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Fatima could not bear the pain of dying. At 63 years of age, she was suffering from metastatic breast cancer with additional growths in her lungs and bones. Her diagnosis had come late in the disease process, shortly after her migration from Morocco to the Netherlands to live with her son's family. Having endured multiple surgeries, radiation treatments, and debilitating rounds of chemotherapy, Fatima was ready to die. Her family accepted this inevitability, and together with members of the local Moroccan community, they rallied at her bedside to provide round-the-clock care and support. Fatima's nurses and physicians rallied as well, providing medical support via the Dutch home health system, which is free of charge within the public portion of a complex, nationally mandated private-public insurance system.

Unfortunately, although Fatima's nurses could provide strong medicines to relieve her physical pain, they were not familiar with the cultural nuances required to balance her need for relief with her need to be awake for her children. Nor could they address the deeper psychological suffering associated with her condition. A hospice organization might provide such support, or at least coordinate the efforts of people who could. In addition to the palliative medicines provided to individual patients by long-term and home health organizations, hospices provide psychological, social, and spiritual support in partnership with families and communities. Regrettably, such hospices are not publicly funded in the Netherlands. Among the nonprofit alternatives, many have explicitly Christian orientations; the remaining secular organizations have little experience attending to the particular needs of immigrant Muslim communities.

Fatima's story is a composite among the many experiences of non-European Muslim immigrants in the Netherlands, people who experience unnecessary personal suffering at the end of life due to the underutilization of hospice services. Yet despite their tragedy, these stories might at first seem too localized, and the topic too particular, for a volume on global citizenship and human rights. But the reasons for these tragedies have everything to do with the major themes of the Faculty Development International Seminar and its proceedings. Insofar as hospice services provide essential relief of human suffering, their unequal provision presents a significant challenge to the attainment of health and well-being as fundamental human rights.

That this inequality exists in a country known for its internationalism, tolerance, and progressive social policies is a puzzling quandary. It is at least partly related to historical contingencies in the diffusion of healthcare practices between nation-states, and partly related to a uniquely Dutch approach to multiculturalism known as "Pillarization." Both factors are linked to a fundamental inequality in global health: the relative *permeability* of health problems across national and cultural boundaries, and the relative *impermeability* of health solutions between these boundaries.

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When we consider the universal rights of global citizenship, we are also challenged to consider our responsibilities for ensuring that these rights are universally attained. The dual nature of rights and responsibilities is evident in most national definitions of citizenship, in which legal protections and economic privileges are closely linked to obligations for taxation, public service, and loyalty to community and government. However, such links are not so clear in the case of global citizenship, especially when it is evoked in the context of international declarations of human rights that remain underfunded or under-enforced. In these circumstances, when do the problems of another society—either within or beyond our political borders—become our problems because we are all supposed to live in the "same place"?

This question is especially pertinent when we consider the challenges of global health. Article 25 of the United Nations "Declaration of Human Rights" calls for the provision of adequate medical care, living conditions, and social services to assure the health and well-being of people throughout the life span.[1] This Article was further developed during a 1995 conference of the International Network of Health and Human Rights Organizations (INHHRO) in The Hague, Netherlands. Here, the INHHRO affirmed the missions of international health organizations to advocate for the provision of basic health services as a fundamental human right and a necessary complement to the identification of health-related human rights violations. These complementary missions are premised on the idea that global health, like world peace, is not simply the absence of its opposite. They also operationalize the concept of global citizenship by treating the entire world as a patient population.

These ideals bring a global perspective to issues of suffering at the end of life. According to the latest World Health Organization estimates, chronic diseases account for more than 60 percent of the 57 million annual deaths worldwide.[2] This increases to more than 70 percent in higher income countries, despite lower overall death figures.[3] Consequently, most people can expect to die from a prolonged disease condition with the likelihood of pain, disability, and other forms of suffering. While it is imperative to reduce these diseases in the first place, we must also recognize the inevitability of human mortality. By increasing human survival rates at earlier ages, we can expect an even higher risk of prolonged death trajectories with the concomitant risk of protracted suffering. We are facing this very issue with the aging of populations in both affluent and developing nations around the world.[4]

Hospices are critical resources for addressing these challenges. Providing more than pain and symptom management, hospices are community-based organizations for addressing the comprehensive needs of dying people and their families.[5] They are distinguished from the more general category of palliative care by several important features. First, hospices work solely with terminally ill patients who have foregone curative treatment and therefore desire to improve the quality over the quantity of their remaining lives. Second, although some hospices provide inpatient facilities, most are oriented toward home-based care. Third, hospices not only provide medical expertise, but also social services, bereavement services, spiritual care coordinators, and community volunteers. Finally, unlike many individually oriented biomedical institutions, hospices typically plan their care activities to include the needs of families and other patient social networks. Stoddard argues that these features comprise a major movement in biomedicine.[6] In anthropological terms, I argue that they are distinctive enough for

hospice to be considered its own healing tradition.[7] In any case, hospice has been a homesteader in uncharted medical territory.

The modern hospice movement traces its origin to the work of Cicely Saunders, who founded St. Christopher's Hospice in 1965 to address the comprehensive needs of the dying in South London communities.[8] Propelled by the momentum of the Death with Dignity movement, St. Christopher's became a major prototype for other hospice organizations around the world. But this global diffusion evokes questions about the translation of a healing tradition into a diverse range of cultural and socioeconomic contexts.

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The Netherlands presents an interesting case for the translation of hospice across communities as well as national borders. Consistent with the Dutch reputation for pragmatism and progressivism, the country became the first in the world to officially allow for euthanasia, or physician assisted death, under special circumstances.[9] Contrary to the warnings of detractors, the following decade saw no significant increase in the demand for those services.[10] That said, one argument continues to echo an ambivalent tone in the Dutch discourse over end-of-life policies: Euthanasia is unnecessary with adequate symptom management.[11]

This argument is especially interesting in light of the fact that the Netherlands does not have a well-developed hospice system, a situation that is unlike most European countries and in contrast to the otherwise progressive nature of Dutch public services. In lieu of hospices, the Dutch government has opted to incorporate palliative care services into its home-care system. Estimates vary regarding the number of hospice organizations that operate independently of major government support. The Agora Foundation, the country's palliative care organization, lists 17 nonprofit hospices among its members, 22 hospice-like "High Care" homes that address complex medical needs, and approximately 160 "Nearly Home" facilities that provide residential services staffed by volunteers.[12] Most of these nonprofit organizations have Christian affiliations, which begs a further question: To what extent do these latter organizations address the needs of Holland's growing population of Muslim immigrants from non-European countries?

To answer this question, I investigated two Dutch institutions: a large hospice in Amsterdam that provides in-patient and at-home services to approximately 200 patients and their families, and a small Nearly Home organization in Utrecht that provides volunteer-based residential care to a handful of patients at a time. Both organizations report that Muslim immigrants comprise less than two percent of their patient populations, less than a tenth of their representation in surrounding urban areas. The reasons for this disparity are enlightening and consistent with reports from the national organization.

Sanctuary Hospice

Located near the heart of Amsterdam, Sanctuary Hospice closely resembles the St. Christopher's model. Founded as a nonprofit Christian organization in 1992, Sanctuary provides an 11-bed residential facility as well as home hospice services for approximately

200 households in the greater metropolitan area. In addition to in-house nurses, physicians, social workers, physical therapists, and chaplains, Sanctuary has about 180 volunteers to care for its residential and community populations. Despite the cultural diversity of Amsterdam, Sanctuary sees almost no patients of Turkish or Moroccan origin, although they sometimes see non-European Muslims from Surinam and the Lesser Antilles.

To discuss this situation, I conducted a joint interview with Sanctuary's director, its nurse educator, and the visiting director of the Agora Foundation. They all agreed that religious differences are the major barrier to the provision of hospice care to Muslim communities. Although ecumenical, they are an explicitly Christian organization, which may deter participation by people of other faiths. When speaking of the Turkish and Moroccan communities, they suggested that a strong tradition of family caregiving may reduce the perceived need for professional services.

Perhaps more importantly, my informants identified a major philosophical difference between Sanctuary's approach to end-of-life care and that of some non-European communities. Consonant with the modern hospice movement, Sanctuary only admits terminally ill patients who have made an informed and voluntary decision to forego curative medical treatment. The consensus of the interviewees was that open discussion of prognosis is often taboo among many non-European immigrant communities. Sanctuary's director, "Helen," emphasized this point, stating that, "they deny everything." Consequently, there are minimal opportunities for informed consent.

Helen stated that home care services try to match nurses with client families having similar cultural backgrounds, and that there are increasing numbers of Turkish and Moroccan nurses in this system. She also notes that Sanctuary often tries to work closely with home health nurses to care for their outpatient communities. But although the providers themselves are very willing to work with one another, the government system presents significant bureaucratic hurdles to achieving an effective interface. These obstacles are especially prevalent when the government provides limited support for public-private collaboration. Consequently, even when patient and professional communities are willing, there are significant structural barriers to cooperation. As a result, hospice and home care continue to be very discrete institutions. Summing up all these challenges, Helen expressed her view that one hospice cannot address the needs of every community, stating that there should be "special places for special groups."

Channel House

Although located on church property, Channel House is among the minority of secular hospice organizations in the Netherlands. Beginning as a volunteer-based home care service in the mid-1980s, Channel House established a four-bed residential facility in 2002. As with its home care services, the residence is primarily staffed by volunteers, with outside medical support from nurses and physicians from the Dutch Health Service. It serves approximately forty "guests" a year, the majority of whom are elderly people of European origin who have been diagnosed with cancer and have a prognosis of three months or less to live. The residence is an important option for people who lack sufficient social supports at home, or whose families need respite from the challenges of providing round-the-clock care.

Channel House presents a striking contrast to its surrounding community, where the merchant streets are lined with Turkish and Moroccan businesses selling textiles and foodstuffs, with storefront signs written in their respective languages. More than 20 percent of the Utrecht population is first- or second-generation immigrants of Turkish or Moroccan origin. Yet these communities comprise less than two percent of the guest population at Channel House.

During my interview with "Sara," the assistant director, she related her concerns about this phenomenon. "I think they find their own way," she stated, explaining that many of these families have strong networks of family and community support in the home. These networks "do their own thing…go their own way," meaning that their methods of care are culturally distinct from those provided by Channel House. Still, she recognizes that her organization could bridge important gaps between these people's needs and their existing resources. Sara identified three challenges in this regard:

- The residential environment must adapt to the needs of larger support groups. Sara identified a few "successes" in which Channel House was able to care for Moroccan guests to the satisfaction of their families. But she noted that these examples sometimes required hosting as many as sixty friends and family members at a time, and that they needed to account for dietary restrictions and schedule times for religious services and singing so as not disturb the other patients. Although challenging, she felt these issues could be addressed with better resources rather than a different organization.

- Local Turkish and Muslim communities are daunted by the perceived Christian affiliation of Channel House and other hospice organizations. Although secular, the majority of Channel House volunteers claim some kind of Christian faith, and the location of the residence on church grounds implies a close association. Christian symbols permeate its architecture, and even I initially confused the church with the hospice during my first visit.

- Some community members associate hospice with discrimination and abandonment. Sara stated that, "they feel not well handled," meaning that they perceive that their medical providers have given them a lesser standard of care at earlier stages of their illness trajectories. Facing the prospect of complex and expensive treatments at later stages, they suspect the hospice option may be an expedient means of abandoning them.

With these themes in mind, Channel House recently employed a Moroccan volunteer and researcher to find new ways to improve community outreach. Results of these efforts are still pending.

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The emerging themes from this preliminary study can be characterized by the historical concept known as *verzuiling* in Dutch, and translated into English as pillarization. This concept originally referred to the segregation of the Dutch and Belgian societies along socially vertical lines according to religious affiliations.[13] In Holland, there were three pillars comprised of Protestant, Catholic, and Social-Democratic communities, each with its own social and political agendas. These pillars began to fall after World War II, and then crumble with the secularization of Dutch society in the 1960s. Yet in recent years,

pillarization has seen a resurgence with the influx of non-European immigrants, particularly those from Muslim-majority countries, who have somehow challenged traditionally Dutch attitudes of tolerance and internationalism.[14] These changing attitudes also reflect increasing ambivalence among some sectors regarding economic and political changes in the European Union.[15]

Framed in processual terms, I offer the tentative argument that pillarization best explains the under-provision and under-utilization of Dutch hospice services for non-European Muslim immigrant communities. These processes occur as historical contingencies at an infrastructural level. At a structural level, they reflect a segregationist approach to multiculturalism that deters the participation of hospice providers in certain communities. Reciprocally, pillarization fosters distrust of hospice organizations among these same communities. These processes explain my preliminary interviews and observations as follows:

- *Historical contingencies regarding the development of palliative care infrastructure:* By the time of the modern hospice movement, the Dutch government had already developed an extensive home care system. Rather than develop new institutions, the government decided to incorporate selected elements of the hospice models into its pre-existing institutions.[16] As such, the hospice model only partially diffused into Holland's publicly supported end-of-life services. Closer to the St. Christopher's model, independent nonprofit hospices emerged with support from local Christian communities. Consequently, Dutch hospice and home care institutions exist as separate pillars of palliative care: one, mostly Christian; the other, entirely secular. Faced with these separate choices, it is understandable that Muslim communities would prefer the secular option.

- *The segregation of immigrant communities:* Although progressive in many respects, Dutch policies and attitudes of multicultural tolerance have also led to social segregation through an ideal that different communities can get along while minimizing intercommunication and interaction.[17] This was reflected in the ghettoization of Holland's first-generation immigrant labor communities in the 1960s and 1970s, and the perpetuation of social segregation among second-generation communities of the present day. This segregation has led to a lack of experience with, or understanding of, Muslim immigrant communities by predominantly Christian and European health providers in the hospice system.

- *Distrust of hospice among immigrant communities:* Social segregation is often reciprocal in nature. In this example, the segregation of immigrant communities has fostered a sense of discrimination and exclusion from the opportunities and resources of Dutch society.[18] It follows that this sense of discrimination would be especially prevalent during the course of a protracted and painful illness leading up to the last months of life. Negative experiences of medical treatment during the curative stages of that trajectory (or similar understandings of other people's experiences) would understandably foster distrust in the final stage, and the appearance that hospice is an institution for medical abandonment. An analogous example can be found in the under-utilization of hospice among African Americans, whose distrust of this option is fueled by a history of discrimination and exclusion from medical resources.[19]

Returning to the themes of human rights and global citizenship, we see how the provision of hospice services addresses two fundamental human rights: the right to live free from suffering and the right to human dignity and well-being, even if only in the last moments of life. Per the tenets of global citizenship, the unequal distribution of this essential resource, in any society, is the problem of every society. In the case of the Netherlands, this inequality has resulted from the pillarization of palliative care, a collection of structures and attitudes created by transnational and local experiences. Solving this challenge requires a similarly multilayered approach and a recognition that global problems are holistic phenomena occurring at both small and large scales. We see this among the environmental, sociopolitical, and legal issues addressed in this volume. The same can be said about the attainment of health care services as a fundamental human right. To turn a phrase from a homesick writer, we must recognize that *there is no there here*, if we are to approach these issues from a global perspective.

Notes

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3. World Health Organization, "Global Summary of the HIV/AIDS Epidemic, December 2008," accessed online at 13 November 2010 at who.int/hiv/data/2009_global_summary.gif.

4. Kevin Kinsella, and Victoria Velkoff, "An Aging World: 2001" (Washington D. C.: U.S. Census Bureau, 2001).

5. Sandol Stoddard, *The Hospice Movement: A Better Way to Care for the Dying* (New York: Vintage, 1992).

6. Ibid.

7. Ron Barrett, "Anthropology at the End of Life," in *A Companion to Medical Anthropology*, edited by Merrill Singer and Pamela Erickson (Indianapolis: Wiley Blackwell, forthcoming).

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10. Ibid.

11. Bert Broeckaert, and Rien Janssens, "Palliative Care and Euthanasia: Belgian and Dutch Perspectives," *Ethical Perspectives* 9, no. 2–3 (2002):156–175.

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13. Erik Bax, *Modernization and Cleavage in Dutch Society: A Study of Long Term Economic and Social Change* (Aldershot: Ashgate Publishing, 1988).

14. Frank Lechner, "Global Citizenship and the European Milieu: Contested and Considered." This volume, 2011.

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16. David Clark, with Henk ten Have, and Rien Janssens, "Common Threads? Palliative Care Service Developments in Seven European Countries, *Palliative Medicine* 14 (2000): 479–490.

17. Ben Spiecker, and Jan Steutel, "Multiculturalism, Pillarization, and Liberal Civic Education in the Netherlands," *International Journal of Education Research* 35, no. 3 (2001): 295–304.

18. Sjoerd Karsten, Charles Felix, and Guuske Ledoux, et al., "Choosing Segregation or Integration? The Extent and Effects of Ethnic Segregation in Dutch Cities," *Education and Urban Society* 38, no. 2 (2006): 228–247.

19. K. Allen Greiner, Subashan Perera, and Jasjit Ahluwalia, "Hospice Usage by Minorities in the Last Year of Life: Results from the National Followback Survey," *Journal of the American Geriatrics Society* S1, no. 7 (2003): 970–978. Compare with Robin K. Matsuyama, Christina Grange, Laurie Lyckholm, et al., "Cultural Perceptions in Cancer Care among African American and Caucasian Patients," *Journal of the American Medical Association* 99, no. 10 (2007): 1113–21.