Catholic health care is one of the key places where the church lives Catholic social teaching (CST). Yet the individualistic methodology of Catholic bioethics inherited from the manualist tradition has yet to incorporate this critical component of the Catholic moral tradition. Informed by the places where Catholic health care intersects with the diverse societal injustices embodied in the patients it encounters, this book brings the lens of CST to bear on Catholic health care, illuminating a new spectrum of ethical issues and practical recommendations from social determinants of health, immigration, diversity and disparities, behavioral health, gender-questioning patients, and environmental and global health issues.

"*Catholic Bioethics and Social Justice* is a gift not only for ethicists, theologians, and mission leaders, but for anyone interested in the integrity of Catholic health care."
Michael Miller, Jr.
System Vice President, Mission & Ethics
SSM Health

"Theoretically sophisticated yet grounded in the daily practice of Catholic health care, this collection breaks out of the traditional locus for bioethics in the clinic and at the bedside to give voice to marginalized communities and invisible populations. Here justice is not an afterthought or a fourth principle but the lens through which we question everything."
Maura A. Ryan
University of Notre Dame

"We talk about micro- and macroethics, clinical and social dimensions of health care ethics, but the specific clinical aspects—especially those around sex and reproduction—continue to absorb a disproportionate amount of ethicists' attention. This volume shows both the social context of health care ethics and the influence that social factors have on clinical issues we face."
Charles E. Bouchard, OP, STD
Senior Director, Theology and Ethics
The Catholic Health Association of the United States

ISBN 978-0-8146-8455-9
53995
9 780814 684559
U.S. $39.95

LYSAUGHT AND McCARTHY

Catholic Bioethics & Social JUSTICE

The Praxis of US Health Care in a Globalized World

EDITED BY M. THERESE LYSAUGHT AND MICHAEL McCARTHY
FOREWORD BY LISA SOWLE CAHILL

work well. While bioethics has commented extensively on global health inequalities, it is my hope that this chapter establishes a framework for evaluating ethically the importance of creating global health partners grounded in a relationship of mutual trust.

Chapter 19

Non-Communicable and Chronic Diseases in Developing Countries: Putting Palliative Care on the Global Health Agenda

Alexandre Andrade Martins, MI, PhD

Michelin was a twenty-six-year-old man with cancer in the final stage of his young life. His existential journey was not long, ending precociously after a journey searching for health care assistance until he arrived at our hospital in Mirebalais, where he died peacefully. Michelin, as is typical of people his age, had dreams and plans for his life. Pursuing his dreams in the midst of poverty and lack of opportunities, as is the reality in Haiti, Michelin bought a small motorcycle and became a moto-taxi driver, blending his passion for motorcycles with the possibility to make some money to survive. One day, already feeling weak, Michelin had a motorcycle accident that severely damaged his left leg. Michelin's friends took him to a public hospital in Port-au-Prince, but the doctors were on strike and not available. His friends took him and searched for another place where they could find a doctor. With no success, Michelin returned home to the small village where he lived with his mother. A few days later, someone told Michelin that he could find a doctor at the University Hospital of Mirebalais, an institution supported by the NGO Partners in Health. Fortunately, after this less-than-ideal delay, Michelin received all the needed treatment for his leg. Unfortunately, his doctors also discovered that he had cancer, which had spread into his bones.

I arrived at Mirebalais about a month after Michelin had begun his cancer treatment; he was already in palliative care. My relationship with him and his mother was short, but meaningful. We provided the best care available, and he died with dignity comforted by his mother.

I learned a lot listening to him and his mother, a strong woman who had to travel two hours to be with her son. She was a widow and had no other children. She did not have money to make this trip every day. She basically stayed all the time in the hospital and, often enough, she had to sleep on the ground outside the hospital because she did not have a place to go. After her son died, she said, "I am sad because my son passed away. But I am thankful for all the care you gave to him and for seeing us as human beings who deserve your attention."

◆ ◆ ◆ ◆ ◆

Michelin's case is useful to show elements involved in noncommunicable diseases (NCDs) and palliative care in low-income countries. It begins with the structural violence that makes poor people vulnerable and generates lack of health care assistance. Michelin was feeling sick before the accident, but finding a doctor to understand why he was feeling weak never appeared to him as an option. As a result, his undiagnosed cancer went untreated. This increased his risk of having a motorcycle accident. After the accident, another violence occurred: no health care! He was lucky to find the Hospital in Mirebalais, but it was too late.

Health care assistance must not be a matter of luck, rather, it is a matter of human rights and responsibilities. In Mirebalais, he received care, first curative treatment, and then palliative care. He could not be healed, but he could be cared for in a respectful way that preserved his dignity. Unfortunately, palliative care was limited because of the lack of resources needed to care for his mother. Her situation revealed the structural violence of which she was also a victim.

NCDs and chronic diseases are present in the reality of the poor. They make many people suffer and kill many others. Global health must address this disease burden. Michelin's case is an example of the need for palliative care as part of the global health agenda in low- and middle-income countries. This agenda needs an integral and holistic vision of care able to integrate health care and social justice. Here narratives and Catholic social teaching have a strong potential to contribute to the expansion of palliative care in poor areas and actions of care along social justice in global health.

The World Health Organization defines palliative care as:

> An approach that improves the quality of life of patients and their families facing the problems 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.[1]

Initially, palliative care focused only on patients who did not respond to curative therapy, relegating palliative care to the last stage of care. It was also centered on patients, neglecting families and communities. Nowadays, the focus on terminal patients still exists in many countries, making palliative care almost synonymous with hospice care.[2] However, palliative care has been extended to embrace chronic, life-limiting diseases without an immediate prospect of death, such as HIV, cardiovascular diseases, and diabetes; involve families and communities; and consider not only the physical needs of patients, but also their social, emotional, and spiritual needs.[3] In addition, palliative care has been put on the global public health agenda by the recognition of its need in low- and middle-income countries.[4]

---

[1] World Health Organization, "Palliative Care," http://www.who.int/ncds/management/palliative-care/introduction/en/#.

[2] This is the perspective of many regarding palliative care in Brazil where many health care providers and institutions limit palliative care to terminal patients, especially those with cancer, and elderly patients with dementia and degenerative chronic disease. For a presentation on this limited perspective on palliative care, see Ludugério de Souza, et al., "Cuidados Paliativos na Atenção Primária à Saúde: Considerações Éticas," *Revista Bioética* 23, no. 2 (May 2015): 349–59; Leo Pessini, "Vida E Morte Na UTI: A Ética No Fio Da Navalha," *Revista Bioética* 24, no. 1 (2016): 54–63.

[3] Cecilia Sepúlveda, et al., "Palliative Care: The World Health Organization's Global Perspective," *Journal of Pain and Symptom Management* 24, no. 2 (August 2002): 92.

[4] Richard A. Powell, "Putting Palliative Care on The Global Health Agenda," *The Lancet* 16, no. 2 (2015): 131–32. See also the WHO general assembly that addressed the need on palliative care in the global health agenda.

Palliative care is not a privilege of high-income countries but a global health commitment that must be part of the agenda of public health actions and advocacy for health care as a human right.[5] Michelin's case shows the importance of accessing palliative care to promote patients' quality of life and death with dignity. We cannot always heal, but we can always care.

Non-communicable, Chronic, and Terminal Illnesses: The Need for Palliative Care in the World of the Poor

Conventional wisdom holds that the immense majority of the poor die because of communicable diseases, especially tropical diseases. The rich, or those who live in high-income countries, die because of non-communicable diseases (NCDs), primarily cancer and cardiopathies. This conventional wisdom captures only part of the truth about the leading causes of death in low- and middle-income countries. True, communicable diseases are killing people in these nations. HIV/AIDS and tuberculosis are still the leading causes of death in Sub-Saharan Africa.[6] However, NCDs also kill people in low- and middle-income countries. NCDs are responsible for 38 million deaths each year, cardiovascular diseases being the reason for 17.5 million deaths annually, cancers 8.2 million, respiratory diseases 4 million, and diabetes 1.5 million. The majority of these deaths occur in low- and middle-income nations.[7]

Evidence-based studies have shown that NCDs are a huge burden for the poor. Cardiovascular diseases are the number one cause of death and disability in the world. Close to 80 percent of these deaths occur in low- and middle-income countries.[8] A study in rural Haiti shows that heart failure is the most common cause of hospitalization and that the "majority of cardiovascular disease morbidity is in low-income and middle-income countries."[9] Health systems fail to reach these people. Available data is only derived from those who arrive at urban hospitals. Therefore, the reality of cardiovascular diseases in low-income countries is worse than the available data shows. Another evidence-based study shows that in the sixteen poorest countries in the world, 34 percent of the combined cardiovascular diseases and congenital heart anomalies accrued in people under 30 years of age.[10] Among other factors for cardiopathies, the most prevalent are increasing "exposure to indoor and outdoor air pollutions, schistosomiasis, tuberculosis and sickle cell disease . . . using solid cooking fuels, over-crowding, poor hygiene and lack of access to basic health care."[11]

Studies also show that cancers have high incidence in low- and middle-income countries. Projections are that by 2025, 75 percent of cancer cases worldwide will occur in developing nations.[12] In most African countries, cancer control is difficult because of low awareness, late-stage treatment, and poor survival.[13] Cancers along with HIV/AIDS are "the two diseases that predominantly contribute to Africa's disease burden for conditions that require palliative care."[14] The world has testified to a shift in the global burden of diseases to NCDs in which cancer claims increasing responsibility for morbidity and mortality in low- and middle-income countries. An estimated 65 percent of cancer deaths occur annually in these countries.[15]

---

[5] Liz Gwyther, et al., "Advancing Palliative Care as a Human Right," *Journal of Pain and Symptom Management* 38, no. 5 (2009): 767–43.

[6] Eve Namisango, et al., "Possible Direction for Palliative Care Research in Africa," *Palliative Medicine* 30, no. 6 (2016): 517.

[7] Ibid.

[8] Gene F. Kwan, et al., "Descriptive Epidemiology and Short-Term Outcomes of Heart Failure Hospitalisation in Rural Haiti," *Heart* 102, no. 2 (2016): 140.

[9] Ibid., 145.

[10] Gene F. Kwan, et al., "Endemic Cardiovascular Diseases of the Poorest Billion," *Circulation* 133, no. 24 (2016): 2562–75.

[11] Kwan, et al., "Descriptive Epidemiology and Short-Term Outcomes of Heart Failure Hospitalisation in Rural Haiti," 142; Kwan, et al., "Endemic Cardiovascular Diseases of the Poorest Billion," 2565.

[12] C. Norma Coleman, et al., "Establishing Global Health Cancer Care Partnerships Across Common Ground: Bridging Nuclear Security, Equitable Access, Education, Outreach, And Mentorship," *The Lancet* 4, special issue (2016): 14.

[13] Sten Z. Zelle, et al., "Costs, Effects and Cost-effectiveness of Breast Cancer Control in Ghana," *Tropical Medicine and International Health* 17, no. 8 (2012): 1031–43.

[14] Eve Namisango, et al., "Possible Direction for Palliative Care Research in Africa," 517.

[15] Faluso Ishola and Oluwatosin Omole, "A Vision for Improved Cancer Screening in Nigeria," *The Lancet* 4, no. 6 (2016): e359.

The burden of NCDs in low- and middle-income countries goes beyond cardiopathies and cancers.[16] Therefore, the global health agenda must include a significant effort to address NCDs in low- and middle-income countries, including palliative care initiatives. According to WHO, over 20 million people require palliative care at the end of life every year.[17] About 80 percent of these people live in low- and middle-income countries.[18] "The great majority of adults in need of palliative care died from cardiovascular diseases (38.5 percent), or cancer (34 percent), followed by chronic respiratory diseases (10.3 percent), HIV/AIDS (5.7 percent), and diabetes (4.5 percent)."[19] Among children, interesting data shows that 49 percent of children in need of palliative care are in Africa.[20] In addition, "as populations age and societies industrialize, the number of people who will need palliative care to manage the problems associated with chronic progressive illness, especially cancer, are predicted to increase in low-income and middle-income countries."[21]

Although the burden of life-limiting and life-threatening diseases is higher in these contexts, 80 percent of palliative care is delivered in high-income countries.[22] This corresponds to less than 14 percent of the total global population that needs this kind of care.[23] Research has shown the cost-effectiveness of hospices and palliative services.[24] This evidence has led to a huge investment in these services in high-income countries, where most of the evidence-based research in palliative care takes place. On the other hand, research in low- and middle-income countries is severely lacking.[25] African specialists, for example, in end-of-life care affirm, "The level of health care coverage remains low in Africa, access to palliative care limited and research systems poor."[26]

These studies provide evidence that NCDs and the need for palliative care are issues to be addressed in global health, especially in low- and middle-income countries. Palliative care is an inter/multidisciplinary approach grounded on an integral vision of the human person and his/her relations with his/her own body, fears, beliefs, and hopes as well as with family, friends, health professionals, community, and society. Studies also show that important actors for an adequate palliative care find it difficult to handle and even most health professionals lack specialized education in this area.[27] In general terms, experiences suggest that four areas must be addressed to develop palliative care services: efficient local and national health policies;[28] specialized education and training for health professionals, caregivers, family members, health workers, and communities;[29] broad availability of medication, including the access to opioid pain relief; and implementation of palliative care in all levels of care, from primary care[30] to tertiary and specialized care.[31]

---

[16] See, for example, this study on chronic kidney disease in Nicaragua, P. A. Clark, J. Chowdhury, B. Chan, and N. Radigan, "Chronic Kidney Disease in Nicaraguan Sugarcane Workers: A Historical, Medical, Environmental Analysis and Ethical Analysis," *The Internet Journal of Third World Medicine* 12, no. 1 (2016): 1–16.

[17] World Health Organization, *Global Atlas of Palliative Care at the End of Life*, 25, http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care.

[18] Ibid., 16, 20.

[19] Ibid., 13.

[20] Ibid., 20.

[21] Richard Harding and Irene J. Higginson, "Inclusion of End-of-Life Care in the Global Health Agenda," *The Lancet* 2, no. 7 (2014): e375.

[22] Ibid.

[23] World Health Organization, *Global Atlas of Palliative Care at the End of Life*, 71.

[24] Ibid., 62.

[25] Ibid., 31.

[26] Eve Namisango, et al., "Possible Direction for Palliative Care Research in Africa," 517.

[27] Souza, et al., "Cuidados Paliativos na Atenção Primária à Saúde." See also World Health Organization, *Global Atlas of Palliative Care at the End of Life*, 27.

[28] World Health Organization, "Palliative Care."

[29] Liliana DeLima, "How Can We Monitor Palliative Care? Suggestions from the Latin American Association for Palliative Care," *International Journal of Palliative Nursing* 19, no. 4 (2013): 161.

[30] The Brazilian Public Health System has developed good initiatives around palliative care in primary care; see, for example, Souza, et al., "Cuidados Paliativos na Atenção Primária à Saúde."

[31] I shaped these areas based on WHO's orientations for effective approach in palliative care and suggestions of the Latin American Association for Palliative Care. See WHO, "Palliative Care"; DeLima, "How Can We Monitor Palliative Care?," 160–61.

The Art of Care as Attention to the Poor's Dignity and Justice

Jesus embraced the principles of the art of care, as he was the master of compassion and solidarity with the destitute sick. In Jesus' time, being sick was a reason for exclusion and marginalization: a sick individual was an unclean person, unworthy of participating in the society. Consequently, marginalization, suffering, and poverty were the natural paths of a sick person. Jesus' encounters with the destitute sick were moments of recognition of the other who suffered in a movement of compassion.

Although technically Jesus did not offer palliative care for the destitute sick, his relationship with the destitute sick offers a paradigm for reflection on palliative care in the context of global health and poverty. Thus, Jesus' encounter with the destitute sick was a revolutionary movement of compassion and *active care*. In a society in which the sick were not worthy of any care, such as the ten destitute people with skin diseases who met Jesus on his way (Luke 17:14-17), Jesus showed his compassion as a concrete act of care and offered them an opportunity of social inclusion. With this act, Jesus not only cared for the destitute sick, but also broke this institutionalized violence by showing that these people were worthy of care by integrating them into society. Palliative care in global health begins when we recognize the destitute sick as those for whom we are all responsible to care for and not only as recipients of crumbs from the table of rich nations. However, palliative care medication for chronic and non-communicable diseases are not considered cost-effective in low-income countries.[32]

Catholic tradition embraces this perception of care from the recognition of the face of the destitute sick, essential to support the urgency of palliative care. The biblical passage suggested above shows Jesus going beyond the healing aspect in caring for someone sick. Jesus' actions toward those who were sick incorporated the social dimension of care because he acted to promote quality of life and to reintegrate the marginalized sick into social life. Jesus was not only worried about the biological aspect of the destitute sick, but also about promoting a life with dignity to the human being and his/her participation in social life.[33] Based on this christological perspective, Latin American bishops say,

> Health is a biographic experience: covering the different dimensions of the human person and it has an intimate relationship with the particular experience that a person has with his/her own corporality, with his/her place in the world, and with the values on which he/she builds his/her existence. In short, we can say that health is a harmony between body and spirit, a harmony between person and environment, a harmony between character and responsibility.[34]

This harmony requires an approach able to integrate palliative care into global health inside socially just actions. Care and justice must walk hand in hand. The parable of the Good Samaritan (Luke 10: 25-37) shows care and justice as active social principles to be embraced by health care delivery. The action of the Samaritan toward the destitute sick embodies solidarity as a social principle[35] that cares and promotes justice without making distinction among people. Cost-effectiveness is not the logic of the Samaritan, but rather the recognition of dignity of the poor sick who need assistance and the neighbors responsibility to provide that. "This parable helps us think about solidarity and vulnerability inside the reality of the poor."[36]

If we fail to contemplate the suffering face of the destitute sick, care and justice are only an abstraction. Our contemporary society talks a lot about poverty, marginalized people, lack of opportunities, and health inequalities. Everyone who is talking about this reality of poverty and suffering with millions of early deaths has suggestions to address these issues. Many develop beautiful theories and systems to end poverty. However, those who are actually suffering are not

---

[32] Paul Farmer, "Chronic Infectious Disease and the Future of Health Care Delivery," *The New England Journal of Medicine* 369, no. 25 (2013): 2424–36.

[33] Conferência Nacional dos Bispos do Brasil, *Campanha da Fraternidade 2012: Texto-Base* (Brasília: Edições CNBB, 2011), 181.

[34] Conselho Episcopal Latino-Americano, *Discípulos Missionários no Mundo da Saúde: Guia para a Pastoral da Saúde na América Latina e no Caribe* (São Paulo: Centro Universitário São Camilo Press, 2010), 8.

[35] John Paul II, *Sollicitudo Rei Socialis* 38.

[36] Conferência Nacional dos Bispos do Brasil, *Campanha da Fraternidade 2012*, 186.

mere numbers, statistics, nor a distant people we do not know.[37] In health care, the sick and the poor are totally anonymous, without face or voice. And they are dying every day. Many people create solutions for them but do not know who they are. These possible solutions are very arbitrary, non-democratic, and elitist because they come from people who are not victims of structural violence nor do they share life with the victims or listen to them. Listening to the poor, engaging them in dialogue, and promoting their participation are essential to caring and to promoting justice in a context of health inequalities. This is the reason that I have not presented here only numbers and evidence-based studies showing the need of palliative care in global health. I also presented Michelin, a real face, a voice in need of care and justice, a representative of the poor suffering from NCDs in low-income countries.

Catholic social teaching presents the preferential option for the poor as a principle to guide actions in global health toward care and justice for the poor.[38] The preferential option for the poor in health is a perspective that integrates care and justice. In addition, this option leads health professionals, policy makers, and global health activists to dialogue with the poor, listen to them, and engage them in actions of health care delivery, including palliative care. Experiences of community-based approaches—with community health workers in the process of caring for those who are sick and more vulnerable to diseases—have proven to be effective in health care delivery. Studies show that community health workers are an essential part of health care delivery in low and middle-income countries.[39] Palliative care strategies must count on the contribution of community health workers. They, along with community-based centers and health professionals, interact directly with families in their homes and communities, providing a care that is also attentive to patients' and families' social and emotional needs.

Practical Recommendations: Starting Points for a Conversation

How might a Catholic health care ministry committed to global health include palliative care in its agenda? While some of these recommendations are referenced in other chapters, I hope here to provide a way to engage with the complex realities of NCDs and the need for palliative care. These thesis statements below stand alone because, as Compton's chapter indicates, they need to be applied in conversation with local partners. Therefore, these recommendations serve as starting points for a conversation, rather than final conclusions:

- Cultivate a missionary spirit, in which Catholic health care ministry goes beyond national borders to serve in areas marked by poverty;
- Create interdisciplinary groups focusing on palliative care and Catholic ministry in global health;
- Invite community members to be part of these groups;
- Introduce Catholic social teaching in these discussions and seek for ways to apply them in global health;
- Create awareness around social issues and their relevance for health/health care;
- Analyze local realities, their social/health issues, and their main challenges for palliative care;
- Promote studies on palliative care and its impacts on health care assistance;
- In global health missions, choose a community-based approach of health care delivery to involve the participation of local members (see Compton chapter);
- Make dialogue a core methodological/pastoral approach;

---

[37] Simone Weil affirms that one of the problems of our contemporary society is that we do not see those who are suffering. They are invisible in our society. She says that only when we can see them, can real transformation happen. And to see them, it is necessary to be touched by suffering. Simone Weil, "L'amour de Dieu et le Malhuer," in *Œuvres*, ed. Florence de Lussy (Paris: Quarto Gallimard, 1999), 691–716.

[38] John Paul II, *Sollicitudo Rei Socialis* 39; Francis, *Evangelii Gaudium* 198.

[39] Kyounghae Kim, et al., "Effects of Community-Based Health Worker Interventions to improve Chronic Disease Management and Care Among Vulnerable Populations: A Systematic Review," *American Journal of Public Health* 106, no. 4 (2016): e3-e28; Farmer, "Chronic Infectious Disease and the Future of Health Care Delivery," 2425.

- Listen to the locals, learn their perspective, engage them in decision-making processes and activities;
- Provide education on end of life to health professionals and local communities;
- Educate and cultivate Catholic social principles, such as solidarity, participation, justice, and option for the poor;
- Train community members to be health workers and to serve in palliative care teams;
- Develop strategies of palliative care that go beyond hospitals and clinics in order to include homecare, involving communities and families;
- Create advocacy groups that strive for the integration and expansion of palliative care in public health care systems.

Conclusion: Expanding Palliative Care on the Global Health Agenda

Evidence-based studies, data, and narratives prove that the poor carry the burden of non-communicable and chronic diseases. They also show the urgent need for palliative care as part of the global health agenda in low- and middle-income countries. From this empirical reality, I suggest reflecting on care as attention to dignity and justice for the poor. Care and social justice together, including an active role of the poor and local communities, provide a foundation to develop strategies to embody palliative care into the global health agenda in low- and middle-income countries. Care and justice cannot be separated in bioethics, especially in the reality of the poor.[40]

Catholic principles that ground bioethics and actions in health care of Catholic organizations put the destitute sick at the center of Catholic health ministry. This tradition is clear in the way it connects care and justice to defend and promote the dignity of the human

being. There is a huge demand for palliative care in low- and middle-income countries. This is not speculation, rather, it is a fact. Therefore, Catholic organizations are encouraged to assume the responsibility of expanding palliative care into the global health agenda and to be partners of other organizations in delivering health care to the poor.

---

[40] Olinto A Pegoraro, "O Lugar Bioético na História da Ética e o Conceito de Justiça como Cuidado," in *Bioética e Longevidade Humana*, ed. L. Pessini and C. P. de Barchifontaine (São Paulo: Loyola, 2006), 56.