. ORDERS FOR LIFE-SUSTAINING TREATMENT <http://marylandmolst.org/index.html> (last visited Dec. 20, 2013); see also interview with Carla S. Alexander, *supra* note 15.

196. See *How Do I Plan for My Health Care?*, *supra* note 195 (noting that, although advance directives address a patient's wishes regarding future treatment, as new problems develop, patients may subsequently decide that they want a treatment they previously did not desire, and that the MOLST form makes such wishes known to health care providers).

197. Interview with Carla S. Alexander, *supra* note 15.

198. See *How Do I Plan for My Health Care?*, *supra* note 195; see also Interview with Carla S. Alexander, *supra* note 15.

199. See *supra* text accompanying notes 161–63.

cultures.²⁰⁰ The MOLST process—entering into plain-language discussion with one’s physician or nurse, one’s family, weighing options, and receiving recommendations—is the two-way, one-on-one communication approach to properly introduce such a sensitive topic to individuals, families, and cultures that have little to no experience with the concept of autonomy.

IX. CONCLUSION

Experience in end-of-life and palliative care has generated general consensus that developing countries—in partnership with the international and local communities—must take a comprehensive, simultaneously top-down and bottom-up public health strategy approach in order to create a space for end-of-life care that honors inherent human dignity and complies with the right to health.²⁰¹ By learning from the mistakes of the developed world and building upon current human rights instruments—in particular UDHR, ICESR, WHO general guidance and its Model List of Essential Medicines, CRPD, CAT, and the International Guidelines on HIV/AIDS and Human Rights—developing countries will ensure, to the highest attainable standard, that end-of-life and palliative care is available, accessible, quality, and acceptable.²⁰² Kerala, India can serve as a model of current best practices that creates a community-inclusive space for dying, and the simple, interactive, and adaptable Maryland MOLST process can serve as model for future end-of-of life planning.²⁰³ Through such a comprehensive approach, developing countries could leap frog and even take the lead in end-of-life and palliative care, with the result of sparing vast current and future populations from needless physical and emotional suffering at the most inescapable point of life: death.

200. Interview with Carla S. Alexander, *supra* note 15; *see also How Do I Plan for My Health Care?*, *supra* note 196; *see also Maryland MOLST Order Form*, *supra* note 191. Dr. Alexander emphasized the importance of portability and simplicity of MOLST for patients, but urged particular caution in presenting it to patients in the developed world because of its sensitive and controversial nature. Interview with Carla S. Alexander, *supra* note 15.

201. *See supra* Part I.

202. *See supra* Parts II–VI.

203. *See supra* Parts VII, VIII.