BOSTON COLLEGE
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The Privilege of Dying Well:
Inequity in Access and Community Development of Palliative Care

Thesis in Moral Theology
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Introduction

The benefits of medical progress, institutionalized medical attention, and other cultural changes seem to have neglected some essential elements of death and dying. The process of dying appears, in many ways, disconnected from life. This has had an effect, for example, on the way illness, aging, and suffering are considered in different contexts. Medical progress has shaped the way people die. Although crucial, responding to the question of how to die well is frequently left unanswered when people, families, and communities face end-of-life situations.

Palliative care has been one of the ways of answering that question within contemporary institutionalized healthcare settings. Palliative care can provide resources for people striving to die well and for their families and communities to accompany them in that crucial process. However, access to palliative care remains an issue in low and middle-income countries, and the effect of inequities can also be found in higher-income countries among the poorer population. This unjust situation neglects essential elements of humanity and healthcare at one of the most important moments in people's lives.

Integral to universal health coverage, palliative care requires a better understanding of its place in global health care. Moral considerations lie behind the reasons for its development regarding the reduction of health-related suffering in its multiple dimensions. Other ethical concerns include its cost-effectiveness and possible contribution to reducing poverty. However, implementing or developing palliative care in a standardized way might mean pursuing an equal but inequitable model of care. A vision of palliative care that includes the social determinants of health highlights the necessity of examining the social context and articulating a culturally appropriate model in consonance with the preferential option for the poor. Models stemming from a community-based palliative care approach seem more appropriate to meet the particular needs of individuals and communities. The community development of palliative care strives to “increase and enhance quality of life for both dying people and their carers, and to increase access to both end of life care support and services.”[1] It provides a way to respond to inequity and injustice by generating an appropriate context for the flourishing of virtues needed at this stage of life.

The current situation of palliative care globally is explored in the first chapter of this thesis, drawing especially on the last two reports of the Lancet Commission on Palliative Care and Pain Relief and the Lancet Commission on the Value of Death. Over-medicalization at the end of life and unequal access to palliative care will be presented as primary descriptors of the problem the thesis will address. The two central claims of the thesis respond to this problem. On the one hand, palliative care offers a possible answer to what dying well means. On the other hand, its development has to prioritize individuals and communities with fewer resources.

Chapter 2 will describe two valuable resources available when assessing palliative care. First, it will present the *ars moriendi* tradition. Before establishing palliative care, there is a long history of how people and societies dealt with death in a non-institutionalized manner. This approach stands out in the Christian tradition. Second, a recent development of palliative care that prioritizes community development from a public health perspective will be offered.

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[1] Allan Kellehear and Libby Sallnow, “Public Health and Palliative Care. An Historical Overview,” in *International Perspectives on Public Health and Palliative Care*, ed. Libby Sallnow, Suresh Kumar, and Allan Kellehear, Routledge studies in public health (Abingdon, Oxon; New York: Routledge, 2012), 1–12.

Chapter 3 will develop an ethical lens that will help judge the current state of affairs and charter the way forward. Regarding the desire of people to die well and the role of palliative care, virtue ethics will be used, drawing on the previously described resources. The complexities of death and dying and a broader perspective that includes communities and relationships require attention to the way structures shape end-of-life care. Virtuous structures have the capacity to enable the person in an end-of-life situation to die well and the community to become a virtuous community that actively accompanies the process. This dynamic is particularly relevant for vulnerable populations. A focus on the ‘preferential option for the poor’ and critiques stemming from liberation theologies will be included. Compassion as a central virtue of end-of-life care will be addressed.

Drawing on what has been previously discussed, the last chapter will explore possible ways to address some of the problems described. Such a proposal will provide a more nuanced approach and insight into possible actions regarding community development of palliative care. Public Health Palliative Care and models stemming from it, such as Compassionate Cities and Communities, will be presented as possible applications.

1. Description of the Problem: On Death and Palliative Care Globally

Approaching the end of life has been a challenge since the origin of humanity. Each historical period and culture have tried, according to its circumstances, to respond using available resources. Today, the challenge endures. The present chapter will present some of the main factors that shape the experience of contemporary dying and focus on a twofold problem. First, I explore how people die while stressing that dying is closely linked to an institutionalized healthcare setting. Although there is an increasing awareness that death and dying as medical events have several undesirable consequences, they are frequently overlooked. Second, one of the ways of responding to that situation is through what has been called 'palliative care.' Within the contemporary institutionalized setting, palliative care has proven to have the capacity to provide resources for people to die well and for their families and communities to accompany the process. However, access to palliative care remains an issue in low and middle-income countries, and the effect of inequities can also be found in higher-income countries among the poorer population. This unjust situation neglects to care for what both human beings and healthcare need at one of the most important moments in people's lives. By problematizing contemporary death and dying, its different elements show up, and it is possible to explore multiple ethical dimensions that characterize palliative care.

1.1. The Way We Die

The development of medical science has enormously impacted the experience of dying. Considering mortality trends, "global life expectancy has risen steadily throughout the world, increasing from 67.2 years in 2000 to 73.5 years in 2019, with important gain made in low-and-middle-income countries (LMICs)."[2] According to the Lancet Commission on the Value of Death, this improvement is mainly due to changes in deaths from communicable diseases, maternal and neonatal conditions, and malnutrition.[3] However, an important question to be answered regards healthy life expectancy, which concerns years lived in self-reported good health. Statistics show that "years lived without good health have increased between 2000 and 2019–from 8.6 years to 10 years."[4]

When one explores death trends, an essential factor to consider is the disparities between countries based on income as well as among different populations within the same country. In its report, the Lancet Commission discussed how inequalities persist in seven selected countries despite the global increase in life expectancy. For example, in a low-income country like Malawi, life expectancy in 2019 was almost 14.6 years less than that of the United States and 17 years less than that of the United Kingdom.[5]

Regarding palliative care needs, the report shows how most people in high-income and middle-income countries die in hospitals or other healthcare institutions, while data are limited for low-income countries.[6] A closer look at trends in examining where people die also provides insights into the experience of death in specific countries. For example, excluding data regarding deaths due to external causes, in the United States, between 2003 and 2017, deaths in hospitals and nursing facilities decreased from 39.7% to 29.8% and 23.6% to 20.8%, respectively.[7] During the

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[2] Libby Sallnow et al., "Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life," *Lancet* 399, no. 10327 (February 2022): 842.
[3] Ibid.
[4] Ibid.
[5] Cfr. Table 1. Ibid., 843.
[6] Cfr. Ibid.
[7] See Sarah H. Cross and Haider J. Warraich, "Changes in the Place of Death in the United States," *New England Journal of Medicine* 381, no. 24 (December 12, 2019): 2369.

same period, the percentage of deaths at home or in hospice facilities increased from 23.8% to 30.7% and from 0.2% to 8.3%, respectively.[8] However, it is important to be cautious when interpreting these figures concerning people's preferred place of death as an indicator of quality end of life care. Research that examined the assumption that home is the preferred place of death has shown a more complex picture that prevents drawing hastened conclusions.[9]

The causes of death also differ, again validating the common assumption that deaths from communicable diseases and maternal, prenatal, and nutrition conditions occur in a higher percentage in LMICs than in high-income countries (HICs) (i.e., 60% in Malawi while 5% in the United States).[10] However, global trends show an epidemiological transition reflecting an increase in chronic and non-communicable diseases in LMICs. Based on data for 354 diseases and injuries and 3484 sequelae, the Worldwide Hospice Palliative Care Alliance (WHPCA) states that in 2017, out of 55,945,730 deaths from 195 reporting countries worldwide, 73.4% were due to non-communicable diseases in contrast to 14.6% due to communicable diseases.[11]

COVID-19

Reflections on death and dying cannot ignore the recent COVID-19 pandemic. Its prominence in media reports and the statistics of deaths have challenged individuals, communities, and countries. In HICs, death from COVID-19, especially during the peak of the pandemic, is associated with medicalized deaths, many in hospitals or intensive care units, in isolation,

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[8] Ibid.
[9] Cfr. Kristian Pollock, "Is Home Always the Best and Preferred Place of Death?," *BMJ* (October 7, 2015): h4855.
[10] See Sallnow et al., "Report of the Lancet Commission on the Value of Death," 843.
[11] See Worldwide Hospice Palliative Care Alliance, *Global Atlas of Palliative Care*, 2nd ed. (London: Worldwide Hospice Palliative Care Alliance, 2020), 19.

separated from family and community or accompanied only by healthcare workers. The distribution of deaths during this period also shows how disadvantaged populations have suffered more from the effects of the pandemic. In the United States, life expectancy fell by 1.87 years (to 76.87 years) between 2018 and 2020.[12] However, "the reductions have been very unequal, with life expectancy falling by 3.88 years among Hispanic people, 3.25 years among non-Hispanic Black people, and 1.36 years among non-Hispanic White people."[13]

The Lancet report states, "This situation has further fueled the fear of death, reinforcing the idea of health-care services as the custodian of death."[14] This is further reinforced by the effect of the rapid development of vaccines on considerations about control over death. On a global scale, the recent COVID-19 pandemic has made visible the seams and limitations of many institutions and policies, but maybe more of those related to healthcare. It has shown that "only by providing care as a whole can a communicable infection such as COVID-19 be controlled."[15]

Although a more exhaustive analysis would be desirable, the described realities lead to one of the commission's central claims: that there is an "unbalanced and contradictory picture of death and dying" in the 21st century, with people being overtreated in hospital settings. In contrast, others remain undertreated, "dying of preventable conditions and without access to basic pain relief."[16] The commission situates contemporary death and dying embedded in or directly depending on the healthcare context. It is through a healthcare lens that death and dying are increasingly

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[12] Sallnow et al., "Report of the Lancet Commission on the Value of Death," 842.
[13] Ibid.
[14] Ibid., 837.
[15] Rachel Fabi and Lilia Cervantes, "Undocumented Immigrants and COVID-19: A Call for Federally Funded Health Care," *JAMA Health Forum* 2, no. 9 (September 3, 2021): 2.
[16] Sallnow et al., "Report of the Lancet Commission on the Value of Death," 837.

understood and experienced, at least in the Global North. This lens points to death as being ultimately reduced to a medical event, although not restricted to a hospital setting, with many consequences that impact some of the foundational elements that characterize people's lives.

Relationality

One of the first consequences of this situation is that "as families and communities have been pushed to the margins, their familiarity and confidence in supporting death, dying, and grieving has been diminished. Relationships and networks are being replaced by professionals and protocols."[17] Understanding people as relational beings challenges a dominant focus on the individual and the person's disease. Families and relational networks are particularly significant regarding the end of life. Relationships have a crucial role in health outcomes, even if their importance goes beyond them.[18] The report highlights the 95% rule that states that "95% of the care of the dying is undertaken by lay communities despite the dominance of healthcare systems." Even in a hospital setting, it is estimated that 5% of nurses' time is spent in face-to-face interactions, while doctors spend about 13-15 minutes a day with an individual patient.[19] Hence, professional care networks should question their capacity to establish partnerships with communities and family networks.

Cultural and Belief Systems

Affected by this vision are also belief systems and cultural practices. When death is treated as a physiological issue, care regarding the person's spiritual dimension is usually relegated or

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[17] Ibid., 838.
[18] Ibid., 853.
[19] Ibid.

addressed in a way that does not grant sufficient space or resources to attend to the person's needs.[20] Spiritual care left to the last moments of a person's life, when death is almost imminent, forsakes the possibility of providing the person with the opportunity of attending to many aspects of their lives and relationships. Spirituality recognizes in those moments an occasion for personal and spiritual growth that could occur in many different ways.

At the same time, valuable cultural practices related to expressing and coping with suffering can be disregarded by focusing only on physical wellbeing. Cultural and spiritual practices, both during the life of the person affected by a life-limiting illness or for those in bereavement, can be very valuable for coping and improving healthcare outcomes.

Economy

Healthcare provided in the last year of life accounts for a large proportion of healthcare costs. The report draws on a 2007 study that "defined expense on medical care as catastrophic if it was more than 40% of an individual's 'capacity to pay' and used that definition to estimate that 150 million people annually were impoverished through catastrophic expenditure on health."[21] These costs further deepen the 'poverty trap' circle related to reduced household income, capability, and wellbeing, low levels of education and training, and late diagnosis of life-limiting diseases. This situation affects not only individuals but also entire health systems. The health expenditure average in HICs is estimated to be 9% of the gross domestic product (GDP), including

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[20] See Allan Kellehear, "The Social Nature of Dying and the Social Model of Health," in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear (Oxford: Oxford University Press, 2022), 22–29.

[21] Sallnow et al., "Report of the Lancet Commission on the Value of Death," 858–859.

government and private out-of-pocket expenditure. However, these figures cannot be taken as evidence of overtreatment.

1.2. Palliative Care

Even if the origins of palliative care date to the first human efforts dealing with suffering, its modern conception as a discipline is associated with Dame Cicely Saunders, considered the founder of the hospice movement. Her work and research with dying patients in St. Joseph's Hospice, which eventually led to the opening of St. Christopher's Hospice in 1967, and the concept of 'total pain' are seen as key moments for the development of the modern hospice movement and palliative care. Since then, increasing efforts have contributed to constructing and advocating this essential dimension of care. Palliative care is one of the four pillars of Universal Health Coverage (UHC), as seen in the WHO definition: "Universal health coverage means that all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course."[22]

The definition of palliative care, however, is a debated issue. In 2002 the WHO established a revised definition that was then modified in the WHO Palliative Care Resolution.[23] In 2018, the Lancet Commission report on Global Access to Palliative Care suggested that this definition be reviewed and revised, recommending "a definition that explicitly rejects any time or prognostic

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[22] World Health Organization, "Universal Health Coverage (UHC)," *World Health Organization. Universal Health Coverage*, accessed January 14, 2023, https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc).
[23] Worldwide Hospice Palliative Care Alliance, *Global Atlas of Palliative Care*, 13.

limitation on access to palliative care, includes complex chronic or acute, life-threatening, or life-limiting health conditions, and considers all levels of the health-care system from primary to specialized care and all settings where palliative care can be delivered."[24] In 2020, the International Association for Hospice and Palliative Care (IAHPC) published a consensus-based definition that included a globally diverse group of more than 450 palliative care workers of different fields of expertise.[25] This definition serves the purpose of delineating the borders of palliative care more clearly and is also valuable regarding practice and policymaking. The new definition also included additional recommendations to governments in order to achieve palliative care integration.

According to the IAHPC:

> Palliative care is the active holistic care of individuals across all ages with serious health-related suffering (suffering is health-related when it is associated with illness or injury of any kind. Health related suffering is serious when it cannot be relieved without professional intervention and when it compromises physical, social, spiritual and/or emotional functioning) due to severe illness (severe illness is any acute or chronic illness and/or health condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress), and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.
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> Palliative care:
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> - Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.
> - Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.

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[24] Felicia Marie Knaul et al., "Alleviating the Access Abyss in Palliative Care and Pain Relief—An Imperative of Universal Health Coverage: The Lancet Commission Report," *Lancet* 391, no. 10128 (April 2018): 1400.

[25] See Lukas Radbruch et al., "Redefining Palliative Care—A New Consensus-Based Definition," *Journal of Pain and Symptom Management* 60, no. 4 (October 2020): 760.

- Is applicable throughout the course of an illness, according to the patient's needs.
- Is provided in conjunction with disease modifying therapies whenever needed.
- May positively influence the course of illness.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
- Provides support to the family and the caregivers during the patient's illness, and in their own bereavement.
- Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).
- Can be provided by professionals with basic palliative care training.
- Requires specialist palliative care with a multiprofessional team for referral of complex cases.[26]

The efforts toward clarifying the meaning of palliative care reflect the difficulties of it being adequately understood not only by patients and their families but also by health providers and health systems as a whole. Misconceptions include the consideration of palliative care as a signal that the person is dying, that the doctor is giving up, that it is not possible to seek further curative treatment, that there is no hope, or that there is nothing more to do.[27]

Frequently palliative care is equated to hospice care, which fosters a reductionist approach to the former. Hospice care might have different connotations in different parts of the world where it is provided, but it is nevertheless end-of-life care that aims to give holistic support to the patient who is usually expected to live six months or less. It can happen at home, a hospice center, a hospital, or a skilled nursing facility. In hospice, "the goal of the care is to help people who are dying have peace, comfort, and dignity. The caregivers try to control pain and other symptoms so

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[26] Ibid., 761.
[27] See M. C. Sullivan, "Catholic Education on Palliative Care: Lessons Learned and Observations Made from the Field," in *Palliative Care and Catholic Health Care*, ed. Peter J. Cataldo and Dan O'Brien, vol. 130, Philosophy and Medicine (Cham: Springer International Publishing, 2019), 203, accessed February 2, 2023, http://link.springer.com/10.1007/978-3-030-05005-4_13.

a person can remain as alert and comfortable as possible. Hospice programs also provide services to support a patient's family."[28]

Taking this into account, it can be said that hospice care is palliative care, but not all palliative care is hospice care. Part of the misconception comes from failing to understand and differentiate the palliative care continuum. As seen, palliative care is not reduced to the last weeks or months of advanced life-limiting illness. This end-of-life care might involve the decision to engage with hospice care, and within that, how to best deal with active pain and symptom management, psychosocial and spiritual needs that might need to be further addressed, and support for bereavement and grief. Previous to that, however, palliative care also offers a broader approach that considers the assessment and management of the needs of the whole person at an early stage, fosters effective communication engaging in advance care planning and goals of care, includes family and community in the conversation, and works with all health providers involved in the person's treatment.

Acknowledging the relevance of the WHO definition, the IAHPC definition will be used in this thesis. As the study establishes, it is not a perfect definition and has the shortcoming that "the focus of the consensus process was on PC providers rather than patients," but it offers a broader approach than other definitions.[29] It will also be used for continuity, as some of the authors involved were also part of the Lancet Commissions mentioned, and their approach stems from

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[28] Medline Plus, "Hospice Care," Text, *Medline Plus. Hospice Care* (National Library of Medicine, n.d.), accessed January 18, 2023, https://medlineplus.gov/hospicecare.html.

[29] Radbruch et al., "Redefining Palliative Care—A New Consensus-Based Definition," 762.

previous work. The definition also is coherent with the perspective of Catholic social teaching, which will be considered later on.

However, it is important to note that there are other definitions of palliative care in use that recently have prompted authors to raise doubts and question its nature. The central claims argue that palliative care and hospice, as understood by certain persons and organizations, are actually euthanasia by another name or “stealth euthanasia.”[30] An example of this critique, although more specific to the United States context, is the suspicion that stemmed from the definition of palliative care offered by the National Hospice and Palliative Care Organization (NHPCO) that in its definition seemed to leave space for assisted suicide and euthanasia, and had connections with some organizations and physicians who promoted those practices. Terms like ‘quality of care’ and ‘choice’ included in the definitions are among those that trigger the alarms of the critics. However, it is not the purpose of this thesis to discuss in detail physician assisted suicide (PAS) or euthanasia and its possible connections with palliative care. Following the IAHPC definition, this thesis considers that palliative care “intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.”

1.3. Access and Need for Palliative Care

In 2018 the *Lancet* published a report entitled “Alleviating the Access Abyss in Palliative Care and Pain Relief–An Imperative of Universal Health Coverage.” The Lancet Commission’s mandate was to “measure global divides in access to palliative care and pain relief and to

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[30] Ron Hamel, “Palliative Care: Euthanasia by Another Name?,” in *Palliative Care and Catholic Health Care*, ed. Peter J. Cataldo and Dan O’Brien, vol. 130, Philosophy and Medicine (Cham: Springer International Publishing, 2019), 59–73, accessed November 9, 2021, http://link.springer.com/10.1007/978-3-030-05005-4_5.

develop systemic solutions that also promote UHC."[31] According to the report, "access to palliative care and pain relief is a health, equity, and human rights imperative that has been largely ignored in the goal to achieve UHC. Indeed, our Commission found no other important health intervention as lacking or inequitably distributed as pain relief, the pillar of palliative care."[32] The report built on the 2014 World Health Association (WHA) Resolution 67.19 on Palliative Care "which states the provision of palliative care is a moral imperative of health systems and it should be integrated into all levels of health care."[33]

Centered on the palliation of suffering, the report explored access to palliative care and pain relief. It acknowledged the need for responsiveness to any kind of suffering but covered mainly physical and psychological suffering. The commission constructed the concept of serious health-related suffering to quantify and measure the magnitude of suffering (SHS). As seen in the IAHPC definition of palliative care, SHS describes the "suffering that compromises physical, social or emotional functioning, cannot be relieved without medical intervention, and is typically greatly ameliorated by palliative care and pain relief."[34]

The global burden of SHS was measured by identifying 20 health conditions "that most commonly result either in death or in suffering that is severe enough to require palliative care intervention for people of any age."[35] These conditions had to be either a major cause of death,

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[31] Knaul et al., "Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage," 1403.
[32] Ibid., 1397.
[33] World Health Organization, "Implementing World Health Assembly Resolution on Palliative Care," *Implementing World Health Assembly Resolution on Palliative Care*, accessed January 20, 2023, https://www.who.int/news/item/12-10-2021-implementing-world-health-assembly-resolution-on-palliative-care.
[34] Knaul et al., "Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage," 1400–1401.
[35] Ibid., 1404.

which causes moderate or severe suffering, or a common cause of moderate or severe suffering associated with a high probability of mortality. The latter mainly focused on LMICs and included diseases such as hemorrhagic fevers, serious injury, or HIV. Estimates were calculated for decedents of the 20 conditions and for non-decedents ("people with SHS conditions who are likely to die of that health condition in the following few years, whose condition could be curable, who could recover although will not be cured, or whose health condition could be controlled for many years").[36] These criteria accounted for approximately 80% of deaths worldwide. The commission also developed two indicators of the duration of SHS related to the number of days of suffering.[37]

The key findings of the analysis discussing the global burden of SHS state that "more than 61 million people experienced SHS in 2015, including 25.5 million people who died, which is 45% of the 56.2 million reported deaths worldwide… [where] almost half of adults (23.1 million) and a third of children aged 15 years or younger (almost 2.5 million) who died in 2015 experienced SHS."[38] Out of the people living with SHS it is estimated that they accumulate "at least 6 billion physical and psychological symptom-days annually and up to 21 billion days summing each symptom; almost 80% of these days are accumulated in LMICs."[39] The analysis of the situation in LMICs shows that there were more than 20 million deaths associated with SHS, many of which are caused by treatable or preventable diseases, and that "more than 95% of all patients in need of palliative care and pain relief associated with HIV disease, premature birth or birth

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[36] Ibid.

[37] Cfr. Ibid., 1404–1405.

[38] Ibid., 1403.

[39] Ibid.

trauma, tuberculosis, and malnutrition live in LMICs."[40] Regarding children 15 years or younger who experience SHS, the estimate is that more than 98% of them live in LMICs and that they account for 12% of deaths associated with SHS in LMICs, and more than 30% in low-income countries.[41]

The results provided by the commission exceed previous estimates due to the inclusion of a greater number of health conditions and types of suffering and the inclusion of non-decedents. It is important to note that the data does not include SHS of family members and caregivers.[42]

Apart from the present need for palliative care, projections to 2060 of the global burden of SHS estimate that "48 million people (47% of all deaths globally) will die with serious health-related suffering, which represents an 87% increase from 26 million people in 2016. 83% of these deaths will occur in low-income and middle-income countries."[43] These data are related to palliative care because "SHS is a proxy for palliative care need."[44] This determination is especially relevant due to the impact this increase might have in the already fragile healthcare systems of LMIC countries. Hence, "these diseases will generate a substantial need for palliative care and will, with time, offset and indeed likely exceed any reduction in the number of poor patients needing palliative care associated with infectious diseases and poverty."[45]

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[40] Ibid.
[41] See ibid.
[42] Ibid., 1407.
[43] Katherine E. Sleeman et al., "The Escalating Global Burden of Serious Health-Related Suffering: Projections to 2060 by World Regions, Age Groups, and Health Conditions," *Lancet Global Health* 7, no. 7 (July 2019): 883.
[44] Worldwide Hospice Palliative Care Alliance, *Global Atlas of Palliative Care*, 18.
[45] Knaul et al., "Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage," 1412.

Even if the commission's work was focused on access to palliative care, the commission clearly stated that such an access "cannot be a substitute for improving access to the public health interventions and treatment that would prevent suffering and premature death in the first place."[46] According to the report, these issues are associated with more than half of SHS in decedents. Efforts in promoting, developing, and accessing palliative care should not be seen as competing with disease prevention, diagnosis, or treatment, especially regarding avoidable and premature deaths. The discussion, especially in LMICs, should not be framed in a mutually exclusive manner but in a broader perspective that could integrate how increased access to palliative care contributes to improved healthcare outcomes for people, especially vulnerable populations. As the commission states, "there is a range of potential benefits of extending access to palliative care and pain relief, and an extended cost-effectiveness analysis," which positively impact patients, families, and communities.[47]

1.4. Barriers to Access to Palliative Care

Accessing palliative can be a challenging endeavor. Some of the main barriers to access that are related to inequity are described in what follows.

Medicines and Medical Equipment

The Lancet Commission sought to elaborate and promote universal access to an affordable "essential package of palliative care and pain relief health services" that could help, at the lowest possible cost, alleviate part of the inequitable and preventable burden of SHS. The package

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[46] Ibid., 1411.
[47] Ibid., 1423.

included a series of medicines available in most countries, with the exception of morphine. Regarding this medicament, the report measured the accessibility of opioids for pain relief, focusing on the "quantity available for prescription to patients," referred to as 'distributed opioid morphine-equivalent' (DOME).[48] Findings reveal that "Canada, the USA, western and central Europe account for almost 95% of DOME and only 9% of the global population."[49] Furthermore, "the poorest 10% of countries and people of the world have access to only 10 mg morphine-equivalent per patient in need of palliative care… sufficient to meet less than 2% of estimated palliative care needs for the relief of severe pain and dyspnoea, and it meets an even smaller proportion of total medical need."[50] Differences between countries and the increasing difference between HICs and LMICs are said to be primarily explained by GDP and Human Development Index.[51] Figure 1 in the appendix shows a more detailed and graphic exposition of data. Acknowledging the pernicious effects of the opioid crisis in the United States, the commission nevertheless draws attention to how the prevention of non-medical use of opioids has hindered access to their use in palliative care.[52]

Policy and the Commodification of Health Care

Efforts in promoting access to palliative care are an essential part of the efforts in achieving UHC. This connection is reflected in target 3.8 of the Sustainable Development Goals (SDGs): to "achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and

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[48] Ibid., 1424.
[49] Ibid.
[50] Ibid., 1440.
[51] Ibid., 1424.
[52] Ibid., 1398.

vaccines for all."[53] However, for this goal to be achieved, changes at the level of policies must take place, and government support for policies that include palliative care and integrate it into the healthcare system is needed. Included in the WHPCA Global Atlas of Palliative Care, a study that reviewed the current global status of all palliative care policy development found only 55 countries with any national plan for palliative care.[54] Nevertheless, according to the 2021-2022 WHPCA Annual Report, there has been an increase in services delivering specialized care to hospice or palliative care patients from 16,000 in 2011 to 25,000 in 2017.[55]

The commodification of healthcare is another factor that poses a threat to achieving UHC, including palliative care. Although this finding will be discussed in the following chapters, it can be affirmed that "commodified medicine invariably begins with the notion that health is a desirable outcome to be attained through the purchase of the right goods and services."[56] This approach to healthcare impacts policies that ultimately negatively affect the health outcomes of entire populations, especially the more disadvantaged. For example, in the United States, documentation requirements to get healthcare services and legal barriers that bar access to insurance have a pervasive impact on healthcare outcomes for the undocumented migrant population.[57]

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[53] United Nations Department of Economic and Social Affairs, "Goal 3: Department of Economic and Social Affairs," *Goal 3: Ensure Healthy Lives and Promote Well-Being for All at All Ages*, accessed January 26, 2023, https://sdgs.un.org/goals/goal3.

[54] See Worldwide Hospice Palliative Care Alliance, *Global Atlas of Palliative Care*, 33.

[55] Worldwide Hospice Palliative Care Alliance, "WHPCA Annual Report 2022," *Worldwide Hospice Palliative Care Alliance*, 4, last modified January 13, 2023, accessed January 30, 2023, https://www.thewhpca.org/resources/whpca-publications-and-reports/item/whpca-annual-report-2022.

[56] Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, California series in public anthropology 4 (Berkeley, CA: University of California Press, 2010), 152.

[57] See Nathan A. Gray et al., "Hospice Access and Scope of Services for Undocumented Immigrants: A Clinician Survey," *Journal of Palliative Medicine* 24, no. 8 (August 1, 2021): 1172.

Formation and Availability of Human Resources

According to the WHPCA, palliative care training is needed at three levels. The first is “basic palliative care training for all health professionals and paraprofessionals including physicians, nurses, mental health professionals, clergy, volunteers and therapists.”[58] The second concerns “intermediate training for those routinely working with patients with life-threatening illnesses.”[59] The third level focuses on “specialist palliative care training for patients with more complex symptom management needs and for those who will teach palliative care and do research.”[60]

However, formation in palliative care is a debated issue as there is no consensus about the amount of instruction needed and, in some parts of the world, part of that training would be considered to be futile as it cannot be put to practice due to the existing conditions of healthcare systems, resources, and policies. Another issue is the influence of the Euro-American perspective on end-of-life healthcare and the under-representation of LMICs in the research literature, seen by some authors as another form of colonization.[61]

The need for human resources is also included in the essential package proposed by the commission, along with the awareness that attempting to respond to the need for palliative care globally “would require a major increase in the professional and para-professional workforce trained in at least basic or primary palliative care.”[62] The WHPCA estimates that there are

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[58] Worldwide Hospice Palliative Care Alliance, *Global Atlas of Palliative Care*, 33–34.
[59] Ibid.
[60] Ibid.
[61] See Sallnow et al., “Report of the Lancet Commission on the Value of Death,” 850.
[62] Worldwide Hospice Palliative Care Alliance, *Global Atlas of Palliative Care*, 37.

400,000 healthcare workers engaged in delivering palliative care, but that at least 2 million healthcare workers would be needed.[63]

Psychological, Social, Cultural, and Financial Barriers

Although some of these elements have been mentioned previously, it is important to acknowledge the particularities and diversity of human responses to disease and end-of-life. Influenced by many of the previous barriers, misconceptions about palliative care, along with fear, prevent many from accessing or inquiring about it. Psychological elements associated with negative personal experiences related to healthcare, social assumptions about death and palliative care, lack of culturally informed practices, and the burden of healthcare costs are among the most prevalent barriers at an individual or family level.

1.5. The Imbalance at the End of Life

As it has been discussed, death and dying are increasingly viewed through a healthcare lens. This perspective has fostered significant benefits for populations with SHS but has also prompted a series of undesirable consequences as people approach death regarding core elements of humanity, such as relationality, belief systems, practices, and economic resources. COVID-19 has fueled a further fear of death and has not led to the health reckoning anticipated by many. Considering death as something to be defeated, rather than considering dying as an important process in the lives of individuals and in the whole society, ultimately neglects an essential dimension of personal and social life. How people and society approach the process of dying directly impacts how people live and relate to each other within the social context. Families and

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[63] Ibid.

communities struggle to find their place in accompanying their loved ones, while cultural elements related to dealing with death, dying, mourning, and grief are overlooked or progressively lost. Healthcare services frequently lack adequate training to address relational, spiritual, and contextual aspects of the dying process. In addition, healthcare expenditures at the end of life can have catastrophic consequences for individuals, families, and healthcare systems and impact the allocation of limited resources in healthcare systems.

Palliative care has the capacity to respond to the described situation and contemporary SHS experienced by an important part of the population. However, only 14% of 56.8 million people who need palliative care actually receive it.[64] This situation is especially dire in LMICs, and among certain populations within countries, due to the limited access to basic palliative care and medicine-based pain relief.[65] Furthermore, the need for palliative care is projected to augment as the population of persons aged 60 or older increases. Barriers to access should be eliminated to adequately provide palliative care that counters what characterizes death and dying today. These challenges will be explored in the following chapters.

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[64] Ibid., 54.

[65] See Knaul et al., "Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage," 1398.

2. The *Ars Moriendi* Tradition and Community Development of Palliative Care

There are multiple ways to approach contemporary death and dying and the problems that have been mentioned. However, part of the challenge relies on being able to frame and identify possible pathways to respond to their complex nature and the interaction between the different elements they are made up of. In order to capture and explore the present complexities, we will introduce and define ‘death systems,’ which will be used as an appropriate framework that facilitates analysis due to its attention to the relationships among the multiple facets. Under this approach and for the purpose of this thesis, two resources, one stemming from the Christian tradition and another one from the development of palliative care will be discussed in this chapter. In different ways, they can provide insight into the value and importance of death, its connection to life, and how access to palliative care could be rethought.

First, the *ars moriendi* tradition will be briefly explored. The medieval practices that fall under this category paid attention to the process of dying and death as something essential to the life of people. The *ars moriendi* will be described in connection to Jesuit end-of-life works in the sixteenth century, specifically through the works of three Spanish Jesuits, namely Gaspar de Loarte, Juan Alfonso de Polanco, and Francisco de Borja. The reasons for focusing on their texts involve exploring concrete examples of the *ars moriendi* tradition and how they responded to the issue of dying well and influenced practices and later texts on the same topic. The texts stem from a Jesuit and Spanish perspective. By exploring the *ars moriendi*, certain significant themes emerge that contribute to reflecting on the value of death and its relation to dying well and virtue. The tradition understood that this moment of a person’s life could foster the development of certain virtues that could help in the process of dying. This connection to virtue underscores their relevance for the moral life and well-being of people facing life-threatening illnesses, their families, and their communities.

In a very different time period, when the historical development of healthcare has led to the current institutionalized setting that frames death and dying, it is still possible to question the virtuous components of certain models of care at the end of life. As seen in the previous chapter, palliative care is one of the main responses to death and dying within the actual institutional framework. However, the development of palliative care has provided diverse approaches. The second resource that will be presented in this chapter is a model of palliative care that integrates a public health perspective and focuses on community development. This model situates the person diagnosed with a life-limiting illness within their own context and draws on available resources for end-of-life care. It challenges present understandings of palliative care by focusing on community development in a way that integrates the social determinants of health and death. Access to palliative care and equity can be reimagined and thought of not only through the provision of certain healthcare services but as something pertaining to the whole society and the communities where people live and are cared for.

2.1. Death Systems

As seen, death and dying are a complex issue. Attempts to respond to some of the problems behind them require detailed consideration of the complexities in a not reductionist manner. The Lancet report on the Value of Death captures this insight by framing their study under the perspective of what has been called ‘death systems.’ As the report states, “death systems are the means by which death and dying are understood, regulated, and managed. These systems implicitly or explicitly determine where people die, how people are dying and their families should behave, how bodies are disposed of, how people mourn, and what death means for that culture or community."[66] They capture both the uniqueness of a specific society and culture and, at the same time, point toward the shared grounds and elements across different death systems. It is an example of one of the adaptive systems present in societies, and its exploration avoids simplistic linear causation explanations for complex problems.[67] This approach fosters attention to the relationship between the different elements that interact within the system, such as personal, social, political, economic, or religious drivers, and also with other systems. Analyzing those interactions can show emerging patterns in the form of loops. For example, "the increased number of deaths in hospital means that ever fewer people have witnessed or managed a death at home. This lack of experience and confidence causes a positive feedback loop that reinforces a dependency on institutional care of the dying."[68] A dynamic map for such a system, established around the events of impending and actual death, can be seen in Figure 2 in the Appendix as an example.

Death systems offer a more nuanced perspective that is able to capture the complex nature of death and dying. It is chosen here because addressing the problem of the meaning of death and access to palliative care requires attention to an important number of factors–such as social determinants of health and death–that a more limited or unilateral approach risks overseeing. Moreover, by exploring and analyzing the relationships between the different elements in a death system, new possible ways that promote positive changes might emerge, ultimately affecting the whole system. Dying is not only a medical event, and access to palliative care is more than just

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[66] Sallnow et al., "Report of the Lancet Commission on the Value of Death," 846.
[67] See ibid., 847.
[68] Ibid.

the provision of certain services at the end of life. In the following section, the *ars moriendi* tradition will be explored in its contribution to safeguarding and promoting essential elements of the dying process and its connection to meaning and life.

2.2. The *Ars Moriendi* Tradition

The way of dealing with death and dying in sixteenth-century Europe was greatly influenced by the *ars moriendi* or the 'art of dying.' This approach implied a particular understanding of what dying well meant. In the medieval period, books and treatises were written on the topic, eventually developing into a unique genre. These approaches were available to Christians seeking to live a good life and die a good death. Today, in a very different theological and pastoral context, a theology of fear and the threat of eternal damnation seem distant. Exploring the long and important *ars moriendi* tradition can provide insight into some possible paths available to respond to contemporary death and dying for believers and non-believers alike.

The Medieval Ars Moriendi

The Black Death and its pandemic presence throughout fifteenth-century Europe shaped societies in many ways. As Allen Verhey states, "in general, the church and medicine cooperated in their efforts to meet the challenge."[69] However, the slight effectiveness of responses increased the uncertainty of a period already marked by conflicts within the Church.[70] At this time, "the fear of physical death was exacerbated by the fear of spiritual death."[71] In this context, the works

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[69] Allen Verhey, *The Christian Art of Dying: Learning from Jesus* (Grand Rapids, MI: William B. Eerdmans, 2011), 82.

[70] See ibid., 83.

[71] Charles Bouchard, "Meeting Mortality: Palliative Care and the Ars Moriendi," in *Palliative Care and Catholic Health Care*, ed. Peter J. Cataldo and Dan O'Brien, vol. 130, Philosophy and Medicine (Cham: Springer

of Jean Charlier de Gerson (1363-1429), the precursor of the *ars moriendi* genre, can be situated. His renewed pastoral perspective pointing toward a reform of the Church underlies his handbook called *Opusculum Tripertium*, which sought to instruct both clergy and laity. Structured in three parts, the last section, *Scientia Mortis,* referred to the ministry to the dying.[72] The pastoral crisis of the time was addressed in the Council of Constance (1415), where de Gerson played an important role.[73] The Council commissioned a handbook on "the art of dying well."[74] This led to the development of treatises called *Speculum/Tractatus Artis Bene Moriendi*.[75]

Influenced by de Gerson, the general structure of the books followed a five-part schema that included: commendation of death; temptations confronted by the dying; instruction on repentance and assurance of God's forgiveness; imitation of the dying Christ and prayers for use by the dying; and prayers to be said by those ministering to the dying person.[76] What was called *Ars Moriendi* was a shorter version that focused on the temptations, accompanied by a series of illustrations that depicted them, the victory over them, and the moment of death itself.[77] It can be said, as Verhey writes, that the *ars moriendi* "names both a particular work from the fifteenth century and the genre of literature to which it belongs… (both) decidedly nonelitist."[78] The ancient practice of *memento mori*, or the remembrance of death, was also included in this genre.

International Publishing, 2019), 46, accessed November 7, 2021, http://link.springer.com/10.1007/978-3-030-05005-4_4.

[72] See Verhey, *The Christian Art of Dying*, 86.

[73] Ibid., 85.

[74] Bouchard, "Meeting Mortality," 47.

[75] See Verhey, *The Christian Art of Dying*, 86.

[76] See Bouchard, "Meeting Mortality," 48–50.

[77] See Verhey, *The Christian Art of Dying*, 87.

[78] Ibid., 79.

Eventually, the *ars moriendi* developed into an *ars vivendi*, highlighting two main points: that life and death are intimately connected and that learning to die is learning to live.

Jesuits and the End-of-Life

In the book "*Los Jesuitas en España y en el Mundo Hispánico*," Javier Burrieza describes how the increased credibility and reputation of the early Jesuits led them to be required by many sick and dying.[79] To some extent, this is not surprising. Not only was it a pastoral need at the time, but serving "those in hospitals" was also included in the "Formula of the Institute" of the Society of Jesus and was developed in the Constitutions of the order. Jesuits in formation spent, and still do, part of their first years serving in hospitals.

Jesuit attention to the sick and dying also stems from the own experience of Ignatius of Loyola and the way the first companions were missioned. Illness was present throughout the life of Ignatius in many different ways. The history of the first Jesuits is also marked by their experiences serving and living in the hospitals of the time. Their response to the pastoral needs was accompanied by some of the works that would become influential in the *ars moriendi* literature, as seen when consulting the number of editions and translations of their works. In doing so, the Jesuits drew on their own experience and spirituality and used and adapted a rich tradition already present in the Church. In these works, fundamental, pastoral, moral, and spiritual theology developments converge.

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[79] See Teófanes Egido López, Javier Burrieza Sánchez, and Manuel Revuelta González, eds., *Los Jesuitas en España y en el Mundo Hispánico*, Marcial Pons Historia (Madrid: Marcial Pons: Fundación Carolina, Centro de Estudios Hispánicos e Iberoamericanos, 2004), 146.

The works that will be described as examples belong to the earlier period, but there are other influential works of this genre by Jesuits such as Robert Bellarmine, Esteban de Palma, Juan Eusebio Niremberg, Luis de la Puente, Juan Bautista Poza or Alonso de Andrade among others.[80] Although the three texts that will be discussed were not written in Spain, and some were not even in Spanish, the three authors lived a significant part of their lives in that country. If there is something like a Spanish perspective of dealing with death, it can be argued that they were also familiar with and influenced partly by it. In this sense, the Spanish perspective is relevant to the connection between life and death because, as Carlos M. N. Eire writes, "Inasmuch as they interwove life with death and actions with paradigms, sixteenth-century Spaniards found it difficult, on the whole, to segregate their attitudes toward death from their attitudes toward life in general… The prevailing Spanish approach to death was above all practical, for dying was not a passive experience."[81]

Gaspar de Loarte, SJ (1498-1578)

Born around 1498 in Medina del Campo, Spain, Gaspar de Loarte joined the Society of Jesus in 1552. He was ordained a priest in 1526 and had been for many years close to Juan de Ávila, an influential figure in sixteenth-century Spain with whom he had taught catechism and preached primarily focusing on children and the poor.[82] After joining the Jesuits, Loarte did his spiritual formation in Rome under the guidance of Luís Gonçalves da Câmara, SJ. According to Charles

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[80] See Juan-Alphonso de Polanco, "El Directorio de ayudar a bien morir (1575)," in *Los directorios de J.A. de Polanco, SJ*, ed. José García de Castro and Francisco Javier De la Torre, trans. Carlos Baciero González, Colección Manresa 59 (Bilbao: Mensajero, 2016), 252.

[81] Carlos M. N. Eire, *From Madrid to Purgatory: The Art and Craft of Dying in Sixteenth-Century Spain*, Cambridge studies in early modern history (Cambridge, U.K.; New York: Cambridge University Press, 1995), 526.

[82] See Gaspar de Loarte, *The Exercise of the Christian Life*, ed. Charles R. Keenan (Chestnut Hill, MA: Institute of Jesuit Sources Boston College, 2016), 1.

R. Keenan, “Ignatius recognized Loarte’s many talents and planned to put them to use.”[83] His first mission was in Genoa as rector of the Jesuit college from 1555 to 1562. It is important to note that during this period, apart from his challenging work as rector, Loarte “remained active in pastoral activities in Genoa as he had in Spain.”[84] He soon received permission to preach in public, and his interest remained focused on teaching Christian doctrine.

During this period, Loarte started writing the “*Esercitio della vita Cristiana*” (“The exercise of a Christian Life”), first published in 1557. It seems that it is not the first time that he had written something of this kind, and he does so “seeing the need of many people who come to us every day with a desire to serve our Lord, who, I believe, can be somewhat helped by the advice I have compiled in that book.”[85] As Charles R. Keenan notes, to better understand this work, it is helpful to point out that the ‘little treatise’ is part of his broader pastoral ministry and was not commissioned; instead, he wrote it on his own initiative.[86] This points to Loarte’s genuine desire and vocation to help people live a good Christian life. Written in Italian, it has ‘common people’ in mind, providing guidance for Christian life, including those on their deathbeds. His work is significantly influenced by Juan de Avila, as mentioned before, and also by Luis de Granada.

It can be said that although Loarte’s work does not focus on virtues explicitly, his text is shaped in the manner of an ‘exercise,’ a “catalyst for inner transformation” where meditation aims to provide “clarity of perception and the acquisition of proper habits.”[87] This format, adaptable to the reader’s needs, resonates to some extent with the Spiritual Exercises, Loarte’s mentor’s

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[83] Ibid., 3.
[84] Ibid.
[85] Ibid., 4.
[86] See ibid.
[87] Ibid., 9.

"*Breve Regla de Vida Cristiana*," published in 1556, and Luis de Granada's "*Guía de Pecadores*" of the same year.[88] It is known that Loarte had read some of Granada's work.

After a general preface that covers the first six chapters, the content of the *Esercitio* can be structured into three main groups. The third group, chapters 16 to 27, constitutes almost half of the text and refers to the vices and temptations that will be encountered by those seeking to live a devout Christian life.[89] Chapters 26 and 27 will be briefly described for their relevance to the topic.

The title of chapter 26 is "The Things a Christian Should Do if They Fall Ill or When They are at the Point of Death." Almost in the first lines, the reader encountered the following warning: "You should not read this advice with less desire than the preceding ones, nor should you execute it with less diligence at the appropriate time. This advice will be primarily useful for those who, when healthy, have been practicing the things that have been described above in this book, preparing themselves continually for death, as the good and faithful Christian should do."[90]

The chapter includes two sets of advice, depending on whether the person is sick but may recover or if the person is sick but will not likely recover. For Loarte, the spiritual is as important or even more than the physical, prioritizing who should be called first if falling ill.[91] This emphasis guides most of his advice when writing about acceptance, humility, faith, trust, gratefulness in case of recovery, and change of life if cured.[92] If the person's illness is terminal,

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[88] Ibid., 10.
[89] See ibid., 7.
[90] Ibid., 105.
[91] See ibid.
[92] See ibid., 105–106.

he addresses the person highlighting the importance of looking "more carefully to order your things, both temporal and spiritual," advising to be accompanied by those who can help "with earnest and fervent prayers" and requesting the sacraments.[93] It is after these considerations that he moves to consider the "Temptations that Are Commonly Experienced during the Hour of Death and the Remedies against Them."

Loarte begins chapter 27 of his 'little treatise' writing on death similarly to Granada's *Guía de Pecadores* and even uses some of the same examples found in it. Granada uses the meditation of death to exhort a virtuous life. The title of the chapter condenses its purpose: "Of the Seventh Motive that Obliges us to the Pursuit of Virtue, which is Death, the First of the Four Last Things."[94] In his approach, the consideration of death propels the reader to live a virtuous life. It is a *memento mori*, framed in the theological context of that time where fear of various things is used as an essential element. However, in his text, Loarte also includes a different approach drawing on the main elements of the *ars moriendi*. He comments on the following temptations:

i. Doubt

Pointing to the core of the process, Loarte writes that "the first and principal temptation with which demons often assail the person who is about to die is of faith, which is the foundation of all spiritual edification, so that by removing the foundation, the whole building easily falls to

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[93] Ibid., 107–108.

[94] Luis de Granada, *Guía de Pecadores*, ed. José María Balcells, Clásicos universales Planeta., Autores hispánicos 119 (Barcelona: Planeta, 1986), 62.

ruin."[95] The remedy he proposes is not to respond to those questions but rather confess one's faith every time.

ii. Blasphemy

He depicts how the demons insist on "persuading those who are about to die that they feel or think something indecent and unworthy about blessed God or his saints."[96] The remedy here is similar to the previous one, placing oneself opposite to the temptation and insisting on blessing God.

iii. Desperation

Those facing death will feel the weight of their sins at that hour, "especially if they have been great sinners," and the demons will persuade them that their contrition is worthless and that the time has run out, generating desperation.[97] According to Loarte, this is a significantly challenging temptation if not assisted by God. The remedy he offers is to humble oneself in repentance and invoke divine mercy.

iv. Complacency

Considering the opposite perspective, the demons may tempt the person in such a way that they make the person turn "toward a dangerous security and complacent blindness in themselves, flattering them that they have fought bravely and that they are well prepared for death."[98] As the

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[95] de Loarte, *The Exercise of the Christian Life*, 110.
[96] Ibid., 111.
[97] Ibid.
[98] Ibid., 112.

text reads, this is especially relevant for “members of religious orders, spiritual persons and those who have carried themselves in a praiseworthy manner.”[99] The remedy is to find a balance between hope and fear, adapting one’s spiritual state according to the different movements.

v. Impatience

Continued pain and suffering can foster impatience. Here Loarte uses as remedy a redemptive account of suffering where God is made responsible for sending affliction “out of the greatest love for the good of your soul.”[100]

Loarte finishes this chapter by proposing three practices: the sprinkling of holy water, embracing the crucifix, and calling upon the name of Jesus–a typical image associated with Christian dying in the sixteenth century. Although many of the elements in his text can be related to the *ars moriendi* as previously described, certain aspects vary. For example, he changes the order and does not include the ‘clinging to earthy things’ in his account of the temptations, but rather in the previous chapter. Nevertheless, the influences of other authors and the tradition can be seen, as well as some of the elements more specific to his approach, such as the adaptability of the text according to the needs of the person who seeks the advice.

Juan Alfonso de Polanco, SJ (1517-1576)

Born in 1517 in Burgos, Spain, this Jesuit is best known for being one of the crucial figures of the early and rapidly growing Society of Jesus. Called to Rome by Ignatius of Loyola in 1547, due to the need for a Secretary General that could offer more professionalized help in the

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[99] Ibid.
[100] Ibid.

organization and increasing bureaucracy of the order, Polanco excelled in his mission. José García de Castro portrays him as having an exceptional talent for management and administration and his care for words, reflected in his many letters and spiritual writings.[101]

Polanco's works can be divided into historical, legal, and spiritual. The latter is where his "*Methodus ad eos adiuvandos, qui moriuntur*" ("Directory to assist those in the process of dying"), which will be briefly described here, can be located. This 'Directory,' first published in 1575, is a sort of handbook for those engaged in a particular ministry. It shares its popularity with two works: the *Directory for Confessors* and the *Directory for Spiritual Exercises*.[102]

Polanco's theology and eschatology make him highlight death as a crucial moment urging careful attention and help to those dying. However, his text is also motivated by the need experienced by many Jesuits being requested to accompany people on their deathbeds. The Jesuits' attention included "popes as well as prostitutes, scholars and children, nobles and the poor."[103] As mentioned, the *Constitutions of the Society of Jesus* also included attention to the dying. Polanco's work responds to one of the declarations found in them: "It is good to have a compendium on the method of helping a person to die well, to refresh the memory when this holy ministry must be exercised."[104] Expressed in Polanco's words at the beginning of the *Methodus*:

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[101] See José García de Castro Valdés, "'Que partan de esta vida en gracia y amor de Dios': el Directorio para ayudar a bien morir (1574) del P. Juan Alfonso de Polanco," in *Discursos después de la muerte: III Seminario "Textos para un milenio" (Madrid, 28-30 de noviembre de 2012)*, ed. Henar Pizarro Llorente and María Jesús Fernández Cordero (Madrid: Ediciones Carmelitanas, 2013), 15–16.
[102] See ibid., 16.
[103] Ibid., 22.
[104] Society of Jesus, ed., *The Constitutions of the Society of Jesus and Their Complementary Norms: A Complete English Translation of the Official Latin Texts*, Series I–Jesuit primary sources, in English translations no. 15 (Saint Louis, MO: Institute of Jesuit Sources, 1996), 173.

> To the pious reader: among all the works that our Society usually performs (in accordance with the raison d'être of its institute) for the glory of God and the edification of the Church, that of helping people who emigrate from this life is judged to be of the utmost importance. For this reason, it is very desirable that the diligence and charity of our priests shine forth in the proper performance of this ministry, in preference to the others.[105]

An in-depth assessment of his text is beyond the scope of this thesis, but some key features will be highlighted. According to García de Castro, the twenty chapters of the *Directory* are built keeping in mind two main guiding principles: "accommodation to the particular situation and the desire to transmit consolation in every circumstance, always acting *prudenter et amanter*."[106]

The first of these two principles can be seen in how the text is articulated and in its dialogical and pragmatic nature. The text is organized according to its protagonists: Those who help the dying person (chapter 1), the dying person (chapters 2–19), and those near the dying person, such as family and friends (chapter 20). In an effort to include a broad typology of situations that could be encountered, the *Methodus* includes a series of 'dialogues.' This dialogical aspect has the form of a polyphony of voices that stand in solidarity with one another and aim to move the dying person's emotions and devotion.[107] The following classification provides a clarification:[108]

- Dialogue "a": Polanco with the one assisting, guiding him in his own behavior.
- Dialogue "b": Polanco with the one assisting guiding him when helping the dying persons in their attitudes.
- Dialogue "c": The dying person with God in the form of prayer.
- Dialogue "d": The one assisting with the dying person fostering affection.
- Dialogue "e": Dialogue of biblical characters with God.

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[105] Polanco, "El Directorio de ayudar a bien morir (1575)," 274.
[106] García de Castro Valdés, "'Que partan de esta vida en gracia y amor de Dios': el Directorio para ayudar a bien morir (1574) del P. Juan Alfonso de Polanco," 27.
[107] See ibid., 31–32.
[108] Ibid.

These different ‘dialogues’ served as examples and as sources of edification for people at the end of life and those assisting them. The different ‘voices’ in the text provide a broader perspective and understanding that could accommodate the particular situation.

The second guiding principle expresses his insistence on consoling throughout the text. It relies on the previous principle when he advises those ministering to the dying to adapt to the person, getting to know them in their particular needs. As he writes, “try to comfort him and win his benevolence, treating him with affection and prudence.”[109] In the sixth and longest chapter of his *Directory*, Polanco develops the prominent expression of this ministry: “how to raise and exercise hope.”[110] This is the chapter that he would request to be read to him on his deathbed.

Francisco de Borja, SJ (1510-1572)

The paradigmatic image of memento mori in the Jesuit tradition is possibly Francisco de Borja, mostly portrayed in artistic representations holding or near a crowned skull. Witnessing death in the form of the decomposition of the body of a once-powerful and beautiful woman apparently had the power to change the Duke of Gandía’s life drastically. Even if the famous story about the impact Isabella of Portugal’s corpse made on him were not entirely true, it conveyed and crystalized a shared account: learning to die meant learning to live adequately.[111]

Published posthumously, in the small spiritual treatise “*Algunos remedios para que los siervos de Dios no teman a la muerte*” (“Some Remedies for the Servants of God not to Fear Death”),

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[109] Polanco, “El Directorio de ayudar a bien morir (1575),” 256.
[110] Ibid., 303.
[111] See Javier Burrieza Sánchez, “Los Jesuitas: De las Postrimerías a la Muerte Ejemplar,” *Hispania Sacra* 61, no. 124 (December 30, 2009): 518.

Francisco de Borja recommends the following five things:[112] the frequent remembrance of death; to remember often the death of Jesus Christ; to think that death is the end of all works, sorrows, and sins; to keep in mind that death will not cease to come because we do not think of it; and, while still healthy, to make the testament and to order and dispose of all one's things.

The saint shares with Polanco that a less fearful approach to death is more helpful. One of the ways to do this is the frequent remembrance of death, which will also bring other benefits. As he writes, "and if we add to this many other benefits that the continuous memory of death has on our souls, there is no doubt that we would wear it like a ring on our finger never to forget it, and so I consider this remedy very effective and important."[113]

As it has been briefly developed, the Jesuits, from their early years, not only responded to the needs of those about to die by attending to them directly at their deathbeds in different settings. They also considered that part of their ministry was providing guidance and instruction to those who were sick and dying and those assisting the dying. In this way, their works formed part of and shaped the *ars moriendi* literature. Their ministry drew and was influenced by the existing literature and incorporated such spirituality and pastoral perspectives.

It can be said that the different works mentioned share the view that life and death are intimately connected and that preparing for death also positively impacts the lives of both the individuals and those surrounding them. Although done in different ways, the development of virtues is encouraged. By analyzing the most frequent temptations at the hour of death, Loarte's remedies encourage the virtue of faith, patience, and hope, among others. Polanco's approach, while

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[112] Francisco de Borja, *Tratados Espirituales*, ed. Cándido de Dalmases (Barcelona: Juan Flors, 1964), 462.
[113] Ibid., 463.

identifying those virtues, also insists on prudence for those assisting the dying. *Memento mori* also holds a special place in their works. Although not always explicitly mentioned, in this literature the understanding of this practice is linked to the virtues, which will be discussed in the following chapter.

The *ars moriendi* tradition is born in a particular context, within a theological tradition, and as a response to a need. Even if those elements have changed, this approach still provides helpful questions to consider when addressing contemporary death and dying. As Christopher P. Vogt writes, "understanding the teaching of the religious writers of centuries past on death and dying can enrich contemporary theological thought and religious practice."[114] It can also enrich medical thought and practice and provide insights into the provision of palliative care.

The *ars moriendi* was not intended to be used only by priests or religious called to a deathbed, but rather it served as a resource for everyone during their lives in order to be prepared for their death. The person, the family, and the community were expected to a certain extent to know what to do when situations regarding a life-threatening illness arose. Another important feature of this tradition is its processual nature. Dying well was considered a process where people could grow humanly and spiritually and pay attention to crucial things in their lives. Death proved to be something valuable, even if not desired. The relevance given to this spiritual dimension emphasizes a balance that is threatened nowadays. Attention to the spiritual dimension broadens the assessment of a person's needs facing a life-limiting illness and acknowledges overlooked factors at play at this stage of life, such as key relationships, meaning-making, or faith-based

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[114] Christopher P. Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well* (Lanham, MD: Rowman & Littlefield, 2004), 16.

decisions. Lastly, it prompts the question about the connection between life and death and the development of virtues, challenging contemporary practices that seem to confine death to the last moments of a person's life and are seen from a predominantly medical perspective. This question highlights the necessary efforts to recover death as part of the natural continuum of life in its multi-faceted complexity and the need to explore how present-day structures where death and dying take place, foster or constrain virtuous approaches.

2.3. The 'Art of Dying' and Palliative Care

Palliative care can be included as one of those structures and efforts to bridge the disconnection between everyday life and the reality of serious illness and death. Even if the approach is broader due to its place in the healthcare system and does primarily focus on the spiritual dimension, as in the *ars moriendi* tradition, within palliative care, it is possible to explore the way certain viewpoints and practices negatively or positively contribute and shape people facing a life-limiting or life-threatening illness, their families, and communities.

However, no single palliative care approach can provide a universal solution. By exploring one of the recent developments of palliative care that stresses the importance of community, it is possible to reimagine new pathways for care at the end of life and what equitable access could look like. Here, a specific model of palliative care that includes a public health perspective is presented as a second valuable resource to assess the problems discussed and offer access to care at the end of life.

Community Development of Palliative Care

As palliative care has evolved, different theoretical models have been proposed. The spectrum goes from a ‘traditional’ model where palliative care was offered once curative treatments were ineffective to an integrated model where palliative care is offered at an early stage, changing gradually as curative treatment decreases, including attention to bereavement. Among those models that stand out, time-based, provider-based, issue-based, or community-based models can be found. The different palliative care models highlight a particular perspective and determine the care approach at the end of life. It is beyond the scope of this thesis to describe and evaluate each model. A community-based model will be explored here due to its attention to the persons with life-limiting illnesses within their own context. This model seeks to identify and develop the resources available for persons in their own settings without being exclusively limited to specialist healthcare, thus reframing the problems concerning access to palliative care.

Julian Abel and Allan Kellehear affirm that while evidence-based research and development in palliative care as well as supportive care in its broadest sense continue to be crucial in providing care, long-term problems remain.[115] Some of the problems mentioned, such as death rate tendencies, delayed diagnosis of life-limiting illnesses, availability of professional care, and the main focus of specialist palliative care on cancer patients, have already been described in the previous chapter. The authors’ proposal argues for the adoption of principles of public health to end-of-life care, drawing on professionals and communities working together. This approach has been called Public Health Palliative Care (PHPC). They affirm that it can contribute to solving

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[115] See Julian Abel and Allan Kellehear, “Palliative Care Reimagined: A Needed Shift,” *BMJ Supportive & Palliative Care* 6, no. 1 (March 2016): 21.

not only the burden of financial demands but also increasing the quality and continuity of care.[116] Especially relevant for LMICs, from their point of view, as the need for end-of-life care increases, “poorer nations with limited access to healthcare services have little choice other than making death a community matter.”[117]

Public Health Palliative Care

Brace Rumbold portrays PHPC not only as an academic or practice discipline but as a “social movement within the wider palliative care field itself… interested in reforming not only specific systems of end-of-life care but also the societies that support them.”[118] Key to the development of this movement was the 1986 WHO release of the Ottawa Charter for Health Promotion, which allowed new ideas of public health to be developed. Social environments could be seen not only as targets for external intervention but as essential components where health promotion and safety could be fostered from within and with the people who inhabited them.[119] This meant the possibility of partnership between health services and communities for such a task. Regarding end-of-life care, in connection with the hospice tradition, this approach gave way to what has been usually referred to as a ‘community approach to end of life.’

The development of PHPC has at its core the work of authors like Suresh Kumar in Kerala, India, and Allan Kellehear in Australia. Kellehear’s *Health Promoting Palliative Care* (HPPC) and *Compassionate Cities* are regarded as core texts that have helped shape PHPC.[120] Among the

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[116] See ibid., 22.
[117] Ibid., 23.
[118] Bruce Rumbold, “A History of Public Health Palliative Care,” in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear, (Oxford: Oxford University Press, 2022), 41.
[119] See Kellehear and Sallnow, “Public Health and Palliative Care. An Historical Overview,” 5.
[120] See Allan Kellehear, *Compassionate Cities: Public Health and End-of-Life Care* (London; New York: Routledge, 2005).

strategies included in Kellehear's HPPC were facilitating education for the end of life, facilitating personal and community social supports, the development of personal skills in addition to those people had regarding the end of life, encouraging the reorientation of palliative care services to health promotion rather than just clinical services, and combating death-denying health policies.[121] The reception of these ideas was mixed between professionals but gave way to questioning palliative care. Regarding the community, questions arose, such as "What sort of community will see end of life as everyone's concern? What sort of community will partner with palliative care and other end-of-life services, rather than simply expect professional services to meet all the needs when they arise (and find that expectation impossible)."[122] These ideas were further developed in *Compassionate Cities.* Professionals in different countries such as the UK, India, Ireland, Bangladesh, Spain, Canada, and Latin America became engaged with this movement developing different strategies and efforts to apply these ideas.

This development of palliative care as a social model of health highlights the social nature of dying in contrast to more medical-centered approaches. Kellehear argues that "dying is fundamentally a social experience for those who live through it… [where] the physical experience of dying is a necessary but not sufficient condition to create 'the experience of dying.'"[123] As previously discussed, it is estimated that in optimal circumstances, 5% of a patient's time is spent in contact with healthcare professionals.[124] This raises the question of

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[121] See Rumbold, "A History of Public Health Palliative Care," 42.
[122] Ibid., 43.
[123] Kellehear, "The Social Nature of Dying and the Social Model of Health," 22–24.
[124] Ibid., 25.

what palliative care can offer to the other 95% in a way that can foster a virtuous approach to the end of life, contributing to the wellbeing of individuals, families, and communities.

The proposal is centered on community care that “emphasizes values around end-of-life care and familiarizing participants with both traditional and contemporary approaches to death and dying… [increasing] the capacity of community members to provide support and care for their dying when called upon to do so.”[125] This model distances itself from an approach based on service delivery, mainly provided by professionalized services, and considers three principles of community development: subsidiarity, empowerment, and structure.[126] Briefly, in this context, subsidiarity implies participation in decision-making at the end of life in a way that resists increased dependency on institutional services fostering community life.[127] Empowerment is understood as one of the desired goals of community engagement, not as something given to others but “as a process that equalizes because disadvantaged groups can compete more effectively with other interest groups… [bringing] an ability to compete with political power… achieved by challenging structural disadvantage through social change.[128] Included in this perspective are formation and training. Lastly, although more will be said regarding structures in the following chapter, attention to this element includes promoting and developing those structures and processes needed to meet the needs of patients and their communities.

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[125] Julian Abel et al., “Circles of Care: Should Community Development Redefine the Practice of Palliative Care?,” *BMJ Supportive & Palliative Care* 3, no. 4 (December 2013): 2.
[126] See ibid.
[127] Kerrie Noonan, “Participatory Relations,” in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear (Oxford: Oxford University Press, 2022), 99.
[128] Ibid.

The 'New Essentials' Model

To answer the question of how communities can be supported to care for people at the end of their lives in a way that enhances meaning and value for both the ill person and all the community members who participate in caring, Abel and colleagues propose a model made of concentric circles that tries to capture the complexities at play (Appendix: Figure 3). The authors write, "the model starts by considering the persons at the center in relation to their community. When thinking about meeting needs, the starting point is the center and moves outward sequentially, looking to see how needs can be met by inner and outer networks, the community, and then finally service delivery."[129] The benefits of this approach are that it enables individuals and organizations to find their place in the spectrum of care, where there are cross-cutting themes such as policies, and where barriers between circles are porous.[130]

The authors further develop this model by identifying four essential elements or components of palliative care and their interactions. These components are specialist palliative care, generalist palliative care, compassionate communities, and civic end-of-life care. The differences between specialist and generalist palliative care lie in the nature of the care needs. Patients who require complex assessment with specialized therapeutic knowledge would need specialized care, while in generalist palliative care, "routine healthcare is combined with social care to allow patients to live with their condition at home."[131] Regarding compassionate communities, these are "naturally occurring networks of support in neighborhoods and communities, surrounding those

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[129] Abel et al., "Circles of Care," 3.
[130] See ibid.
[131] Julian Abel, Allan Kellehear, and Aliki Karapliagou, "Palliative Care—the New Essentials," *Annals of Palliative Medicine* 7, no. S2 (April 2018): 4.

experiencing death, dying, caregiving, loss, and bereavement."[132] These communities especially relate to the authors' inner and outer circles of care. The support these communities can provide depends to a certain extent on community activation, which concerns fostering connections and engagement between different actors within the community. Their strength is that they bring networks closer to people and not the other way around.[133] Lastly, these communities require the support and participation of public and private civic institutions. A way of putting this into practice has been proposed by the 'Compassionate City Charter.' It is a "succinct way of organizing a purposeful program of civic action oriented toward the end of life," a tool that aims to reorient healthcare toward civic partnerships and can be adapted into a wide range of contexts.[134] It provides recommendations for institutions such as, for example, schools, churches and temples, universities, care homes, or trade unions.[135] The model proposed by the authors integrates processes and operations of the four components (i.e., specialist palliative care, generalist palliative care, compassionate communities, and civic end-of-life care) in a way that effective coordination can provide "improved wellbeing at the end of life for every citizen affected by a life-limiting condition."[136]

A model like the one briefly described, focused on community care, preserves the patient-centeredness quality of palliative care and is attentive to the intervening psychosocial elements but challenges an individualistic and reductionistic approach to what that care might mean. By including a public health perspective, this community-based model situates the patient within a

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[132] Ibid., 5.
[133] See ibid.
[134] Ibid., 12.
[135] See ibid., 6.
[136] Ibid., 7.

particular community, context, and system and identifies the strengths and limitations of four different components to provide the best care at the end of life. This approach distances itself from an understanding of healthcare provisions exclusively or primarily limited to medical settings. This broader vision considers the social determinants of health and death, prompting attention to overlooked personal, social, and communal elements at the end of life and eliciting participation and agency from patients, healthcare institutions and providers, and communities. Both *ars moriendi* and community-based models of palliative care prove to be valuable resources to reimagine pathways to the aforementioned problems regarding contemporary dying and access to care for persons with a life-limiting illness. As mentioned in this chapter, these two resources point toward the development of virtues and the relevance of bridging death and life, doing so in a balanced way that contributes to efforts aimed at fostering equity and sustainability at the end of life.

In the last decades, palliative care has seen significant developments. Nevertheless, attention to contemporary problems associated with death and dying and the limitations of equitable service provision requires further analysis regarding healthcare and palliative care models and their impact on people and their communities at the end of life. The next chapter will develop an ethical lens that will contribute to this purpose.

3. Ethical Lens: Structures of Virtue and Vice, the Preferential Option for the Poor, and Compassion

The Christian tradition recognized the importance of accompanying death and dying, an essential process in a person's life, and considered that behind 'the art of dying' lay the potential development of a series of virtues. Dying well had not only to do with the biological needs of persons and with a response to physical suffering but also with the social and spiritual dimensions in play. The genre's different authors sought to offer guidance that would contribute toward the desired goal. As we have seen in the previous chapter by exploring the *ars moriendi,* dying is intimately connected to the development of virtues and human flourishing. Today, when healthcare is understood mainly from a medical and institutional perspective, palliative care has been established as a discipline within the system and aims to provide quality care at the end of life. In this sense, we can say that even in a very different context and time period, the task of palliative care to help people die well resonates with the efforts that informed the *ars moriendi*. However, how can healthcare systems and palliative care foster the development of virtues that help people die well and impede those vices that threaten their well-being?

Attention to the complexity of dying broadens the perspective in a way that, while keeping the persons at the center, is able to acknowledge the relevance of the networks surrounding them and the importance of the relationships and connections that people have. As said previously, from a death system's perspective, certain interconnected structures can impact others and shape the whole system. In this thesis, we have explored some of the problems associated with contemporary death and dying and possible responses to them. We will argue that, in this context, structures of care have a significant say and can be a relevant factor when facing death.

It is also necessary to question how healthcare systems, and palliative care within them, help balance the current unbalance experienced at the end of life and promote a way of dying well accessible to everyone. Moreover, we need to ask whether there is a type of healthcare and palliative care that would be more suitable for this task. To what extent can palliative care promote a different kind of dying that addresses contemporary problems?

The first section of this chapter describes some of the reasons for choosing virtue ethics as the appropriate ethical framework to address our topic. The second section will present and develop Daniel Daly's proposal of structures of virtue and vice as an ethical lens that helps judge the current state of affairs and charter the way forward. It will provide insight into how social structures contribute to the problematic unbalance in death and dying referenced in the first chapter and denounced by the Lancet Commission on the Value of Death. In light of this perspective, it will be possible to explore palliative care as a response to the needs at the end of life in connection to its way of fostering a virtuous approach at the individual, community, and institutional levels. What will be argued here is that structures of virtue and vice are involved in shaping moral character and can help develop virtuous settings and communities that contribute to the care of persons with life-threatening illnesses.

Linked to the way structures can be virtuous or vicious and affect the well-being of people and groups, especially the most vulnerable, the third section stresses how the preferential option for the poor is one of the main contributions of liberation theology and can contribute to addressing important concerns regarding end-of-life issues. The promotion of virtues should always include a liberating perspective. Even if what I am proposing does not develop a particular set of virtues, the fourth section focuses on compassion as one of the central virtues involved in care at the end of life and how it can provide guidance. Lastly, the chapter ends with some remarks regarding death and dying, opening the way to the last chapter, where ‘compassionate cities’ and ‘compassionate communities’ pertaining to a public health palliative care model will be presented as a possible appropriation of what has been discussed.

3.1. Virtue Ethics

One of the main aims of the *ars moriendi* literature, in which the works of authors like Loarte and Polanco can be situated, is to help people live a virtuous life and death. As Vogt writes, “these authors saw the development and practice of virtues–especially patience, compassion, and hope, all supported by faith–to be an effective way to instruct readers about practices crucial for living the good Christian life and thus to prepare for death as well.”[137] Vogt’s work shows how these particular virtues are essential when considering death and dying. In this chapter, this perspective will be broadened, including relationships between individuals and structures.

Virtue ethics is the ethical framework for the proposal described in this chapter. There are a number of reasons for this choice. Drawing from different authors that have written on this topic, we can briefly point out some of them.

First, virtue ethics uses ordinary language and deals with ordinary life. As seen with the *ars moriendi* literature, virtues are available and intended to be accessible to everyone. The language of virtue ethics relies on ordinary language and incorporates the ordinary life experiences that

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[137] Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well*, 7.

also shape the dying process.[138] As Daniel Daly writes, "virtue ethics also pertains to every area of the moral life… [attending] to the mundane aspects of life, avoiding the reduction of ethics to moral quandaries."[139] Second, virtue ethics focuses on moral character. As Vogt writes, "This approach defines the central task of ethics as coming to know what constitutes good character and a life well lived, rather than passing judgment upon whether this or that particular act is right or wrong."[140] This approach provides the possibility for a more nuanced analysis of human agency. Third, virtue ethics shows how all virtues are connected. Vogt highlights that virtue ethics "develops a rich description of what constitutes a good human life, which serves as *telos* or end toward which we should strive."[141] Hence, the interconnectedness of the virtues can easily be seen.[142] Although we will be focusing on compassion, the 'art of dying' is not only about developing one virtue. The complex process of dying requires a delicate balance where several virtues play crucial roles.

Fourth, virtue ethics provides action guidance and assessment. Virtue ethics also has the capacity to offer normative guidance. In contrast to authors questioning such possibility of virtue ethics, Daly, acknowledging possible difficulties, argues that "virtue ethics provides a practicable method for normative action guidance."[143] For James F. Keenan, this is also true, and he affirms that "a virtue-based ethics that generates its own norms and principles is more capable of guiding

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[138] See James F. Keenan, "Seven Reasons for Doing Virtue Ethics Today," in *Virtue and the Moral Life: Theological and Philosophical Perspectives*, ed. William Werpehowski and Kathryn Getek Soltis (Lanham, MD: Lexington Books, 2014), 5.

[139] Daniel J. Daly, *The Structures of Virtue and Vice*, Moral traditions (Washington, DC: Georgetown University Press, 2021), 125.

[140] Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well*, 3.

[141] See ibid.

[142] See Keenan, "Seven Reasons for Doing Virtue Ethics Today," 13.

[143] Daniel J. Daly, "Virtue Ethics and Action Guidance," *Theological Studies* 82, no. 4 (December 2021): 569.

us in action than a simple normative or principlist ethics."[144] One of the main benefits is that virtue ethics is not agent-blind, providing action guidance for different agents.[145] Lastly, its relevance for Christian ethics speaks to "how God's grace is operative in the moral life… [and] because the final and full human good is the person's loving relationship with God and neighbor."[146] Nevertheless, virtue ethics has limitations, such as the claim that it is still undertheorized and that certain approaches still lack articulation with contemporary theological anthropology.[147]

Due to these reasons, exploring the complexities of death and dying and palliative care within this ethical approach is especially fitting. The following sections will present a proposal of an ethical lens within this framework.

3.2. Structures of Virtue and Vice

Daniel Daly, in his book *The Structures of Virtue and Vice*, develops "concepts that explain how structures shape moral development and agency, as well as how structures causally contribute to or impede the well-being of people and groups."[148] His approach will be described and used as an ethical lens to reflect on the problems associated with contemporary death and dying and access to palliative care described in the first chapter. The reason for using the author's proposal has to do with its suitability to capture and analyze two key elements, namely, the development

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[144] Keenan, "Seven Reasons for Doing Virtue Ethics Today," 9.
[145] See Daly, "Virtue Ethics and Action Guidance," 582.
[146] Daly, *The Structures of Virtue and Vice*, 126.
[147] See ibid., 126–127.
[148] Ibid., 3.

of virtues or vices at the end of life and its association with structures that people inhabit that affect the well-being of individuals and communities.

Daly's proposal stems from Catholic virtue ethics and responds to the limitations found in Catholic ethics and Catholic social teaching (CST) regarding its capacity to analyze sociostructural problems and the relation between social realities and moral agency. Catholic ethics has used the concept of "structures of sin" to point analogously to the moral categorization of structures, but according to Daly, the attempt lacks precision and coherence, becoming problematic when evaluating the injustice associated with structures.[149]

The genesis of the concept of "structures of sin" can be found in the beginnings of the social encyclicals such as *Rerum novarum* and Vatican II's insistence on "the moral importance of society and its influence on the moral character of the person."[150] This approach was further developed by Latin American liberation theologians who, in light of the historical conditions experienced in the continent, stressed the structural nature of sin and the influence of structures on the unjust situation many people were living. Subsequent papacies dealt with the concept differently, mindful of the possible danger of diluting 'personal sin' at the expense of stressing the structural and social aspects. During the papacy of John Paul II, there was an increased acknowledgment of the influence of structures of sin, and, among other documents and allocutions, the notion was included in *Sollicitudo rei socialis*.[151] However, it is important to note that out of the possible meanings of 'social sin,' interpretations that hinted toward a separation

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[149] See ibid., 1–2.
[150] Ibid., 35.
[151] See John Paul II, *Encyclical for the Twentieth Anniversary of Populorum Progressio Sollicitudo Rei Socialis* (The Holy See, 1987).

between structures and the individual agency were firmly rejected.[152] In *Reconciliatio et paenitentia*, John Paul II draws on the work of the International Theological Commission and the Congregation for the Doctrine of Faith regarding the analogous understanding of ‘structural sin’ and ‘sinful structures,’ pointing out only three acceptable meanings.[153] Nevertheless, on a broader perspective of magisterial use of the language of social sin, Margaret Pfiel sees a “shift from a description of the social dimensions of sin as the effect of personal sin toward attempts to regard both the social and the personal aspects of sin as essential pieces of a fuller and more intelligible account of sin.”[154]

During Pope Francis’ papacy, attention has been given to the structural causes of injustice, both in writings and speeches. Daly points out three themes in the pope’s attention to this issue: the real and moral nature of structures, their implication in causing poverty, and the dialectic relation between structures and persons.[155] Francis’ critiques of structures, cultures, institutions, and their relationship with people are especially present in writings such as *Evangelii gaudium* and *Laudato si’*.[156] His teaching concerning social structures moves “toward a moral theory that takes seriously social structures and institutions as moral agents.”[157]

However, Daly claims that regarding the structure-agency problem, even if Catholic ethics and the magisterial teaching contain abundant implicit views, they have not been able to produce a

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[152] See Christine Firer Hinze, “The Drama of Social Sin and the (Im)Possibility of Solidarity: Reinhold Niebuhr and Modern Catholic Social Teaching,” *Studies in Christian Ethics* 22, no. 4 (November 2009): 445.
[153] See Ibid., 140; John Paul II, *Apostolic Exhortation on Reconciliation and Penance in the Mission of the Church Today Reconciliatio et Paenitentia* (The Holy See, 1984).
[154] Margaret Pfeil, “Doctrinal Implications of Magisterial Use of the Language of Social Sin,” *Louvain Studies*, no. 2 (2002): 146.
[155] See ibid., 45.
[156] See Francis, *Apostolic Exhortation on the Proclamation of the Gospel in Today’s World Evangelii Gaudium* (The Holy See, 2013); Francis, *Encyclical on Care For Our Common Home Laudato Si’* (The Holy See, 2015).
[157] Daly, *The Structures of Virtue and Vice*, 47.

precise account of the nature of social structures.[158] This limitation impedes understanding the complex social reality, a necessary factor for moral analysis. Moreover, the question remains as to "how social structures shape the virtues and vices of moral agents."[159] Having described such a need, the author draws on critical realism social theory and turns to a theocentric and personalist theology connected to virtue ethics in order to offer a possible framework to address the structure-agency problem.

The author's proposal transcends an ethical analysis based on interactions and strives for "an ethics that accounts for all realities that produce human outcomes and affect personal actions and character."[160] This choice is especially relevant to our topic because we are not exclusively focusing on the problems generated by certain kinds of relationships at the end of life, such as the physician-patient relationship. As we stressed above, persons with life-threatening illnesses belong to complex networks that shape how contemporary dying is understood. These networks are comprised of different complex, irreducible structures which could themselves be analyzed as virtuous or vicious and that are related to the different agents who inhabit them. They influence but do not determine people's agency and moral action.

Structures, Daly writes, "are a collection of relations among social positions… [and] relations emerge when many persons assume specified social positions and when cultural realities support those positions."[161] He also establishes a distinction between normative social institutions and organizations, where "normative social institutions are arrangements involving large numbers of

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[158] See ibid., 54.
[159] Ibid., 55.
[160] Ibid., 161.
[161] Ibid., 162.

people whose behavior is guided by norms and roles… [and] an organization is a normative social institution that contains well-defined positions of authority."[162]

In his analysis of circumstances concerning structures, Daly establishes that "structures are not merely the 'conditions surrounding the action'; they are conditions *facilitating* or *impeding* the action."[163] Following the author's development, it could be argued that global or national healthcare structures regarding death and dying facilitate certain actions and impede others. Similarly, it could be said more specifically about palliative care as a structure within the healthcare system that deals directly with death and dying.

The framework that Daly proposes defines structures of virtue and vice in a twofold manner:

> First, virtuous structures contain social relations that enable and facilitate a person's performance of virtuous actions and subsequent acquisition and cultivation of the virtues. Such structures engender habits that dispose the agent to recognize and promote human dignity and human well-being, especially that of the vulnerable… Second, virtuous structures are those webs of relations that consistently promote the normative human dignity and well-being of all affected by those relations, especially the vulnerable. These are structures that encourage decisions that contribute to social justice, and its fruit, the common good. This aspect of the structures of virtue concerns the effects that structures have on those affected by them.[164]

The contrary would be true of vicious structures. In these structures, promoting relationships that foster recognition and love of neighbor, God, and creation would be constrained, similarly affecting social justice and the common good.

According to Daly, structures can be virtuous or vicious in two ways. The first one has to do with the way they can shape agency and character of persons. The author argues that such shaping is

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[162] Ibid.
[163] Ibid., 166. Emphasis in the original.
[164] Ibid., 168–169.

done in a non-deterministic way by enabling or constraining actions and character traits.[165] The second way has to do with the well-being of people and groups, and in this case, the outcome is linked to the attention given to the most vulnerable and the common good. These two ways briefly described are relevant to what has been discussed so far in this thesis. There is a way in which certain structures, which people at the end of life and their communities inhabit, shape possible actions and moral character regarding the experience of dying. Moreover, there is also a way in which those structures might promote or limit access to the needed goods for a dignified existence at the end of life, such as access to palliative care.

Even if a complete account and exploration of this ethical framework is beyond the scope of this thesis, it is important to consider some aspects highlighted in Daly's work. First, "structures are only metaphorically virtuous or vicious. Only persons have moral agency and are capable of acquiring moral character. Structures do not act; instead they exist in and through the actions of persons. However, structures have a moral character because of the way they enable and constrain personal agency."[166] This distinction speaks to the concern seen in the Catholic tradition regarding personal sin and the need to articulate well the morally complex nature of structures and how they have both virtuous and vicious aspects, as well as how, within structures, relationships influence moral character. As described, the emergence of moral character is distinct from structures but, at the same time, is influenced by structural circumstances.

Second, "structural virtues and vices develop asymmetrically… [and] vicious structures often are perpetuated through a failure to account for the well-being of all who are affected by the

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[165] See ibid., 170.
[166] Ibid., 169.

structure."[167] Considering structures as emergent realities, Daly shows how structures created for good or neutral ends might have vicious effects. Virtuous structures, on the contrary, are "more typically the result of coordinated social action."[168] Regarding healthcare, in connection to the approach of liberation theology, Paul Farmer and Andrea Vicini write that "examining what it means to make a preferential option for the poor in global public health invites us to revisit how a preferential option has more commonly been made for the rich and white. An option for the privileged has burdened our past and continues to influence our present."[169] Coordinated action and the changing of structures is, therefore, much more intentional and must consider the complexities of social structures, engaging with them at different levels.

Third, "social justice emerges in a society of virtuous structures where preexisting social relations enable persons to recognize the inherent dignity and promote the well-being of all with whom they relate."[170] Daly links social justice to virtuous structural character, one that promotes the well-being of the most vulnerable and constrains those actions that foster vicious effects on them. When examining healthcare structures, it is possible to trace and analyze their vicious aspects by paying attention to the conditions experienced by those more disadvantaged.

Regarding the second way in which structures can be virtuous or vicious, Daly writes that "in order to determine the character of a structure, one should ask, first, how does the position affect the well-being of the vulnerable, the poor and socially marginalized?... The preferential option

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[167] Ibid., 186.
[168] Ibid., 187.
[169] Paul Farmer and Andrea Vicini, *Ethical Challenges in Global Public Health: Climate Change, Pollution, and the Health of the Poor*, ed. Philip J. Landrigan and Andrea Vicini, Global Theological Ethics 1 (Eugene, OR: Pickwick Publications by Wipf & Stock, 2021), 194.
[170] Daly, *The Structures of Virtue and Vice*, 189.

for the poor serves as the fundamental test of a structure's character. This is a distinctively theocentric test of a structure, as it attends first to the weakest members affected by a structure because those are the ones for whom God first opts."[171] The following section will focus on the preferential option for the poor as one of the main contributions of liberation theology and as part of the ethical lens being developed.

3.3. The Preferential Option for the Poor: A Liberating Perspective

The preferential option for the poor cannot be understood without attention to history and context. The 'irruption' of the poor, in the words of Gustavo Gutiérrez, and framed as a "vast historical event," marked a crucial point in the development of theology.[172] According to Gutiérrez, the poor had been absent from the conversation, but the invitation of Vatican Council II opened the path to "read the signs of the times" and "discern the values and limitations of this event, which read from the standpoint of faith also represents an irruption of God into our lives."[173] Even if Vatican II followed a Eurocentric approach and was not attuned to the struggles present in Latin America then, it gave the church the tools necessary to listen to reality, judge the situation, and envision possible ways for action.[174] Attention to history and the question of the place of the church in the world were articulated in documents like *Gaudium et Spes* and helped channel efforts and movements sensitive to injustice and poverty that had been present in Latin America, especially after 1950.

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[171] Ibid., 182.

[172] Gustavo Gutiérrez, "Option for the Poor," in *Systematic Theology: Perspectives from Liberation Theology*, ed. Jon Sobrino and Ignacio Ellacuría (Maryknoll, NY: Orbis Books, 1996), 22.

[173] Ibid., 23.

[174] See O. Ernesto Valiente, "The Reception of Vatican II in Latin America," *Theological Studies* 73, no. 4 (December 2012): 800.

Nevertheless, this effort could only be attempted due to the process that had been taking place in Latin America during the years building up to Vatican II. Milestones shaping the Latin American church include the influence of new theological currents introduced by European and North American clergy, the work of the lay movement of *comunidades eclesiales de base* (CEBs), and the establishment of the Latin American Episcopal Council (CELAM).[175] Without considering the impact of new theological thoughts resounding in a different context, the development of communities where people could read their own reality from the perspective of faith, and the ecclesial connection between bishops facing similar challenges, it is difficult to understand the 'preferential option for the poor.'

It was not until the conference at Puebla in 1979 that the 'preferential option for the poor' was explicitly stated in a church document. The foundations for this to happen had already been set in the conference at Medellín in 1968. Preceded by the encyclical *Populorum Progressio* and regional conferences examining the 'signs of the times' with the help of experts in a wide range of social sciences, at Medellín "the bishops 'incarnated' the insights of the council in a way that would empower the local Latin American church to become an evangelizing force in the dynamic transformation of its own culture and society."[176] Poverty and injustice were the most pressing issues, and there was a substantial effort to identify their causes, including a structural dimension. The analysis and perspectives rejected a dual interpretation of history as separately sacred and profane and moved away from reformist approaches stemming from dependency theory.[177] The hermeneutical accomplishment of Medellín included the self-understanding of the

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[175] See ibid., 798.
[176] Ibid., 805.
[177] See ibid.

Latin American church in relation to the poor, in solidarity with the poor, and as a development of John XXIII's invitation to be a 'church of the poor.'[178]

At the third General Conference of the Latin American Episcopate (CELAM III), which took place in 1979 in Puebla de los Angeles, Mexico, despite the ecclesial tensions and controversies, three crucial theological elements–namely, attention to the signs of the times, the preferential option for the poor, and communion ecclesiology–were "confirmed, clarified and further developed."[179] Regarding the preferential option for the poor, Puebla provided a deeper understanding of 'the poor' and the mechanisms at play in their oppression, their capacity not only to be protagonists of their liberation but also to be bearers of evangelizing potential, and it also allowed to surface the cultural aspect of fostering attention to the different realities existing within the continent.

The commitment to making a 'preferential option for the poor,' included in the conference's Final Document, is rooted both in the following of Christ and his gratuitous love.[180] This commitment is one of the main contributions of liberation theology to the church and holds several crucial elements in balance from a theological perspective. In the first place, 'preferential' speaks to the biblical roots and the core of the Christian message. Rejecting exclusivity, "the universality of God's love and the divine predilection for 'history's last'" is highlighted.[181] Secondly, 'option' refers to the nature of the commitment. However, as Gutierrez states, "this option for the poor is not optional in the sense that a Christian need not necessarily

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[178] See ibid., 806.
[179] Ibid., 809.
[180] See ibid., 813.
[181] Gutiérrez, "Option for the Poor," 26.

make it, any more than the love we owe every human being, without exception, is optional."[182] Solidarity, in this framework, is again related to the gratuitous love of God. It is also essential to consider that the poor themselves must make the decision. Finally, 'for the poor' reflects the turn to history in the theological approach. Such a turn is again rooted in biblical accounts and provides a particular standpoint that is not sectarian or ideological but radically connected to faith. Even if what is meant by 'the poor' needs further attention, and some authors have distinguished between real, evangelical, and spiritual poverty, it can be said that from the perspective of the poor, faith and history, soteriology, and ethical commitment are part of the same theological commitment.

Incorporating the preferential option for the poor into the ethical lens implies understanding the framework of virtues and vices presented by Daly from a liberating perspective. In his book *The Cry of the Poor: Liberation Ethics and Justice in Healthcare*, Alexandre Martins acknowledges the preferential option for the poor as contributing to the promotion of population health and preventing some of the undesirable risks or vices present in healthcare approaches and structure.[183] He identifies five main contributions of the preferential option for the poor that are particularly relevant to the topic.

First, he writes, "the preferential option for the poor challenges us to see reality from a new perspective, that is, from the hermeneutical lens of the poor. This shift of perspective has significant impact on our decision-making process once it establishes a dialogue with the poor

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[182] Ibid.
[183] See Alexandre Andrade Martins, *The Cry of the Poor: Liberation Ethics and Justice in Health Care* (Lanham, MD: Lexington Books, 2020), 180.

and the ability to recognize their crucified faces and knowledge."[184] This emphasizes ground-up approaches and attention to the participation of the poor in the decision-making processes regarding healthcare. Second, it provides a clearer view of the vicious structures at play and helps identify who the poor are, with their "names, families, traditions, histories and want voices."[185] Third, it underscores the poor as agents of transformation and not merely passive recipients. This speaks to the efforts related to empowerment and solidarity. Fourth, "the preferential option for the poor reveals where the needs are and where we should go to join the unfortunates in their labor to liberate themselves from injustice."[186] Accompaniment stands out as an essential element when working within a virtuous structure.[187] Lastly, Martins states that "the preferential option for the poor invites us to an existential commitment to the life of the least ones of society, in an act of sensitive courage."[188]

However, there is still a question regarding the capacity of the preferential option for the poor to be relevant in a non-theological framework. Possible paths include considering the preferential option for the poor being pre-theological or emphasizing its anthropological roots. In the case of Martins, there is an element of recognition of shared human suffering. He develops an "anthropology of suffering in which the experience of suffering reveals the contingency of the human condition. It shows how personal suffering opens us to transcendence in an experience of compassion that leads to an encounter with the other who suffers."[189] Following Simone Weil, he speaks about 'essential *malheur*' and 'accidental *malheur*.' The first is a shared condition

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[184] Ibid., 182.
[185] Ibid.
[186] Ibid., 183.
[187] See Michael P. Griffin and Jennie Weiss Block, eds., *In the Company of the Poor: Conversations between Dr. Paul Farmer and Fr. Gustavo Gutierrez* (Maryknoll, NY: Orbis Books, 2013), 168.
[188] Martins, *The Cry of the Poor*, 184.
[189] Ibid., 103.

regarding suffering, while the second is due to unjust conditions and structural violence experienced by those who suffer.[190] The preferential option for the poor shapes the ethical option in its effort to combat structural injustice.

This movement echoes Sobrino's 'principle of mercy' as a restatement of the option for the poor, who argues that "mercy stands at the origin and basis of all moral activity; that mercy is not one activity among others but rather that which is prior to all others; and that mercy endures throughout the work of justice."[191] This is the reason why Sobrino considers mercy as a principle. As he writes, it is "the first thing and the last… [Mercy] is a basic attitude toward the suffering of another, whereby one reacts to eradicate that suffering for the sole reason that it exists, and in the conviction that, in this reaction to the ought-not-to-be of another's suffering, one's own being, without any possibility of subterfuge, hangs in the balance."[192] The radicality of mercy, articulating the right responses to the causes of suffering systematically, lies in its connection to what it means to be human and what salvation means, not only in relation to transcendence but also in historical terms.[193]

Critical voices like Ivan Petrella go further to the extent of advocating for a concrete 'historical project' stemming from the bearings of liberation theology. It can be argued that the capacity and strength of the preferential option for the poor in this aspect is ascribed to the shaping of an

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[190] See ibid.

[191] See James F. Keenan, "Radicalizing the Comprehensiveness of Mercy: Christian Identity in Theological Ethics," in *Hope & Solidarity: Jon Sobrino's Challenge to Christian Theology*, ed. Stephen J. Pope (Maryknoll, NY: Orbis Books, 2008), 189.

[192] Jon Sobrino, *The Principle of Mercy: Taking the Crucified People from the Cross* (Maryknoll, NY: Orbis Books, 1994), 18.

[193] See Keenan, "Radicalizing the Comprehensiveness of Mercy: Christian Identity in Theological Ethics," 192.

ethical lens and not a tool supporting a particular ‘historical project’ that risks confining liberation to an ideological agenda.[194]

Read in the context of structures of virtue and vice, the preferential option for the poor points to a series of virtues to be cultivated that ultimately contribute to the well-being of people and groups, especially those most vulnerable. Unlike Christopher Vogt’s work, this thesis will not develop a specific set of virtues that structures involved in end-of-life care should develop. However, due to its centrality in the virtues and connection with the proposal of “compassionate cities” and “compassionate communities,” we will briefly address the virtue of compassion in the following section.

3.4. The Role and Practice of Compassion

As discussed, there is a way in which it can be said that structures are virtuous and can foster virtues. One of the central virtues of healthcare, particularly death and dying, is compassion. However, how is compassion understood? Compassion is a contested virtue in the healthcare world. As an example of this, it is used both by those in favor and against physician-assisted suicide (PAS). On the one hand, in the United States, organizations such as “Compassion and Choices” advocate for the possibility of ending life on “one’s own terms,” which includes access to PAS. On the other hand, when reflecting on end-of-life issues, the Catholic tradition, also in the United States, uses compassion in an opposite way by linking it to continuing Christ’s

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[194] See Ivan Petrella, *The Future of Liberation Theology: An Argument and Manifesto* (Aldershot, Hants, England and Burlington, VT: Ashgate, 2004).

mission and understanding that “suicide and euthanasia are never morally acceptable options.”[195] It is beyond the scope of this thesis to discuss in detail PAS, and compassion will not be discussed here concerning the debated principles involved in ethical deliberation regarding PAS, such as non-maleficence or non-abandonment. As mentioned in the first chapter regarding the definition of palliative care, we are considering that palliative care sees dying as a natural process and does not intend to hasten or postpone death.

Compassion here will be explored in its Christian account as an essential virtue in end-of-life care that can provide action guidance and assessment in connection with other virtues for individuals, communities, and institutions. This exploration will consider the framework of structures of virtues and vice, and it will be linked to a liberationist perspective intimately connected to the preferential option for the poor. From this viewpoint, compassion has the capacity to guide healthcare in a way that is attuned to the needs and suffering of the most disadvantaged population, especially those who lack proper access to palliative care.

For Vogt, even if there is not a singular understanding of compassion among Christian ethicists, it is possible to encounter some consistencies.[196] He sees this virtue as having four components: listening to the voice of who is suffering, entering into the suffering of the other and experiencing it as one’s own, acting on behalf of and in concert with the dying, and integrating and connecting the experience of dying to the Christian community and its memory of the suffering and death of Jesus.[197] Elements of this approach can be seen in the account of Thomas

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[195] United States Conference of Catholic Bishops, *Ethical Religious Directives for Catholic Health Care Services*, 6th ed. (Washington, DC: United States Conference of Catholic Bishops, 2018), no. 20, accessed March 18, 2023, https://www.usccb.org/resources/ethical-religious-directives-catholic-health-service-sixth-edition-2016-06_3.pdf.
[196] Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well*, 61.
[197] See ibid.

Aquinas, on whom we will focus. Before doing so, it is important to acknowledge several difficulties involved in this task. First, it is not easy to pinpoint only one place where Aquinas deals with compassion in his *Summa Theologica*. Secondly, translation makes it more problematic, and we can find *misericordia* as ‘compassion,’ ‘mercy,’ or ‘pity.’ Secondly, in Aquinas’ *Summa,* ‘*misericordia’* can be found discussed in three parts: “concerning God and divine omnipotence, as part of charity, and in one specific question on the morality of the emotions.”[198] Here we will briefly refer to specific points of the last two.

ST II-II, q. 30

Aquinas uses Augustine’s definition of “heartfelt sympathy for another’s distress, impelling us to succor him if we can.”[199] Hayden Ramsay, commenting on this definition, states that it is part of our common humanity and, if genuine, “compassion, unlike sincere sympathy, always moves us towards action.”[200] Nevertheless, we must examine this dynamic. In his first article, Aquinas discusses that compassion responds to the evil that is “anything contrary to the will’s natural appetite, namely corruptive or distressing evils, the contrary of which man desires naturally… contrary to deliberate choice… (and) entirely contrary to the will, as when evil befalls a man who has always striven to do well.”[201] Hence, a compassionate person will try to respond to the presence of evil in those who are distressed by it.[202] The second article explores pity highlighting that we might experience pity because of our love for the sufferer or because it projects us into

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[198] Thomas Ryan, “Aquinas on Compassion: Has He Something to Offer Today?,” *Irish Theological Quarterly* 75, no. 2 (May 2010): 159.
[199] ST II-II, q. 30, a.1.
[200] Hayden Ramsay, “Euthanasia: Compassion, Dignity and Respect,” *Sophia* 36, no. 2 (September 1997): 44.
[201] ST II-II, q. 30, a. 1.
[202] See Ramsay, “Euthanasia,” 44–45.

experiencing a similar situation in the future. The third article discusses the connection between virtue and what makes compassion a virtue. With Aquinas, Ramsay states that “if the compassion is just felt, it is not a virtue… [it also needs] an intellectual recognition of the other’s condition as undesirable, a recognition which can help to regulate her feelings.”[203] This is especially relevant because our action might be misguided if one of these aspects is missing.

Ramsay insists on the importance of “veridical recognition of the evil” and warns against possible distortions of that recognition due to our love for the person and acting inappropriately in engaging them and their suffering.[204] Therefore, if the previous insights were to be applied to end-of-life care, the following three points could be taken into consideration. First, the complexity of suffering requires scrutiny. Where sympathy may be appropriate in case of certain causes of suffering, compassion understood as motivating further action may not.[205] This approach implies that even if considering that the person’s suffering is genuine, it is necessary to discern the object of their suffering and where that might lead the person. Second, there is a significant danger in not identifying the true nature of the problem, even when one is not misled by feelings. Failure to identify genuine evil might indicate the limitation or narrowness of the approach.[206] Third, there is a sense of community that must be included. Reliability of compassion takes into account beliefs that include “the good of both parties.[207]

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[203] Ibid., 45.
[204] Ibid.
[205] See ibid., 46.
[206] See ibid.
[207] Ibid., 47.

ST I-II, q. 24

The other account of compassion in Aquinas that will be described involves a discussion of emotions.[208] Ryan explores how, in Aquinas, compassion as an emotion is related to compassion as a virtue and does this in five different stages. Only the first three will be mentioned due to their relevance to our topic.

According to Ryan, the first step Aquinas takes concerns the possibility of defining emotions by noting that "an emotion's moral status is discerned to the extent that it is guided by, or 'in tune with,' reason and only in a relational context."[209] These two elements also appeared and were described in the previous *quaestio* mentioned above.

The second step implies establishing compassion in the context of friendship. Without discussing what friendship entails for Aquinas, in this context, such a choice implies going beyond an understanding of compassion that limits it to self-love. It is not only sorrow for the other "as if it were 'one's own' since this is still distinct from the suffering of another."[210] This approach leads to a deeper understanding of compassion and a fuller realization of it, highlighting its relationality, especially in the context of true friendship.[211] In addition to this, for Ryan, emotions that express compassion "as felt evaluations and affective virtues that 'define' us, they provide, as no other emotions can do, a psychologically sound platform for the moral life."[212]

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[208] See ST I-II, q. 24.
[209] Ryan, "Aquinas on Compassion," 159.
[210] Ibid., 161–162.
[211] Ibid., 162.
[212] Ibid.

In a third step, he describes compassion as having a triple dimension: cognitive, affective, and volitional. Ryan draws on Oliver Davies' *A Theology of Compassion*.[213] In the comparison between Aquinas and Davies, he argues that Aquinas offers "a fuller account of the 'identifiable structure' of an emotion in terms of the working relationship between the three elements."[214] Emotions do not belong to a separate part of the human being, but instead, they are "in relation to deliberation and will (as cognitive, affective and volitional) as either consequent or antecedent."[215] Due to the limitations of this thesis, it is not possible to expand on this virtue or enter into a deeper analysis of consequent and antecedent emotions.

Nevertheless, it can be stated that if an antecedent emotion is to be considered as one previous to the act of deliberative will, there is a danger of a double distortion, both of perception and judgment, when considering compassion. Taken only in its affective moment, compassion would be "'mere pity' (*sola passione misericordiae*)."[216] If this is the case, Ryan concludes that "compassion may be insufficient in grounding any duty concerning the suffering of others."[217] In order to be virtuous, any response needs to include the other elements, which also highlight the role of prudence. Following this approach, it is essential to remember that many virtues are required to evaluate various moral situations and that in the conflict of competing virtues, prudence, animated by love, will help to discern moral priorities.[218]

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[213] See Oliver Davies, *A Theology of Compassion: Metaphysics of Difference and the Renewal of Tradition* (London: SCM Press, 2001).
[214] Ryan, "Aquinas on Compassion," 164.
[215] Ibid.
[216] Ibid., 166.
[217] Ibid.
[218] See ibid., 172.

Although Aquinas discusses relational virtues, Daly notes that his anthropology is "not fundamentally relational."[219] Contemporary appropriation needs to incorporate Daly's remark on the need for a relational anthropology as the ground for an articulation of the virtues. This is especially relevant when reflecting on structures and moral agency. His distinction between 'relation' and 'relationship' helps understand the moral connections to structures or organizations, highlighting that "a relation is not necessarily with an identifiable person; nor is it necessarily interactive… So, though all relationships are relations, not all relations are relationships."[220] More accurate and fitting to experience, Daly shows the relevance of this distinction concerning the created world (i.e., the oceans) and the moral concepts needed to explore this relation. These will differ from those that help explain interactive relationships, such as the physician-patient relationship.

The Christian tradition provides a thick account of compassion that requires a much more in-depth presentation. However, what has been briefly described offers valuable insight into how the virtue of compassion could inform moral action. As an example, we will refer to the work of the late Paul Farmer, an anthropologist and physician committed to improving and treating adverse health conditions of vulnerable populations among whom he worked and lived. Farmer recalls reflecting on the causes of poor treatment adherence outcomes with his team. In their critical assessment they highlighted two poles, "a cognitivist-personalistic pole that emphasized individual patient agency… and a structural pole that emphasized the patients' poverty."[221] In the

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[219] Daly, *The Structures of Virtue and Vice*, 127.
[220] Ibid., 129.
[221] Paul Farmer, "Health, Healing, and Social Justice: Insights from Liberation Theology," in *In the Company of the Poor: Conversations between Dr. Paul Farmer and Fr. Gustavo Gutierrez*, ed. Michael P. Griffin and Jennie Weiss Block (Maryknoll, NY: Orbis Books, 2013), 48.

context of the structural pole, compassion was connected to the realization of the effects of what he called ‘structural violence’ on the most vulnerable.[222] This approach would lead him to work for creating compassionate, non-commodified healthcare systems where addressing suffering had not only to do with a capitalistic understanding of charity or development but with social justice.[223] At the same time, compassion also informed his vision of accompaniment in a double way. On the one hand, as Keenan writes, it was about engagement with the patient’s well-being, “an encounter with others whose health suffers because of inequitable, unhealthy contexts,” always in a way that recognized and promoted the agency of the one accompanied.[224] On the other hand, accompaniment entailed challenging structures and policies that, on their drive for cost-effectiveness, constantly threatened the practice of compassion, reducing it to “a useful quality supplementing a far more important—and measurable—attribute: technical competence.”[225]

3.5. Death and Dying and the Virtues

As described, structures have the potential to shape individuals and communities. Persons inhabit structures when faced with life-limiting, life-threatening illnesses in their process of dying. Those structures can have a significant influence on how people die, as well as on their well-

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[222] See Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, California series in public anthropology 4, (Berkeley, CA: University of California Press, 2010), 157.
[223] See ibid., 153.
[224] James F. Keenan, “From Amoris Laetitia to Ebola: Accompaniment as a Model for Medical and Pastoral Care,” in *A Prophet to the Peoples: Paul Farmer’s Witness and Theological Ethics*, ed. Jennie Weiss Block, M. Therese Lysaught, and Alexandre A. Martins, Global Theological Ethics 4 (Eugene, OR: Pickwick Publications by Wipf & Stock, 2023), 208–210.
[225] Brian Volck, “Wasting Time with the World’s Poor: Theological and Scriptural Foundations for Paul Farmer’s Praxis of Accompaniment,” in *A Prophet to the Peoples: Paul Farmer’s Witness and Theological Ethics*, ed. Jennie Weiss Block, M. Therese Lysaught, and Alexandre A. Martins, Global Theological Ethics 4 (Eugene, OR: Pickwick Publications by Wipf & Stock, 2023), 225.

being and that of their communities. When dying is mainly framed from a medical perspective, the development of certain virtues that could help dying well is constrained, creating undesirable and unjust situations. For example, a commodified understanding of healthcare impedes access to palliative care services that enable people to navigate suffering in all its dimensions. Moreover, an understanding of palliative care as a specialist service provision without strong connections and attention to the context where people live their lives also constrains and negatively shapes the dying process.

If we think about dying as pertaining primarily to healthcare settings, most probably the main demands from people suffering from life-threatening illnesses and their families will be to have better access to those services. Similarly, if palliative care's focus is only on the provision of certain services linked to clinical settings, its contribution to reshaping and rebalancing death and dying will, at best, reach those who can access those services. As discussed, many of those who are in greater need of palliative care will never be able to access those services if the structure offering palliative care stays as it is. In the first chapter, we showed how there is a growing need for palliative care which will put increased pressure on healthcare systems that might already be struggling. The possibility for developing compassion at a community level comes from acknowledging that the end of life is not only a medical event.

Putting compassion into practice is not a straightforward task. We have argued that it is not only an individual endeavor. As Paul Farmer writes, "Accompanying the destitute sick on a journey away from premature suffering and death–out of the country of social suffering, through the door of yes–is not a single life's work, but rather the work of many, pulling together and over long years and many miles."[226] The embodiment of compassion is intrinsically related to the structures that people inhabit. There is not only one such structure; as we indicated above, people are part of several structures simultaneously. Some might be more virtuous than others. Some might be more oriented to or facilitate putting compassion into practice. By promoting a healthcare model at the end of life that is predominantly medically based or restricted to professional healthcare settings, communities might feel that it is not their moral duty to care or be attentive to those experiencing life-limiting illnesses around them. Opportunities for virtuous agency–i.e., embodying compassion or putting compassion into practice in these cases–are not something that might be on their radar, preventing personal and social virtuous growth. Moreover, it could prevent accompanying one another's suffering, shaping the moral character of individuals and communities regarding the process of dying.

As discussed, palliative care can be seen as a structure of that sort. It is an institutionalized response to the questions and needs that accompany death and dying. However, as we indicated, not all responses are equally virtuous. A population health, community-based approach to palliative care can promote compassion in ways that foster virtuous people and communities. A critical awareness of structures of virtue and vice and their dynamics "enable persons to acquire habits in which they recognize the value of the other, promote the normative dignity of the other and enter into loving and merciful relations with others."[227]

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[226] Paul Farmer, "Conversion in the Time of Cholera: A Reflection on Structural Violence and Social Change," in *In the Company of the Poor: Conversations between Dr. Paul Farmer and Fr. Gustavo Gutierrez*, ed. Michael P. Griffin and Jennie Weiss Block (Maryknoll, NY: Orbis Books, 2013), 135.
[227] Daly, *The Structures of Virtue and Vice*, 172.

The last chapter will propose a model of palliative care that considers the elements described here as a way of rebalancing contemporary experiences of death and dying and the practices associated with them.

4. Envisioning Paths Forward

As seen in the last chapter, the promotion and development of virtuous structures that can help shape the agency and character of persons and contribute to the well-being of people, especially the most vulnerable, is typically an intentional, socially coordinated endeavor. The ethical lens presented helps address the deficiencies found in contemporary death and dying and envision possible paths forward. This chapter will present different possible applications of what has been previously discussed, along with their limitations. The main focus will be on initiatives that might contribute to the development and reform of structures that can foster a more virtuous approach to death and dying. These initiatives speak to the double way in which structures can be vicious or virtuous: helping shape agency and character, and being involved in the well-being of people and groups, especially the most vulnerable, in relation to the common good.

First, we will explore one of the recent developments of care at the end of life, which has been called Public Health Palliative Care (PHPC). As briefly introduced and mentioned in the second chapter, it is one of the approaches available in palliative care and one of our contemporary institutional responses to death and dying. These structural responses have their own limitations and are connected with some of the problems individuals, families, and communities face at the end of life. PHPC is not exempt from contributing to the vicious effects already present in healthcare structures; however, it will be argued that it can provide alternative virtuous development. Second, within PHPC, Compassionate Cities and Communities will be described as a model that aims to overcome some of the present barriers in end-of-life healthcare, fostering virtuous, compassionate care. An application of the model in Seville, Spain, will be presented. Third, drawing on one of the specific ways PHPC can foster virtue, attention to the social determinants of health will be explored. From a gendered perspective, we will focus on the context of LMICs and the benefits and limitations of applying such a model. Lastly, from a different perspective, a contemporary application of the *ars moriendi* model as a tool for spiritual assessment will be discussed.

4.1. Public Health Palliative Care

As described in the second chapter, including a public health perspective in palliative care opens the possibility for new ways to provide care.

PHPC's conceptual frame fosters new approaches to end-of-life care regarding the creation of new systems and helps address structural issues of healthcare at the end of life. Rumbold states it "provides a radical critique of palliative care… [reclaiming] aspects lost as those community projects were drawn into mainstream health."[228] It also critiques public health ideas because it stresses that death, dying, and loss, as well as communities with all their agents, must be included in organized care efforts.[229]

In order to incorporate and address the social nature of death and dying, the model of health should be reframed to a social model where many of the overlooked aspects can be included.[230] According to Kellehear, behind PHPC approaches lies precisely a social model of health because it reflects a series of themes present within that model:

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[228] Rumbold, "A History of Public Health Palliative Care," 44.

[229] See ibid.

[230] See Allan Kellehear, "The Social Nature of Dying and the Social Model of Health," in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear, (Oxford: Oxford University Press, 2022), 26.

> (1) an emphasis on the social determinants of health while living with ageing, dying, caregiving, and grief and bereavement; (2) an emphasis on practice methods in public health as equal priority alongside clinical practice methods; (3) an emphasis on cultural awareness that minimizes anguish about social differences by employing a participatory style of working rather than assuming the traditional 'expert' stance of authority and paternalism; (4) an emphasis and awareness of the politics of health that means working equally for prevention and health-promotion sciences and priorities alongside those from clinical management; and (5) recognizing and working with other voices in the health, social care, civic, and community contexts of practice.[231]

Many of these ideas, included in the WHO guide for planning and implementing palliative care, have taken shape in the Compassionate Cities and Compassionate Communities paradigm which will be briefly addressed.[232]

4.2. Compassionate Cities and Communities

Allan Kellehear's *Compassionate Cities* has significantly influenced the development of PHPC. An exploration of Kellehear's proposal in *Compassionate Cities* shows what he calls 'seven conceptual tensions' between the ideas of palliative care and public health. By exploring and expanding these tensions, we are able to capture some of the complexities at play and envision ways in which structures regarding care at the end of life can be virtuous and address possible vices. He challenges a series of set ideas that are part of the current understanding of palliative care offering a more nuanced approach to what a new model could offer. As an example, he argues that the valued psychosocial dimension in 'mainstream' palliative care "is not public health end-of-life care because its definition of the community is marginal, its idea of personhood barely goes beyond the idea of the patient, and because its policy development is

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[231] Ibid., 27.

[232] See Gonzalo Brito-Pons and Silvia Librada-Flores, "Compassion in Palliative Care: A Review," *Current Opinion in Supportive & Palliative Care* 12, no. 4 (December 2018): 5.

hopelessly committed to self-interested notions of service sector and professional development rather than community development and citizen participation."[233]

Regarding the tensions, first, even if palliative care is patient-centered, Kellehear establishes that there is a challenge forward translating a patient-centered approach to a citizen-centered one in order to "transform its understanding from services and learning for patients to partnerships with citizens and learning from communities."[234] Public health approaches in end-of-life identify individual and family needs concerning services available and aim to establish systems that "allow active participation of people and their social networks in the care provided at the end of life."[235] Informal care is also considered in this perspective as the model aims to connect and establish partnerships among the different borders of the 'circles of care' referred to in the second chapter of this thesis. However, participatory relations and relationships need to be assessed. Participatory models vary, and differences can be appreciated between 'community development,' 'community engagement,' or 'social networks.' However, they can foster ways in which existing capacities and virtues can be developed even if there is still much growth regarding power dynamics within healthcare structures.[236]

Another tension is the capacity of palliative care to build 'social capital' in a community rather than just dedicating efforts to consolidate its place in the healthcare system by including a greater number of occupations under its umbrella. Kellehear writes that this self-interest movement in

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[233] Kellehear, *Compassionate Cities,* 25.

[234] Ibid., 47.

[235] Rumbold, "A History of Public Health Palliative Care," 49.

[236] See Kerrie Noonan, "Participatory Relations," in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear, (Oxford: Oxford University Press, 2022), 102.

palliative care is understandable due to the limited time it has been part of the health system, but it should not be restricted to that.

In the family-community tension, the author writes that one of the challenges is paying attention to those networks “capable of sharing the burden of care in practical ways beyond members of a family.”[237] It is in this context that will “the idea of ‘community-based’ transform into a genuine community development, a framework that not only extends the idea of family but underpins and supports it.”[238]

Regarding holistic care, Kellehear advocates for a type of care closer to the understanding of public health, which includes ecology, politics, community, settings, and environments. This approach highlights the individual-in-community aspect of things. According to the author, “the ‘whole person’ care–the body and mind of the person is disconnected from his or her usual physical place at the work desk, the bar, the club, the church or the theatre. The whole person is really the whole patient.”[239] Whole person care really means whole community care.[240]

Another tension that is identified is occupational capacity building versus community capacity building. Here the shift would entail a reorientation of the understanding of what service providing in palliative care means, recognizing that “addressing complex human needs is not simply adding yet another occupation to the ever-growing ‘interdisciplinary team.’”[241]

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[237] Kellehear, *Compassionate Cities,* 49.
[238] Ibid.
[239] Ibid., 50.
[240] See Kellehear, “The Social Nature of Dying and the Social Model of Health,” 29.
[241] Kellehear, *Compassionate Cities*, 51.

Kellehear also writes about a tension mentioned before regarding the distinction between palliative care and hospice. He uses ‘palliative approach’ to refer to care not limited to the last days or hours of life. Early intervention in palliative care resonates with much of the public health approach. Lastly, another tension is moving from cancer care to end-of-life care. *Compassionate Cities* was written in 2005, and palliative care has evolved, considering care at the end of life not mainly addressed to cancer patients, even if these are the people that most benefit from or use palliative care. Some of the problems regarding unequal attention to causes of mortality have been previously described.

In Kellehear’s proposal, these tensions are situated in a framework where compassion is one of the central concepts that shape its implementation. Compassion is thought of as “an ethical imperative for health.”[242] However, a more detailed account of what the author means by that would be needed. Similar palliative care proposals have also established compassion as a crucial virtue in healthcare at the end of life.

Compassion in Palliative Care

Compassion is at the core of human experience and is an essential virtue concerning healthcare at any point in life. Some of the models of PHPC, such as Compassionate Cities and Communities, have incorporated it as the cornerstone of their proposal. In a study regarding compassion in palliative care, Gonzalo Brito-Pons and Silvia Librada-Flores highlight that models “that integrate communal, social, and medical resources could serve as a natural place of entry of a humanizing mindset that takes better care of patients and caregiver for the whole

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[242] Ibid., 44.

healthcare system."[243] From a patients perspective, compassion, differing from sympathy, empathy or pity, is highly valued and seen as a "virtuous response that seeks to address the suffering and needs of a person through relational understanding and action."[244]

Moreover, the benefits of this compassionate care extend to healthcare professions and systems. Brito and Librada-Flores also explore the possible negative aspects associated with compassion in healthcare, such as 'compassion fatigue.' However, they conclude that even if the term is widely used, research shows that behind it really lies a composite of other elements such as burnout, secondary traumatic stress, and other possible work-related factors such as moral distress, economic pressures, toxic organizational cultures, work overload, or job insecurity.[245] Pointing to compassion as the cause of fatigue, and the reasoning that less compassion would foster less fatigue "goes against the need expressed by patients, families, and professionals to increase compassion in healthcare."[246] Nevertheless, there is a need to have a good understanding of the suffering experienced by healthcare professionals and the possible ways of addressing it.

In her work regarding the implementation of Compassionate Communities, Librada-Flores establishes that "compassion has been shown to improve the quadruple aims of improving patient experiences, population health, professional experiences, and organizational effectiveness."[247] In this model of care, compassion is not only something available but

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[243] Brito-Pons and Librada-Flores, "Compassion in Palliative Care," 6.

[244] Ibid., 1.

[245] See ibid., 2–3.

[246] Ibid., 2.

[247] Silvia Librada-Flores et al., "'Compassionate City' in Patients with Advanced Illnesses and at the End of Life: A Pilot Study," *International Journal of Environmental Research and Public Health* 20, no. 3 (January 26, 2023): 1.

something that can also be trained and fostered. The centrality of this virtue can provide action guidance promoting healthcare and palliative care models where the development of this and other related virtues is not constrained. Moreover, compassion has the potential to question and help the reorientation of previous existing models.

Churches in Compassionate Cities and Communities

Included in the Charter for Compassion, churches can have an important role in compassionate cities and communities. As a structural part of the communities that people inhabit, their role underscores the importance of taking into account the spiritual dimension of people at the end of their lives, but it is not limited to that. Churches can contribute actively to the promotion of virtuous structures at the end of life and can themselves question how they are engaged in such care. Due to the limitations of this thesis, this role will not be discussed in detail.

As a concrete action stemming from the virtues suggested throughout his work and a possibility of training compassion, Vogt studies the example of a parish-based lay ministry program for the dying. He writes: "Participants would learn to listen to the voice of suffering, to seek and enter into that suffering and feel it as their own, and to act on behalf of and in concert with the dying. The ministry would itself serve as the embodiment of the fourth dimension of Christian compassion, namely integrating and connecting the dying to the Christian community."[248]

Vogt agrees with the need for decompartmentalizing care for the dying.[249] However, his solution draws on the work of volunteers and reflects on the positive impact of that kind of ministry in the

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[248] Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well*, 136–137.
[249] See ibid., 137.

community. He sees a triple benefit of the ministry he proposes: institutionalizing the connection between dying and the rest of life, making some understandings of Christian anthropology concrete, and allowing people to prepare for their own death by serving those dying.[250]

Implementation of Compassionate Cities and Communities

Currently, within this PHPC approach, three main models stand out: top-down models from health services to the community, bottom-up models of community participation through actions where communities are involved in their health promotion, and models where organizations and communities through participation ensure, assess, offer tools, and propose solutions to population needs.[251]

One of the methods for developing Compassionate Cities and Communities is the 'All with You' method proposed by professionals of the non-profit organization New Health Foundation (NHF), which aims to foster "a new model of integrated health, social, and community care by improving the effectiveness and efficiency of organizations and the well-being of people with advanced stage diseases, high dependency situations and at the end of life."[252] The 'All with You' method was designed following the 13 changes contained in the Compassionate City Charter promoted by Public Health Palliative Care International (PHPCI).[253] As Librada Flores et al. write, its main objective "is for people who are living with advanced illness or facing the

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[250] See ibid., 138.
[251] See Silvia Librada-Flores et al., "Implementation Models of Compassionate Communities and Compassionate Cities at the End of Life: A Systematic Review," *International Journal of Environmental Research and Public Health* 17, no. 17 (August 28, 2020): 1.
[252] Silvia Librada-Flores et al., "All with You: A New Method for Developing Compassionate Communities—Experiences in Spain and Latin-America," *Annals of Palliative Medicine* 7, no. S2 (April 2018): 2–3.
[253] See Klaus Wegleitner, Katharina Heimerl, and Allan Kellehear, eds., *Compassionate Communities: Case Studies from Britain and Europe*, (New York: Routledge, 2015).

end of life to be able to satisfy their primary needs through the social and health care services provided by palliative and community care, together with their support networks."[254] An overview of the eight-phase method includes:

i. Identification of the sponsoring institution and establishment of contractual agreements
ii. Definition of the scope of the project and development of a map of key stakeholders
iii. Baseline analysis and identification of the desired outcomes
iv. Design and implementation process including:
v. Community promoter or promoters
vi. An intervention protocol to enable the creation and management of care networks (RedCuida protocol) [255]
vii. Verification of achievements
viii. Certification and recognition as a compassionate community, institution, or city
ix. Evaluation and follow-up
x. Renewal of certification where appropriate[256]

This method was used in several cities in Spain, such as Seville, Badajoz, Pamplona, and Getxo, and in Latin America, in Colombia, and Argentina. The authors acknowledged several barriers in the implementation process, including the identification and referral of patients and the incorporation and connection to social and community services. Apart from this, they highlighted the need to analyze and evaluate the model's implementation. An example of this evaluation of the impact on the health of the population beneficiary of the program was recently done by Librada-Flores et al. in Seville, Spain, for the '*Sevilla Contigo, Compassionate City'* pilot experience from January 2019 to June 2020.[257] The authors concluded that the method and systemic evaluation "allow for the verification of the improvement in the quality of life and well-

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[254] Librada Flores et al., "All with You," 3.
[255] See Silvia Librada Flores et al., "Development and Management of Networks of Care at the End of Life (the REDCUIDA Intervention): Protocol for a Nonrandomized Controlled Trial," *JMIR Research Protocols* 7, no. 10 (October 12, 2018): e10515.
[256] Librada Flores et al., "All with You," 5–6.
[257] See Librada-Flores et al., "'Compassionate City' in Patients with Advanced Illnesses and at the End of Life."

being of the patients, a greater satisfaction of the family and their care networks, an improvement in loneliness, an increase in the care network and a greater number of needs satisfied by the network."[258] A similar experience is reflected in the work of Julian Abel and Lindsay Clark in the town of Frome, Somerset, UK, and captured in the book *The Compassion Project: A Case for Hope & Humankindness from the Town that Beat Loneliness*.[259] Among the results of implementing a compassionate community model in Frome was the reduction of hospital emergency admissions by 30%, leading to a 6% reduction in the total cost of the health system.[260]

Although literature regarding the evaluation of this model is scarce, authors like Librada-Flores et al. point out several indicators, such as satisfaction of the beneficiaries of the programs, cost-effectiveness, and effects on ethical decision-making processes and ethical behavior.[261] Moreover, even if only through descriptive evaluations, positive outcomes can be seen, such as "quality of life, decrease in loneliness, increase of the number of networks, [and] decrease in the main carer burden."[262] However, due to differences in the aims and frameworks of some of the programs, comparative analyses between them have not yet been possible. The variability in the design of implementation methods of Compassionate Communities and Cities has made it difficult to evaluate and assess the programs.

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[258] Ibid., 16.
[259] See Julian Abel and Lindsay Clark, *The Compassion Project. A Case for Hope & Humankindness from the Town That Beat Loneliness* (London: Aster, 2020).
[260] See Brito-Pons and Librada-Flores, "Compassion in Palliative Care," 6.
[261] See Librada-Flores et al., "Implementation Models of Compassionate Communities and Compassionate Cities at the End of Life," 12.
[262] Ibid.

4.3. Public Health Palliative Care and Social Determinants of Health and Death

One of the crucial ways PHPC can contribute to creating and promoting virtuous structures is through its attention to the social determinants of health and death. PHPC has at its core "a focus on equity, inclusivity, and diversity."[263] Attention to the structural conditions that create or are complicit with the inequities at the end of life implies attention to intersecting inequities of those experiencing disproportionate barriers in access to healthcare, specifically palliative care.[264] Avoidance of healthcare or palliative care services is not infrequent among populations that have experienced or experience different kinds of oppression, discrimination, or stigmatization. As Kelli Stajduhar and Merryn Gott write, "for many, mistrust of health professionals is compounded by a lack of culturally safe and trauma and violence informed care, as well as a lifetime of not being believed or deemed worthy of help."[265] For example, fear affects healthcare to the extent that undocumented migrants in the United States who require health assistance refrain from using their limited available options due to the concern that their information could be shared with other government agencies, leading to arrest and deportation.[266]

Equity-oriented palliative care should also question how attention to the most vulnerable population is framed to prevent and address the undesirable effects of colonization within healthcare. As discussed in the previous chapter, certain structures designed for good or neutral ends can eventually have vicious effects on the population they intend to serve. That is why

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[263] Holly Prince et al., "Public Health Palliative Care, Equity-Oriented Care, and Structural Vulnerability," in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear, (Oxford: Oxford University Press, 2022), 197.
[264] See Kelli Stajduhar and Merryn Gott, "Closing the Health Equity Gap in Palliative Care: The Time for Action Is Now," *Palliative Medicine* 37, no. 4 (April 2023): 424.
[265] Ibid.
[266] See Roxanne P. Kerani and Helena A. Kwakwa, "Scaring Undocumented Immigrants Is Detrimental to Public Health," *American Journal of Public Health* 108, no. 9 (September 2018): 1165.

"using strengths and community-based, equity-oriented and harm reduction approaches, these initiatives strive to address the problems created and sustained through political, economic, and social systems of disadvantage."[267]

As we saw in the first chapter, the situation regarding palliative care in LMICs is dire. Many of the barriers described, namely, access to medicine and medical equipment, access to services in increasingly commodified healthcare systems, formation, and availability of human resources, and psychological, sociocultural, and financial barriers, have a considerable impact on the health outcomes of already vulnerable populations. Even if this is the situation, Suresh Kumar and Jariam K. Ramakrishnan argue that "income poverty does not mean and should not mean poverty of community supports and relationships."[268]

LMICs face a double challenge: a structurally and functionally weak healthcare system and largely unmet palliative care needs.[269] Against a perspective that would oppose the development of the healthcare system to the development of palliative care, Kumar and Ramakrishnan argue that the latter "must not wait for the health system to develop to the best standard feasible."[270] Doing this would mean consigning individuals, families, and communities to unnecessary suffering. However, the development of palliative care in this context must search for and envision alternative ways to avoid confining people to the limits of service provision. In this sense, "if the limits of palliative care–and the limits of healthcare–are to be defined by the

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[267] Prince et al., "Public Health Palliative Care, Equity-Oriented Care, and Structural Vulnerability," 204.
[268] Suresh Kumar and Jairam Kamala Ramakrishnan, "Public Health Palliative Care Design and Practice in Low-and-Middle-Income Countries," in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear, (Oxford: Oxford University Press, 2022), 209.
[269] See ibid., 210.
[270] Ibid.

location of a service provider, palliative care will never penetrate beyond most urban areas or certainly only provide elementary services when they do."[271] Even if the perspective is challenging, and palliative care initiatives in LMICs are still in the early stages, this could be seen as a unique opportunity for palliative care.

4.4. A Gender Perspective in PHPC Programs in LMICs

Merryn Gott, Tessa Morgan, and Lisa Williams have highlighted the neglect of gender in palliative care policy, practice, and research.[272] In their study, they focus on the experience of cis-women and argue that "any commitment to the sex and gender-blind nature of the status quo within palliative care is disadvantaging to everybody, regardless of gender identity."[273] Taking into account the gendered nature of death and dying, the authors draw on studies performed in different countries to describe how the reality today is that most caregivers at the end of life are women.[274] This situation has implications that PHPC programs cannot overlook. Gender stereotyping ideas regarding the role of women as caregivers at the end of life and cultural expectations are also part of the healthcare system and can even be reinforced by healthcare professionals and those who design palliative care programs.

This finding is especially true in LMICs, where it is "more pressing than ever to address the question of how feminization of poverty plays out at the end of life."[275] In Cameroon, for example, the reality of women's work shows the particularly vulnerable situation faced by many

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[271] Kellehear, "The Social Nature of Dying and the Social Model of Health," 28.
[272] See Merryn Gott, Tessa Morgan, and Lisa Williams, "Gender and Palliative Care: A Call to Arms," *Palliative Care and Social Practice* 14 (January 2020): 1.
[273] Ibid., 9.
[274] See ibid., 3.
[275] Ibid., 8.

of them, especially those that belong to the 37.5% of the population that lives below the poverty line, 90% of which live in rural areas.[276] Even if Joseph Loïc Mben does not directly address end-of-life care in his work, his analysis of unpaid reproductive labor depicts an imbalance that "betrays the fact that Cameroonian society clearly views unpaid reproductive labor as the primary duty of women. On average, employed women spend three times more than employed men on unpaid caring labor."[277] Regarding care at the end of life, apart from actual care given by women, there is a need to acknowledge and address cultural practices associated with death and dying as they can contribute "significantly to gender inequality and gender-based violence around the world."[278]

From this perspective, Gott and colleagues establish some important critiques concerning PHPC programs in their study. The first is the "uncritical assumption in palliative care policy internationally that end-of-life care 'in the community' is both desired and achievable for all."[279] Part of the challenge here is articulating responsibilities at the end of life. The second criticism underscores the risk of portraying communities as homogeneous and free of conflict.[280] Third, most community care is done and carried by women, being broadly unacknowledged, undervalued, and expected.[281] Associated with this reality is the risk of further obscuring it by not including the cost of 'informal care' in economic analyses of palliative care. The last critique

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[276] See Joseph-Loïc Mben, *A Gendered African Perspective on Christian Social Ethics: Empowering Working Women in Cameroon* (Lanham, MD: Lexington Books/Fortress Academic, 2021), 112.
[277] Ibid., 114.
[278] Sallnow et al., "Report of the Lancet Commission on the Value of Death," 854.
[279] Gott, Morgan, and Williams, "Gender and Palliative Care," 10.
[280] See ibid.
[281] See Libby Sallnow, "Prevention and Harm Reduction," in *Oxford Textbook of Public Health Palliative Care*, ed. Julian Abel and Allan Kellehear, (Oxford: Oxford University Press, 2022), 82.

refers to the scarcity of "gendered analyses of concepts such as 'compassionate communities' and attention will need to be paid to ensuring 'community' does not equal 'women's work.'"[282]

4.5. A Contemporary Application of the *Ars Moriendi*

Even if what has been previously discussed is more related to how structures can promote or constrain virtue and vice, this last section presents a possible application aimed at persons facing the end of their lives and in reference to a clinical or home care setting, although not limited to them. The *ars moriendi* model discussed in the second chapter highlighted the connection between life and death and how the spiritual dimension could be crucial in examining virtues at the end of life. An example of how the *ars moriendi* can be applied in contemporary end-of-life care is the 'Ars Moriendi Model' (AMM) used for spiritual assessment in palliative care. It is a reinterpretation of the model used in the context of palliative care. The model proposed by Carlo Leget has been applied in the University Hospital of Louvain, and pilot studies have been carried out in palliative home care.[283] In his book *Art of Living, Art of Dying*, he draws on the *ars moriendi* tradition and revisits some of its aspects. In his model, Leget focuses on the five temptations that the dying person would experience:

i. The loss of one's life (the loss of faith)
ii. The loss of one's confidence in salvation (desperation)
iii. The hanging on to temporal affairs (avarice)

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[282] Gott, Morgan, and Williams, "Gender and Palliative Care," 10.

[283] See Carlo Leget, "Retrieving the Ars Moriendi Tradition," *Medicine, Health Care and Philosophy* 10, no. 3 (September 2007): 313–319; Mieke Vermandere et al., "Implementation of the Ars Moriendi Model in Palliative Home Care: A Pilot Study," *Progress in Palliative Care* 21, no. 5 (November 2013): 278–285; Mieke Vermandere et al., "The Ars Moriendi Model for Spiritual Assessment: A Mixed-Methods Evaluation," *Oncology Nursing Forum* 42, no. 4 (July 1, 2015): 294–301; Mieke Vermandere et al., "Spiritual History Taking in Palliative Home Care: A Cluster Randomized Controlled Trial," *Palliative Medicine* 30, no. 4 (April 2016): 338–350.

iv. The inability to deal with pain and suffering (impatience)
v. Pride (complacency)[284]

For the author, these are “five themes that still play a pivotal role in the dying process.”[285] However, acknowledging the cultural shift that distances the medieval period from contemporary society, he rethinks the model from a different perspective because “the five-fold choice between two extremes is too rigid for contemporary culture. Dying seems to be approached as a final test or exam in which there is no place for the process of searching and trying.”[286] He wants to move away from an *ars moriendi* model that, as he understands it, provides only an either/or choice to the dying patient.[287]

His proposal would work like “a common framework for interdisciplinary communication and a model for personal reflection and meditation that can easily be remembered.”[288] He changes the medieval model by inverting the five themes, translating them into ‘non-moral categories’ and reframing them into the following questions:

i. Who am I, and what do I really want? (Oneself – The other)
ii. How do I deal with suffering? (Doing – Underdoing)
iii. How can I say goodbye? (Holding on – Letting go)
iv. How do I look back on my life? (Remembering – Forgetting)
v. What can I hope for? (Knowing – Believing)

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[284] See Leget, “Retrieving the Ars Moriendi Tradition,” 313.
[285] Ibid., 315.
[286] Ibid.
[287] See ibid., 314.
[288] Ibid.

This model would work more like a field of tensions rather than choices. Figures 4 and 5 in the Appendix visually depict the tensions as they are understood and used. Figure 4 refers to the original theoretical approach explained in his book. Figure 5 is the application to a particular clinical setting, as referred to in the articles.

Essential to this model is what he calls ‘inner space.’ Its availability will influence the success of working with the Ars Moriendi Model.[289] Leget defines inner space as “a metaphor for a state of mind in which one is able to experience a number of thoughts, emotions, impulses, feelings and so on, without identifying with them or being swept away by them.”[290] When a further description is provided, he highlights that it is “composed of two spatial concepts and refers to a non-spatial phenomenon that can be perceived in an individual’s inner life.”[291]

Three strengths of this ‘new *ars moriendi*,’ as Leget calls it, can be pointed out. Firstly, although the concept of ‘inner space’ is not a robust one, the model provides interesting flexibility to be easily appropriated by patients, caregivers, and healthcare professionals regardless of their specific cultural or religious backgrounds. It highlights both the individual and the communal aspect, privileging relationality, considering the patients holistically in all their dimensions, and fostering an interdisciplinary patient-centered approach to care at the end of life. A second strength is the possibility of exploring the ‘five themes’ as tensions. It could be argued that the medieval *ars moriendi* could also be understood as having that capacity, but in Leget’s model, the processual aspect is clearly emphasized. With the diagnosis of a terminal illness, patients

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[289] See Carlo Leget, *Art of Living, Art of Dying: Spiritual Care for a Good Death* (London; Philadelphia: Jessica Kingsley Publishers, 2017), 60.
[290] Ibid., 49.
[291] Ibid., 62.

start a journey that will challenge their relational way of being, which, according to Keenan, is at the same time “general, specific, and unique.”[292] This journey entails, among other things, a process that implies searching and locating oneself and others in a field of tensions. Lastly, it maintains one of the strongest points of the *ars moriendi*–the connection between life and death–with the person being at the center of the process. Although patient-centered, palliative care also addresses the caregiver and the community where the person belongs. Including the ‘inner space’ in its approach highlights the importance for people to explore their own spiritual dimensions.

Regarding the limitations of the model, it can be said that, to some extent, it risks being reduced to another more or less helpful tool to assess the spiritual care of patients in end-of-life care. Over the years, several studies have been developed with different methodologies to evaluate the model applied to palliative home care in Belgium. Their findings have not been conclusive, mainly due to small sample size, although they indicate the model’s usefulness in palliative care.[293] In that sense, although it is somehow implied, the model lacks a more explicit account of the virtues, despite the fact that Leget discusses virtues in his book. In particular, he advocates for virtues in his exploration of ‘inner space’ but seems inconsistent when acknowledging their capacity to provide action guidance.

When revisiting his five tensions or ‘five struggles,’ Leget’s account seems similar to a generic exploration of virtue and vice. However, he insists on multiple occasions on reframing what he considers ‘moral categories’ into ‘non-moral categories.’[294] For example, if in the traditional model dealing with pain and suffering were linked to the virtue of patience and the vice of

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[292] James F. Keenan, “Proposing Cardinal Virtues,” *Theological Studies* 56, no. 4 (December 1995): 723.
[293] See Vermandere et al., “Spiritual History Taking in Palliative Home Care.”
[294] See Leget, *Art of Living, Art of Dying*, 54.

impatience, by re-establishing the poles as "doing and underdoing," virtues could be seen as non-moral categories. The question accompanying this particular point is, "How do I deal with suffering?"[295] By asking this question, Leget is trying to avoid what he considers to be the "highly moralistic" component of the medieval model which would impede its universal application. Hence, it could be argued that his interpretation of the moral component is understood almost as an exclusively normative account, where virtues would seem incapable of providing that more open account, guidance, and assessment. He writes, "This is a highly reductionist and deductive way of dealing with morality. It does not allow new experiences to be integrated in moral deliberation: the map has already been drawn, and those who use the map are not entitled to change it."[296] However, as we have suggested, his approach is reductionistic, and virtues can offer action guidance. As seen in the previous chapter, even at the end of life, the virtues speak to the complexities of moral life, and their way of providing normative guidance is not agent-blind. One last limitation is the focus on the individual, without considering the family and the wider community fully as virtuous agents involved in the person's dying process. Implied in the exploration of the different tensions, there is attention to the relationships the persons might have with their family and community, but the development of virtues is limited to the individual patient's view. As we have suggested, the perspective and the tools used to help those facing a life-limiting or life-threatening illness must take into consideration the structures they inhabit. Sometimes it might not be possible to make it an explicit component of a particular tool or approach, but it would be beneficial if included in their design, application, and evaluation.

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[295] Ibid.
[296] Ibid., 51.

In relation to the lens developed in the previous chapter, here we have explored some concrete ways in which the problems associated with death and dying could be solved. Public Health Palliative Care, as a movement within palliative care, with its different developments and specific tools, has the capacity to foster virtues and address vices at the end of life.

Conclusion

Unjust situations at the end of life, like those described in this thesis, require attention to the people experiencing life-limiting or life-threatening illnesses in a way that does not neglect the relations and contexts they inhabit. Individual change is insufficient in pursuing social justice at the end of life. Envisioning possible paths for care at the end of life requires attention to its complexities in a non-reductionistic way that promotes virtuous individuals, communities, and institutions.

Chapter 1 showed how the approach to healthcare from which death and dying are primarily understood had generated a series of undesirable consequences. Healthcare, examined from a medical and institutional perspective, has led to a problematic imbalance at the end of life, undermining the value of death and disconnecting it from life. This situation and its associated issues have been made more clearly manifest with the COVID-19 pandemic. Considered one of the pillars of universal health coverage, palliative care, as a structure within healthcare, aims at providing a response to accompany people at that moment in their lives. However, the current palliative care approaches and provisions are not accessible to an increasing number of people experiencing serious health-related suffering, especially more vulnerable populations. Regrettably, there is a significant contrast in providing palliative care between the Global North and the Global South.

Over time there have been different ways to provide care for those dying. Chapter 2 addressed two different resources on care at the end of life. In a historical and theological approach, the *ars moriendi* tradition, presented by discussing the works of three Jesuits, explored how care for the dying was connected to virtuous behavior. Although palliative care goes beyond the *ars moriendi* tradition, we showed how it could also be seen as pursuing a similar goal in the contemporary setting. The second resource that we present–i.e., the recent development of a palliative care model that integrates a public health perspective–also sheds light on the question of the value of life, what dying well means, the connections between life and death, and how a just approach to end of life care can be rethought.

An ethical lens was developed in the third chapter in order to address the problems presented. Understanding death and dying from a systems perspective, structures and relations that shape the experience of dying had to be explored. Virtue ethics was chosen as the more appropriate framework to do this. Its attention to all the aspects of moral life, and its capacity to provide action guidance in a different way compared to other ethical approaches, are among the reasons for this choice. Daly's proposal of structures of virtue and vice, along with the 'preferential option for the poor,' offered a way to address the promotion of virtues at the end of life that takes into consideration a liberating perspective emphasizing attention to the most vulnerable. The virtue of compassion was discussed due to its centrality within the virtues and its pertinence in care at the end of life.

The last chapter has shown what the socially coordinated endeavor of creating or re-creating virtuous structures could look like by presenting and assessing a number of initiatives related to our discussion and ethical lens. We have considered how Public Health Palliative Care (PHPC) and models that stem from it can contribute to this work due to its characteristics, such as attention to the social determinants of health and death, combined public health and clinical practice methods, cultural awareness reflected in its participatory style, awareness of politics of health, and ability to work with others. One of the applications of this approach is the

Compassionate Cities and Communities paradigm that was described. Essential to this initiative is how compassion shapes the whole design, implementation, and evaluation process of these endeavors.

The interrelationship between virtues and dying underscores the need for the connection between life and death, as seen in the *ars moriendi*. Death cannot only be seen as a medical event but as a possibility for virtuous growth and well-being that is not restricted to the individual. PHPC proposes a model of health where ‘health promotion’ in its broad sense can also happen at the end of life until the last moments of one’s life. That is why a social model of health, a public health palliative care approach, can help address many of the important barriers that currently make dying well harder and a privilege for some. This is especially true for people without access to ‘mainstream’ palliative care services, as it happens in the current healthcare system.

We have argued that crucial to the achievement of social justice at the end of life is the development of virtuous structures which contribute to both shaping moral agency and fostering relations that promote human dignity and well-being, with special attention to the most vulnerable.[297] As a structure with the potential to address existing vices and cultivate potential virtues, this kind of palliative care must be developed, promoted, and able to offer equitable access. As Vogt writes, there is a potentially transformative effect in the pursuit of virtue, even in situations otherwise predisposed to despair.[298]

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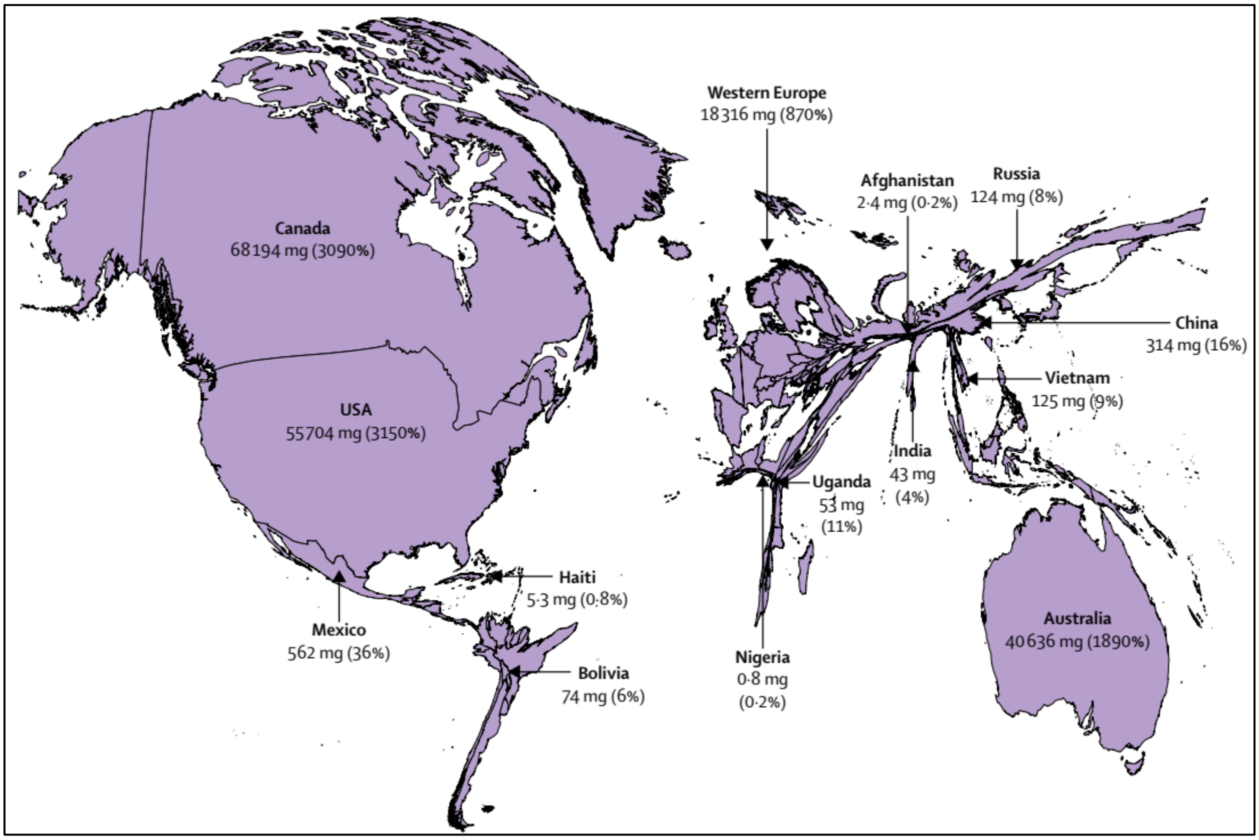
[297] See Daly, *The Structures of Virtue and Vice*, 169.
[298] See Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well*, 136.

Appendix

Figure 1: Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010-2013) and estimated percentage of need met for the health conditions most associated with serious health-related suffering.[299]



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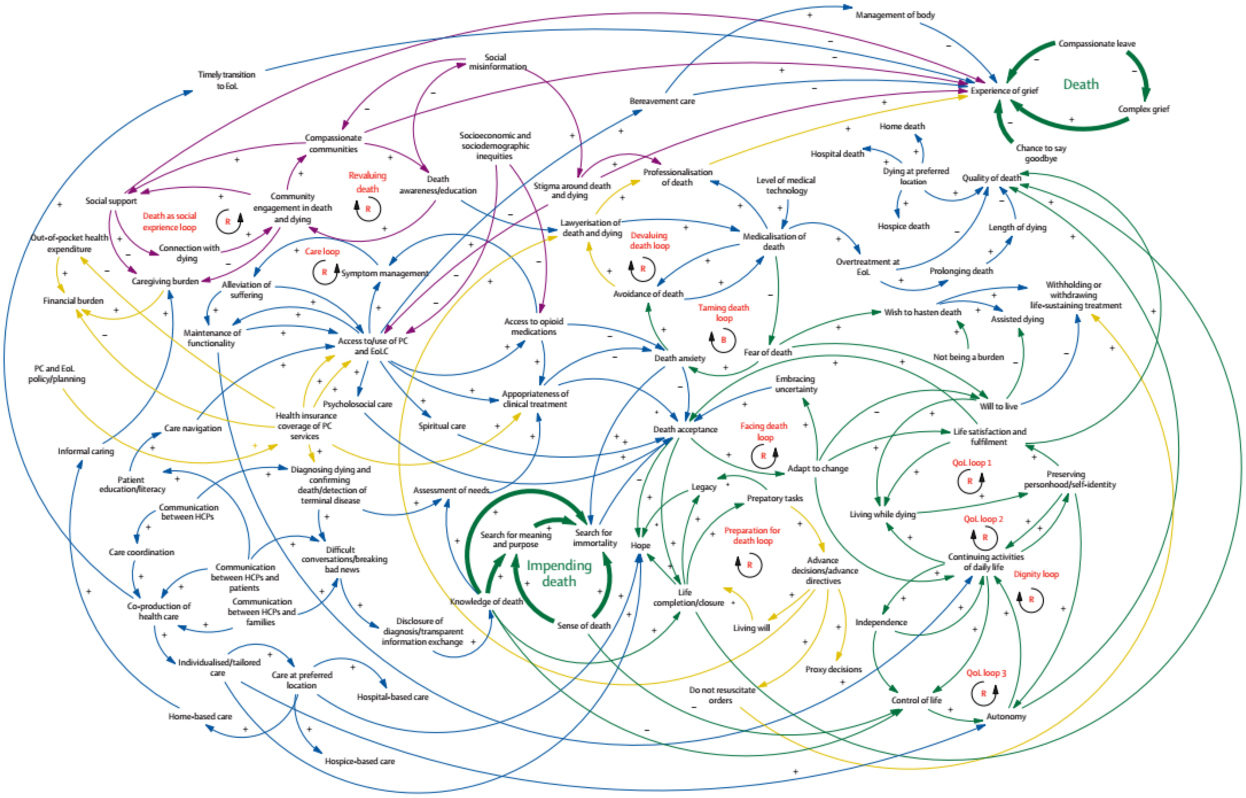
[299] Knaul et al., “Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage,” 1392.

Figure 2: Example of a dynamic map of an end-of-life system[300]



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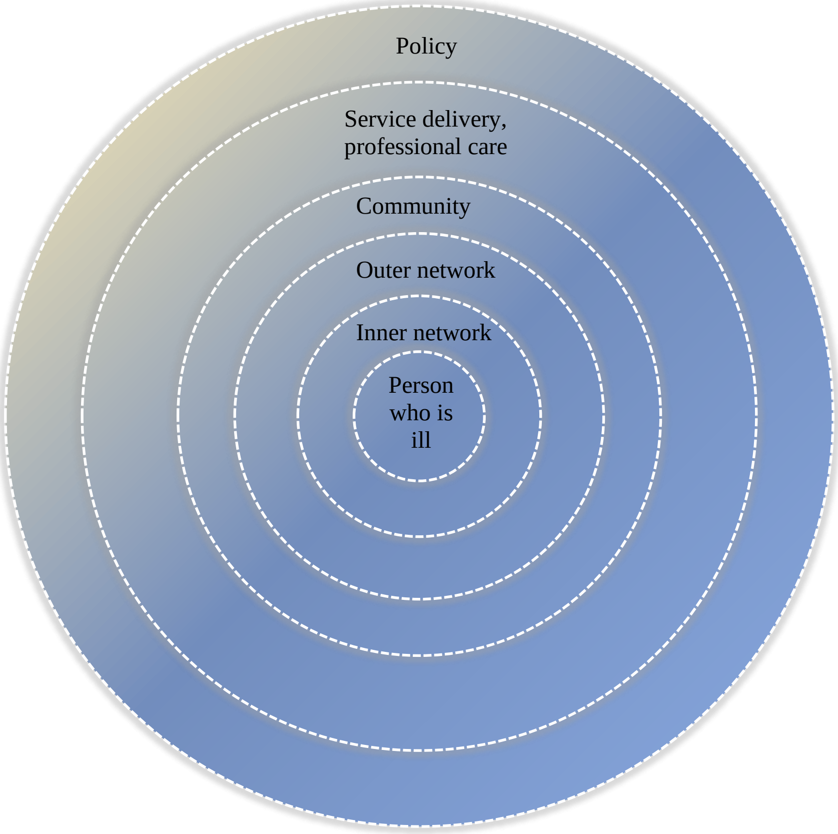
[300] Sallnow et al., "Report of the Lancet Commission on the Value of Death," 847.

Figure 3: Circles of Care[301]



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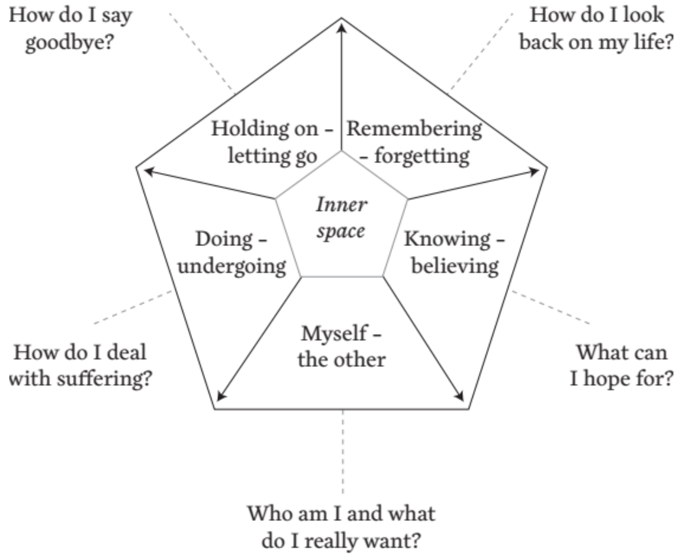
[301] Adapted from Abel et al., "Circles of Care."

Figure 4: Ars Moriendi Model I.[302]



How do I say goodbye?

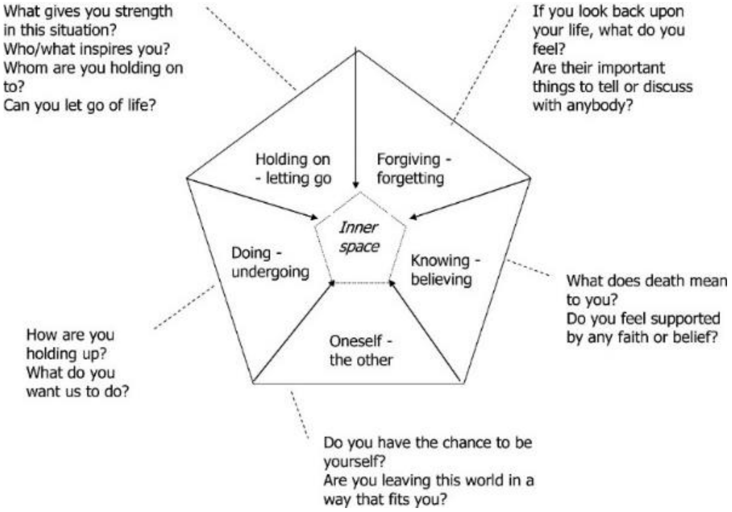
How do I look back on my life?

How do I deal with suffering?

What can I hope for?

Who am I and what do I really want?

Figure 5: Ars Moriendi Model II.[303]



What gives you strength in this situation?
Who/what inspires you?
Whom are you holding on to?
Can you let go of life?

If you look back upon your life, what do you feel?
Are their important things to tell or discuss with anybody?

How are you holding up?
What do you want us to do?

What does death mean to you?
Do you feel supported by any faith or belief?

Do you have the chance to be yourself?
Are you leaving this world in a way that fits you?

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[302] Leget, *Art of Living, Art of Dying*, 57.

[303] Vermandere et al., "Implementation of the Ars Moriendi Model in Palliative Home Care," 279.

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