

# Providing a “peaceful death” in the twenty-first century

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**Abstract:** *Advances in medical technology have not only raised our expectations that medicine can perform miracles and keep us alive; it has also raised conflicts in allowing death to take its natural course. Many dilemmas are faced by physicians as well as families in end-of-life care and relieving the suffering. Ethical dilemmas about how to ensure individuals with terminal illness/end-of-life experience a “peaceful death,” when the meaning and perception of death has changed due to technology? In the past, death was expected and accepted, with rituals. Today, death has been reduced to an unheard phenomenon - shameful and forbidden. The advances in technology brought with it a change in culture of medicine from caring to curing, where medicine is expected to heal any disease. This advance has also acted as a double-edged sword, where longer lives come at the price of greater suffering, illness, and higher costs. While most Americans want to die at home, surrounded by loved ones - the “medicalization” of death does not allow the natural course of death to take place. Although recent studies indicate that more Americans are dying at home, most people still die in hospital beds – alone. This paper looks at the transition that took place in the concept of death and dying, and the impacts of technology, and makes suggestions for facilitating a “peaceful death” in the twenty-first century.*

## I. INTRODUCTION

Advances in life-prolonging technologies has generated ethical concerns in end-of-life care.<sup>(1)</sup> The advancement of biomedical technology is like a double-edged sword- longer lives often come at the price of greater suffering, illness, and higher costs. Achieving the goal of the relief of suffering remains a challenge.<sup>(2)</sup> Ethical issues arise with end-of-life care and relieving the suffering – especially when decisions need to be made concerning the treatment of dying patients and the best treatment to ease a patient’s final pain, or even whether to allow a patient to end life by terminating treatment altogether. These confront people from all walks of life. <sup>(3)</sup> People are more apprehensive about suffering and medical expenses associated with unnecessary technological interventions at the end-of-life, renewing interest in a humane end. How can we ensure that individuals at the end-of-life experience a peaceful death? There needs to be a better balance between care and cure, bringing back care to the forefront. <sup>(4)</sup> This paper looks at the transition that took place in the concept of death and dying, and the impacts of technology, and makes suggestions for facilitating a peaceful death.

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<sup>1</sup> Dr Michael Fett. “Occasional Papers: Health Financing Series. Commonwealth Department of Health and Aged Care.” *Commonwealth of Australia*, 5 (2000), 10

<sup>2</sup> Stephanie C. Paulus. “Palliative Care: An Ethical Obligation.” *Markkula Center for Applied Ethics*. 2008, 1

<sup>3</sup> “End of Life Care: An Ethical Overview.” *Center for Bioethics, University of Minnesota*. (2005): 2

<sup>4</sup> Daniel Callahan, and Peter Augustine Lawler. “Ethics and Health Care: Rethinking End-of-Life Care.” *Center for Policy Innovation*. 4, (2012), 2

## II. TRANSITION FROM DYING WELL TO LIVING WELL TILL THE END-OF-LIFE

In the past, death was usually forewarned or known. The person dying knew that death was coming, that they were going to die based on signs or symptoms, with which they could be sure that death was approaching soon. People had rituals and “an art of dying” that they maintained. With time, however, death was less acceptable, people forgot they were mortals, and aging and dying was part of the natural process.<sup>(5)</sup> This section looks at the art of dying and its evolution.

### A. Phases of death and dying – changes in attitudes

In the past, people expected death. The dying person would prepare for death, and the whole process would be straightforward. The dying person would look for signs - such as crimson blood running from the mouth, nose and ears. Preparations included looking up at the sky to heaven, and asking for God’s help and forgiveness. People knew that death was inevitable, and they knew they were mortals.<sup>(6)</sup> Everyone, regardless of their status, behaved the same way - pious monks behaved the same way as knights. They all looked for warnings that came from natural signs, or even more, frequently came through an inner conviction - something very simple, something prevailing throughout ages, something that persists even today as a custom.

Death was a sort of spontaneous realization, even to those very religious. There was no way of cheating or pretending one hadn’t noticed. Young people usually would accept death from signs but would be rebellious, but they would still accept that they were dying.<sup>(7)</sup> The rituals were also very simple. The dying person had certain gestures from old customs - gestures they were taught needed to be carried out when one was dying. They would remove weapons (if any) from their bodies upon the ground; spread their arms out, with bodies forming a cross. Most importantly, the tradition was to lie on one’s back in such a way so that the face was always turned toward heaven; this was stipulated by the thirteenth-century liturgists.<sup>(8)</sup>

Per Philippe Aries, the preparation process for the dying man was of several steps, which became “the traditional ceremony,” with the first step being able to “express sorrow” over the end-of-life, a sad but discreet recollection of beloved beings and things, a summary which was reduced to a few images. After this, came the pardoning of the always numerous companions, and helpers who surrounded the deathbed. Family and friends asked for forgiveness. The dying man commended the survivors to God. The question of tomb or selection did not arise and did not exist until much later on.<sup>(9)</sup> Death was a time to think about the world and think about God. The prayer had two parts, one about confessing sins and begging God to grant paradise, the gesture of the penitent looking up toward the heaven with hands joined. The second part was that of absolution.<sup>(10)</sup>

The meaning and perception of death changed over time. It evolved from being a public event with people, including the doctor and the priest, surrounding the dying person in his bedside; to not allowing too many people around the bedside due to principles of hygiene in the eighteenth century.<sup>(11)</sup> Passers-by who met the priest bearing the last sacrament could still form a procession and accompany him into the sickroom in the nineteenth century.<sup>(12)</sup> Parents, friends, and neighbors were expected to be present, and children would be brought in later on. However, that has changed today - children are kept away from anything that

<sup>5</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present.* (Baltimore: The Johns Hopkins University Press, 1974) 2-3

<sup>6</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 3-4

<sup>7</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 4-5

<sup>8</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 8-9

<sup>9</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 9-10

<sup>10</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 10-11

<sup>11</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 11-12

<sup>12</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 12

has to do with death. The old attitude of death was simple, and dying was carried out in a ceremonial manner - not with any theatrics, no great show of emotion. Death was something people prepared for and accepted calmly.<sup>(13)</sup>

Dying people had responsibilities to take care of – such as who gets what, before they departed quickly - as if moving into a new house. People had been dying like that for centuries or millennia. In a world of challenge, death traditionally appears to be inert and static. The old attitude in which death was both familiar and near, evoking no great fear or awe, offers too marked a contrast to ours today, where death is frightful that we dare not utter its name.<sup>(14)</sup>

Traditional ideas and feelings regarding death shifted considerably. Death was reduced to an unheard phenomenon –so omnipresent in the past that it was familiar to all - would become shameful and forbidden.<sup>(15)</sup> This occurred in a well-defined cultural era. As Philippe Aries points out in his book: *Western attitudes towards death: From the Middle Ages to the present*, in the second half of the 19th Century, the sentiment surrounding the dying person *tended to* “spare them” by hiding the gravity of the person’s condition. Although they acknowledged that it was not possible to conceal such information for too long, they admitted they did not have the cruel courage to tell the “dying person” the truth.<sup>(16)</sup>

Death was no longer accepted calmly by observers and those who were left behind. In the nineteenth century, survivors expressed their loss or separation through a new passion of sorrow. Emotion shook them, and they cried, they prayed, gesticulated. They did not refuse to go through activities dictated by custom; on the contrary, while they performed them, they stripped them of their banal and customary character. People were troubled not only at the bedsides of the dying or the memory of the deceased, but the very idea of death moved them.<sup>(17)</sup> They feared death, and the truth was beginning to be challenged. People began to lie to the sick person to spare the person of the ordeal and fear of death.<sup>(18)</sup>

### ***B. Shaping the vanishing line between life and death***

The role played by the dying man himself in the ceremonies surrounding his death has evolved from the past to how we see death as today. In the past, the dying man was still at the center of activity, presiding over the event as in the past, and determining the ritual as he saw fit.<sup>(19)</sup> This perception and acceptance changed significantly over time. This section looks at the transition of attitudes toward death and dying.

It was thought that there is a close relationship between death and the biography of each life. This is why the ritual solemnity of the deathbed which persisted into the nineteenth century, by the end of the middle ages, had assumed among the educated classes as a dramatic character, an emotional burden which it had previously lacked.<sup>(20)</sup> These ideas changed in the seventeenth and eighteenth centuries. Spiritual writers struggled against the popular belief that it was not necessary to take such pains to live virtuously since a good death redeemed everything. However, they acknowledged that there was moral importance in the way the dying man behaved and in the circumstances surrounding his death. It was not until the twentieth century that this deeply rooted belief was cast off, at least in industrialized societies.<sup>(21)</sup>

The horror of physical death was completely absent from the common mentality.<sup>(22)</sup> Feeling of personal failure and the fragility of life was foreign to the man in the Middle Ages, maybe because the man did not feel too attached to life since they did not

<sup>13</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 12-13

<sup>14</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 13

<sup>15</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 85

<sup>16</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 86

<sup>17</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 59-60

<sup>18</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present.*, 86-87

<sup>19</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 38

<sup>20</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 37-38

<sup>21</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 38-39

<sup>22</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 41

live too long back in those days.<sup>(23)</sup> Today it is agreed that between the year 1000 and the middle of the thirteenth century, the manner in which men applied their thoughts to their surroundings – world – and to their concerns underwent a profound transformation, while the mental processes – the manner of reasoning or perceiving concrete or abstract realities and of conceiving ideas – evolved radically.<sup>(24)</sup> This change can be grasped in the mirror of death – each man discovered the secret of his individuality in the mirror of their death. This has never seemed to have any impression on Western civilization. The man of the first Middle Ages became resigned to the idea that we are all mortal. Since the Early Middle Ages, Western man has come to see himself in his own death.<sup>(25)</sup>

Death was a concern that concerned only the one who was dying. Thus it was up to the person to express his ideas, his feelings, and his wishes. For that, he had an available tool – his last will and a testament which was more than a legal document for the disposal of his property.<sup>(26)</sup> Man still retained the initiative in the ceremonies surrounding his death, and he continues until the first three decades of the twentieth century. In the second half of the 18th century, a considerable change occurred in wills. The will became a legal act of distributing fortunes as we see today. This is an important event in the history of mentalities.<sup>(27)</sup> Excessive mourning was ritualized in the Early Middle Ages, also known as the era of *hysterical mourning*.<sup>(28)</sup> At times mourning reached the point of madness; people cried, fainted, languished, and fasted.<sup>(29)</sup> It was sort of return to the excessive and spontaneous demonstrations of the Early Middle Ages, after seven centuries of sobriety. This is indeed, significant. It means that survivors accepted the death of another person with greater difficulty than in the past. The death which is feared is no longer the death of the self, as the death of another.<sup>(30)</sup>

The Bubonic plague in 1347 played a role in guiding in preparing for one's death at home.<sup>(31)</sup> According to historical records, the Catholic Church, then the leading religious authority in Western Europe issued *Ars moriendi* to guiding the preparation for one's death. These emphasized that a Christian can prepare for a good death by leading a repentant and righteous life. These books were quickly translated and widely circulated until the end of the nineteenth-century.<sup>(32)</sup> However, the American Civil War revised the *Ars moriendi*, gearing towards Protestantism, which dominated nineteenth century America's religious landscape. The Civil War forced a radical rethinking of death. Death was no longer solely a matter of God receiving his faithful into eternal glory but became patriotic, and sacrifice connoted citizenship and honor. The Civil War also changed the context in which death was experienced. Death used to be a domestic affair in the nineteenth century, in which loved ones ministered to and received direction from the dying. War, however, offered no guarantee that soldiers could die at home. Often they died far away in the company of strangers or even enemies. Death became a national commitment, and national commitments shaped death. The Civil War forced death out of the community – with its tradition, rituals, and religions – into the public sphere in which death and the associated practices were decontextualized.<sup>(33)</sup>

Death came under the domain of the state, and the hospital, and the deathbed ritual began to lose its appeal. After the war, churches began to deemphasize the concept of dying well and to promote instead the notion of living well. Within an increasingly secularized society, the medical sciences offered new glimpses of immortality achievable on earth – the advent of the ICU brought the advances of cardiopulmonary resuscitation and intensive care – these promised an indefinitely prolonged life. This further distanced death from *Ars moriendi* model in two ways – by permanently removing death from the purview of community,

<sup>23</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 44-45

<sup>24</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 51

<sup>25</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 52

<sup>26</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 63

<sup>27</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 64

<sup>28</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 68

<sup>29</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 66-67

<sup>30</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 67-68

<sup>31</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 6-7

<sup>32</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 7

<sup>33</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 8

and by transferring power over life and death to the doctor.<sup>(34)</sup> This was the new physical phenomenon that took place between 1930- 1950; hospitals became the place to receive care which no one could give at home.<sup>(35)</sup> Death became a technical phenomenon obtained by a cessation of care, a cessation determined by a decision of the doctor and hospital team. As stated by Philippe Aries, in the majority of cases “the dying person has lost consciousness, death has been dissected, cut to bits by series of little steps, which finally makes it impossible to know which step was the real death - the one in which consciousness was lost, or the one in which breathing stopped.”<sup>(36)</sup>

### III. ROL OF MEDICINE

Until the nineteenth century, the doctor would remove himself when healing proved impossible and the priest would usually take over, but now physicians control the life-sustaining technology that delays the moment of death. Approaches to dying have varied across periods, places, and cultures; however, no religious authority exists in the United States that can guide in answering spiritual and other concerns to death and dying. Americans, as observed by a bioethicist, typically relies heavily upon healthcare for death and dying.<sup>(37)</sup> This section looks at how advances in medicine raise issues about death and dying, particularly with humanely treating dying patients.

#### A. The medicalized death

With the change in the culture of medicine from caring to curing, it is expected that medicine can heal any disease.<sup>(38)</sup> The creation of CPR and ICU lead the way to a power transfer from clergy to doctors, making physicians the keeper of the keys of everlasting life. The ICU has created everlasting immortality, and it is an attempt to maintain physical life and function indefinitely. The implications of the paradigm shift as doctors became gatekeepers of death-delaying technology, the line between life and death became increasingly blurred; as a result, it affected how people died, and where they died.<sup>(39)</sup> The art of living has been promoted, neglecting practices concerned with dying. Scientific advances represented progress, and death suggested failure. By the middle of the twentieth century, technology's ability to delay the moment of death fostered a ‘medicalized’ death. Medicalized death, replaced the prayers and practices of the *Ars moriendi* with procedures and protocols for the efficient management of patients in intensive care units. People who previously had difficulty discerning when a person had died, now relied upon experts to determine whether a patient was good and alive, barely alive, or dead-but-appearing to be alive. Patients entered the *black box* of the ICU, received various interventions, and often exited in a state of restored health.<sup>(40)</sup>

When the World Health Organization (WHO) in 1948 redefined health as “a state of complete physical, social and mental well-being and not merely the absence of disease,” the medicalization of life was established - resulting in a therapeutic society<sup>(41)</sup> It has now been recognized that individuals will experience some form of serious illness with aging, especially due to chronic illnesses such as heart disease, stroke, COPD and so on; and people aged 85 and over will likely require some form of long-term care services or medicalization to help them to stay alive. However, as advanced illnesses occur and the chances for maintaining the values of the patient declines, there is no point in continuing the interventions. Patients often suffer through unnecessary as well as harmful treatment despite expert opinions. At some point, more treatment is not equal to better treatment.<sup>(42)</sup> The issues addressed here

<sup>34</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 9

<sup>35</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 87-88

<sup>36</sup> Aries, Philippe. *Western attitudes towards death: From the Middle Ages to the present*, 88-89

<sup>37</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 5-6

<sup>38</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 10

<sup>39</sup> Merrick, J. C. *Death and dying: The American experience*, in R.H. Blank and J. C. Merrick (eds): *End-of-life decision making. A cross-national study*. (Cambridge: The MIT Press, 2005), 220

<sup>40</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 11

<sup>41</sup> Marcella Colbert. “The Medicalization of Death & Dying”. *Life issues.net: clear thinking about crucial issues*. 2

<sup>42</sup> Diane E. Meier. “Palliative Care Programs: What, Why and How?” *Physician Executive* 27, no. 6 (2001), 2

are associated with the over-medicalization of life. There are physical as well as emotional and economic burdens associated with this issue.<sup>(43)</sup> High medical costs at the end-of-life do not only affect insurance plans, and society - but also individuals and families. For more than 40 percent of people, the medical bills exceed their financial assets.<sup>(44)</sup>

For most of American history, discussions about death and dying were a taboo. Neither policymakers nor patients and their families openly discussed the circumstances under which patients would die; thus, few public policies existed. It was not until Elisabeth Kubler Ross published her publication "*On Death and Dying*" that this scenario began to change in the late 1960s. Her work focused on how terminally ill patients were often shunned and lied to about their prognosis for survival - became a triggering event for a public discussion about the roles and needs of terminally ill patients, their loved ones, and their healthcare providers. Also, cases like the Quinlan case became a major agenda-setting event in Americans' discussion about terminal care.<sup>(45)</sup> Allowing the "dying" person to die humanely still faces challenges. One never knows when to withdraw life support. Quinlan's case helped the court to make important distinctions between curative and palliative care - this case became the turning point in America's public discussion about terminal care, particularly for patients whose conditions were hopeless.<sup>(46)</sup>

As noted by Renea L. Beckstrand et al., out of the 2.4 million (plus) deaths recorded annually in the United States (2006), 80% occur in hospitals. Often critical care unit nurses care for these patients, of which 20% die in ICU while hospitalized. The author points out that death in the ICU can be complicated and often unnatural/prolonged, and painful.<sup>(47)</sup> However, more recent studies from 2003 to 2017 by Gina Kolata (2019) has shown that the numbers have greatly changed since the study in 2006, indicating that "*29.8 percent of deaths by natural causes occurred in hospitals, and 30.7 percent at home,*" which only highlights the progress towards achieving higher home rate deaths - as Americans have long said that they prefer to die at home, not in an institutional setting. The same study has highlighted that the progress was due to having "difficult conversations" with loved ones about end-of-life care - often revealing that older relatives *did not wish* for heroic or death prolonging measures in hospitals. Also having Advanced Care Plans that clearly expressed their wishes at end-of-life were also positively instrumental in achieving this success.<sup>(48)</sup>

Data from CDC (2013) demonstrated that although most Americans prefer to die in their own homes - most deaths occurred in short-stay, general hospitals. From the National Hospital Discharge Survey (NHDS) data from 2000 - 2010 it was presented that although the number of inpatient deaths decreased 8% from 776,000 in 2000 to 715,000 in 2010, there was an increase of 11% in the number of total hospitalizations. The report also highlighted that patients who died in the hospital had longer hospital stays than all patients.<sup>(49)</sup> Stanford Palliative Medical School states: despite the fact that 80% of Americans prefer to die at home, 60% die in acute care hospitals, 20% in nursing homes and only 20% at home. This clearly shows that fewer patients are dying at home even if that is what they want.<sup>(50)</sup> Moreover, one of the drivers highlighted by Kaiser Health News (2014) is: "every region has its own medical "culture," and it's built on around *highly trained specialists and sub-specialists* who see it as their *job to cure illness.*"<sup>(51)</sup>

With medical advancements enabling better diagnosis and treatment of acute and chronic diseases, patients are spared impending death at the cost of suffering from prolonged death. Western medicine effectively "medicalized" human life in the name of therapy, rendering individuals and societies less able to deal with the "natural" processes of aging and dying. Dying in one's bed

<sup>43</sup> Diane E. Meier. "Palliative Care Programs: What, Why and How?" 3

<sup>44</sup> Diane E. Meier. "Palliative Care Programs: What, Why and How?" 5

<sup>45</sup> Merrick. J. C. *Death and dying: The American experience*, 224-225

<sup>46</sup> Merrick. J. C. *Death and dying: The American experience*, 226

<sup>47</sup> Renea L. Beckstrand et al. "Providing a "Good Death": Critical Care Nurses' Suggestions for Improving End-of-life Care". *American Journal of Critical Care*, 15, no 1 (2006), 38-39

<sup>48</sup> Kolata, Gina. "More Americans Are Dying at Home Than in Hospitals." *New York Times*, 2019. Accessed: <https://www.nytimes.com/2019/12/11/health/death-hospitals-home.html>

<sup>49</sup> Centers for Disease Control and Prevention. "Trends in Inpatient Hospital Deaths: National Hospital Discharge Survey, 2000-2010." 2013. Retrieved from: <https://www.cdc.gov/nchs/products/databriefs/db118.htm>

<sup>50</sup> Stanford Palliative Medical Center: <https://palliative.stanford.edu/home-hospice-home-care-of-the-dying-patient/where-do-americans-die/>

<sup>51</sup> Mogul, Fred. Kaiser Health News. 2014 "Too Many People Die In Hospital Instead Of Home. Here's Why." Retrieved from: <https://khn.org/news/too-many-people-die-in-hospital-instead-of-home-heres-why/>



became a rare practice – resulting in dying poorly - tethered to technology in antiseptic rooms, largely lonely, isolated, and feeble. Opponents of this advancement of medicine that leads to the medicalization of death argue that modern death has become too medicalized, even "sterilized," where dying in your own bed is an increasingly uncommon occurrence. According to scholars like Tony Miksanek, only about 20 percent of Americans die at home, while dying in hospitals and nursing homes has escalated<sup>(52)</sup> Medicalization is a complicated issue, not perceived by all *as good* under all circumstances.<sup>(53)</sup> Healthcare has become a commodity today, with people expecting the need for maximizing health with minimized effort and time to preserve health. Biomedical technology has driven social expectation so high that people now want quick fixes and cures for everything. Societies may demand that medical professionals medicalize certain problems to find efficient, marketable solutions.<sup>(54)</sup> To medicalize may be to transcend human nature - the possibility of the scientific conquest of death.<sup>(55)</sup> The next section looks at the opposite of the medicalized death.

### B. The redeeming death

We believe that modern medicine can cure any illness.<sup>(56)</sup> Advances in medicine has forced patients to decline mortality, in hopes of living a little bit longer, even if the procedure would turn out to be deadly or worse.<sup>(57)</sup> Doctors are not prepared to fail, and death means failure for the doctors, who enjoy being competent.<sup>(58)</sup> As stated by Atul Gwande, doctors have no issue talking about options, and about the dangers associated with them; but they never touch on the reality of the disease, or the ultimate limits of their "capabilities, let alone, what might matter most to the patient as they near end-of-life".<sup>(59)</sup> Death will someday come, but until that last backup system inside each of us fails, medical care can influence whether the path is steep and precipitate or more gradual, allowing longer preservation of the abilities that matter the most in life.<sup>(60)</sup>

Death should be viewed as the natural order of things. Death used to be expected and accepted in generations before our own. Doctors today are willing to recognize the signs, but are arrogant to deny them.<sup>(61)</sup> The truth is that we are all aging from the day we are born; we need to accept this fact. Doctors are in a profession where they are successful because of their ability to fix; otherwise, their experiments to treat lead to troubling, causes callousness, inhumanity, and extraordinary suffering.<sup>(62)</sup> As Atul Gwande points out, the progress of medicine and public health has been an incredible boon. Gwande adds people get to live longer, healthier, more productive lives than ever before, with our average life span in much of the world climbing past eighty years, we are already living well beyond our appointed time.<sup>(63)</sup> Medicine has been slow to apply the knowledge we have about how to make old age better.<sup>(64)</sup> According to Gwande, it is not death that the very old fear, it is "what happens short of death" – losing their hearing, their memory, their best friends, their way of life. By maintaining a good quality of life, overall wellbeing, people can often live longer and manage for a very long time.<sup>(65)</sup> Most people want to die a death that is not painful, and amidst their loved ones at home, and dying in hospitals also cost a lot more.

Most Americans as suggested by previously discussed studies want to die at home, surrounded by loved ones. This implies that death is desired with some warning, allowing some time to make plans. Unfortunately, as discussed earlier, most Americans die

<sup>52</sup> Miksanek, Tony. "Modern Death: How Medicine Changed the End of Life." Booklist, *Literature Resource Center* 21 (2016), 1

<sup>53</sup> John Z. Sadler et al. "Can medicalization be good? Situating medicalization within bioethics." *Theor Med Bioeth*, 30 (2009), 411

<sup>54</sup> John Z. Sadler et al. "Can medicalization be good? Situating medicalization within bioethics." 416

<sup>55</sup> John Z. Sadler et al. "Can medicalization be good? Situating medicalization within bioethics." 419

<sup>56</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 2

<sup>57</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 4

<sup>58</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 7

<sup>59</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 5-6

<sup>60</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 44

<sup>61</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 8

<sup>62</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 9

<sup>63</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 32

<sup>64</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 36

<sup>65</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 55

in hospitals because death has been medicalized,<sup>(66)</sup> This medicalization is concentrated on preventing or staving off death and interferes with people's abilities to experience deaths that are rich in values such as love of family, rootedness, closure, and religious enlightenment. Kubler-Ross' work was central to the movement of medicine from the pursuit of technological mastery of death to the pursuit of psychological mastery of death – to owning death, to accept it.<sup>(67)</sup> People need to start preparing for death by talking about it and accepting that it is inevitable.<sup>(68)</sup>

Advocates working to improve care for dying patients try to determine what elements are necessary for a "good death" to take place. Common elements of a good death have been identified as the following per the University of Minnesota's Center for Bioethics', "*End of Life Care: An Ethical Overview*:"

- Adequate pain and symptom management;
- Avoiding a prolonged dying process;
- Clear communication about decisions by patient, family, and physician;
- Proper preparation of death, for both patient and loved ones;
- Feeling a sense of control;
- Finding a spiritual or emotional sense of completion;
- Affirming the patient as a unique and worthy person;
- Strengthening relationships with loved ones.
- Not being alone.<sup>(69)</sup>

"Hospice care" comes up when discussing end-of-life care. At its base, end-of-life care aims to help dying patients. The purpose is not to lengthen the patient's life span, but to improve the patient's quality of life. This includes looking after the patients, relieving their psychological problems, and comforting them. It makes more significant efforts to control and ease their pain, soothing the anxiety and terror of death for patients and their family members. In this way, it is hoped it maintains the dignity of patients and let them die quickly in comfort.<sup>(70)</sup> The main goal at the heart of all efforts is to relieve the patient's pain. Just before the end-of-life, many patients suffer from extreme and unbearable pain. There need to be appropriate policies that allow the use of analgesics, e.g., morphine, in relieving the pain to maintain the patient's dignity and reducing suffering - the best way to show our respect. Moreover, this approach to end-of-life care can help to reduce the family members' spiritual, psychological, and economic burden.<sup>(71)</sup>

Additionally, the "*End of Life Care: An Ethical Overview*," also states that hospice care is about providing a holistic and philosophical approach to end-of-life care. That hospice care brings together "doctors, nurses, social workers and other professionals together as a care team," with the goal of making the patient as comfortable as possible during their final days, with emphasizing in "pain control, symptom management, natural death, and quality of life to comfort the patient's physical body." The principle of autonomy is the guiding principle for all "good deaths" that empowers individuals to control situations and circumstances and encourages individuals to choose and participate in end-of-life decisions. As emphasized by the "*End of Life Care: An Ethical Overview*:" part of the philosophy of hospice involves restoring and supporting both the patient and patient's family control over the circumstances of death. The hospice team may very well provide emotional and other support services such as social services, nutrition counseling, and even grief counseling to both patient and family in addition to medical care.<sup>(72)</sup> The next section looks at the ethical challenges with end-of-life care.

<sup>66</sup> Gwande, Atul. *Being mortal. Medicine and what matters in the end*, 43

<sup>67</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 12

<sup>68</sup> Dugdale, Lydia. *Dying in the twenty-first century: Toward a new ethical framework for the art of dying well*, 19

<sup>69</sup> "End of Life Care: An Ethical Overview." 12

<sup>70</sup> Yiting, L. et al. *End-of-life care in China: A view from Beijing*, 35

<sup>71</sup> Yiting, L. et al. *End-of-life care in China: A view from Beijing*, 37

<sup>72</sup> "End of Life Care: An Ethical Overview." 15



#### IV. ETHICAL CHALLENGES

Advancements in medicine have been successful in helping us live longer, and in prolonging death.<sup>(73)</sup> Death has been dissected into so many small sections that it is no longer easy to recognize death; technology has rendered near-invisible the line between a living person and biologically functioning body.<sup>(74)</sup> Ethical issues arise today regarding death and dying, since medical technology has the capacity to prolong lives beyond the point of all sense and value, that death is institutional and requires a specific decision to discontinue medical treatment (also called 'managed death'); and this is terrorizing, because of its uncertainty and its contrived quality - it inspires fear and dread. Medical practices are thought to stand in the way of a tolerable death.<sup>(75)</sup> Physicians face many dilemmas regarding how to help terminally ill patients' bear pain, suffering, and fear.<sup>(76)</sup> This section looks at the goals of medicine, and the limits, and ethical issues of prolonging death by technological means.

##### A. Futility and limits

Success in medicine has changed the way people perceive threats of diseases, illnesses, and death.<sup>(77)</sup> We are no longer able to predict death, or that disease is terminal well in advance like we used to before.<sup>(78)</sup> Medicine's capacity to prolong life even when health has been irrevocably lost can generate the moral dilemmas of treatment termination.<sup>(79)</sup> Maintenance of health as a goal has led to not accepting illnesses; as a result, aging and death is averted.<sup>(80)</sup> The biased concept of cure as the goal of medicine has harmed the concept of care that used to exist before. The constant and expensive wars against lethal diseases such as cancer, heart disease, and stroke, have too often obscured the need for care and compassion in the face of mortality.<sup>(81)</sup> Modern medicine has the eagerness to cure patients, while sometimes neglecting its caring function. According to the Hastings Center Report: *Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan*, "caring is not simply the manifestation of concern, empathy, and a willingness to talk with patients." It is also a capacity to talk and listen in a way that is cognizant of those supportive social and welfare services needed to help people, and their families cope with the wide range of non- medical problems that can and usually will accompany their illness. It is a necessity that good caring incorporates technical excellence as a crucial ingredient. The healing function of medicine encompasses both curing and caring - and healing may be possible in the form of caring in those cases where medicine cannot cure - such as helping a person better cope with permanent/chronic/terminal conditions where, in other words, the illness will continue over time regardless of what is done medically.<sup>(82)</sup>

Contemporary medicine has often treated death as the supreme enemy - sometimes extending the life beyond any point of human benefit, and by neglecting the humane care of the dying. Medicine should accept death as the destiny of all humans; treatments should be provided in ways that enhance, rather than threaten, the possibility of a peaceful death. In medicine's struggle against death, an appropriate aim first and foremost is to reduce premature death, in populations generally and individuals particularly. If avoiding premature death should be a high goal for medicine, it would be a mistake to act as if all death is premature, no less than to over-emphasize eliminating death at the expense of other important health needs. Medicine has averted its eyes

<sup>73</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*. (Washington, D.C: Georgetown University Press, 2000), 33

<sup>74</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 46

<sup>75</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 23

<sup>76</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 14

<sup>77</sup> "Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan" *The Hastings Center Report*, Vol. 26, No. 6, (1996), S1

<sup>78</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 44

<sup>79</sup> "Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan," S3

<sup>80</sup> "Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan," S2

<sup>81</sup> "Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan," S5

<sup>82</sup> "Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan," S12

almost altogether from the biological fact of mortality, focused its attention single-mindedly on the causes of death, with unhappy consequences such as the illusion that mortality can be eliminated by eradicating lethal diseases.<sup>(83)</sup>

Advances in medicine have brought various changes that can be summed-up as: longer lives and worse health; longer illnesses and slower deaths; and longer aging and increased dementia.<sup>(84)</sup> Medical technology gives us enormous power at all levels of life, especially at the end-of-life, denying death and dying.<sup>(85)</sup> The technologies of medicine can sustain failing organs and have made understanding of mortality more difficult by opening up new possibilities, misleading us into believing that we have greater dominance over our mortality than before.<sup>(86)</sup> It is increasingly difficult today to find any clear line between living and dying, and the ambivalence, exacerbated by medical science, that many are confused about whether to fight or accept death? Death is no longer believed to be a part of nature but has become a human responsibility - making it difficult to terminate treatments in end-of-life care – since it carries the moral weight and responsibility as directly killing. Technology is pushed as far as possible to save a life, even though there are questions about preserving a decent quality of life.<sup>(87)</sup> The limits of contemporary medicine must be recognized and applied. There will be times when patients will suffer pain that is not diagnosable, or not about bodily discomfort, but more emotional. Medicine, as such, can offer no answers to such questions; they are not in its domain. Moreover, as human beings, physicians and nurses will be looked to for some response. Medicine and morality have combined forces to create powerful pressure against acceptance of death, implying that accepting death means rejecting modern medicine and the value of human life, making it difficult to advocate for a peaceful death when it is inevitable.<sup>(88)</sup>

Moreover, the Hastings Center Report: *Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan*, adds that “the potential misuses of medical knowledge may roughly be divided into four categories: those that are unacceptable under any and all circumstances; those that fall outside the traditional goals of medicine but serve morally acceptable social and individual purposes; those that may, under some circumstances and with clear procedures and safeguards, be employed; and those that, while not clearly or patently wrong, raise such serious concerns that only the most compelling social reasons could justify them.”<sup>(89)</sup> For all the power of medical research and advancement, human beings will continue to get sick and die. Death can be delayed and diverted but never conquered. Pain and suffering will remain part of the human condition. People will always have to be cared for when curative medical skills reach their limits; medicine must acknowledge death as part of nature and offer palliation as part of caring terminally ill patients, through pain and a process of a peaceful death.<sup>(90)</sup> We will have to make responsible choices about the use of medical skills and knowledge to shape and modify mood and behavior and to end life-sustaining treatment.<sup>(91)</sup> The next section looks at an intervention that can help patients achieve a better death.

### ***B. Palliative care – the role of compassion***

Addressing and alleviating pain and suffering is an important part of end-of-life care. Contemporary medicine has raised the fear of dying alone and a painful death. To help patients overcome this fear, physicians need to understand the limits of medicine and use compassion. As a virtue in medicine, compassion is more than pity or sympathy.<sup>(92)</sup> It is the capacity to feel and understand the suffering from the sick patient’s perspective – the definition as stated by Sinclair Shane and Colleagues as: “a virtuous response that

<sup>83</sup> “Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan,” S13

<sup>84</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 47

<sup>85</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 13

<sup>86</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 188

<sup>87</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 41

<sup>88</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 89

<sup>89</sup> “Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan,” S14

<sup>90</sup> “Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan,” s24

<sup>91</sup> “Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan,” S25

<sup>92</sup> David C. Thomamsa and Thomamsine Kushner. “Compassion: What Does It Really Mean? A Dialogue on Compassion and Supererogation in Medicine.” *Cambridge Quarterly of Healthcare, Ethics*, 4 (1995): 416

seeks to address the suffering and needs of a person through relational understanding and action.”<sup>(93)</sup> Understanding what suffering is and how it relates to medical care, can help the physician with advanced knowledge and technology, truly understand the terminally ill patient in designing treatment strategies, and when to stop treatment.<sup>(94)</sup> Two other aspects are important in understanding suffering: the relation of “meaning” to the way the illness is experienced, and “belief” for that aspect of meaning concerned with implications and ‘values,’ and the degree of importance to a particular person. The personal meaning is a fundamental dimension of the person that cannot be divorced from any other; no understanding of human illness or suffering will be possible without taking it into account.<sup>(95)</sup> Although the value of suffering is not always the same and suffering can even be low and vicious, it is still suffering, and all suffering deserves compassion.<sup>(96)</sup>

Beneficence must go well beyond the minimalistic interpretation of avoiding harm. It entails helping others even when that involves inconvenience, sacrifice, and risk to our self-interest.<sup>(97)</sup> The patient-doctor relationship matters – communicating and understanding the patient can help to make decisions regarding terminating treatment. Talking about anxiety, uneasiness, fears, access to all forms of information about one’s disease, concerns can ease the patient and relieve the pain somewhat, helping the patient through pursuing a peaceful death instead.<sup>(98)</sup> According to Callahan, patients are thought to go through three phases of suffering:

1. Mute Suffering- patients are so confounded by what has happened to them that they cannot explain exactly the cause and nature of their suffering. The compassionate physician listens for clues that might help the patient give voice to the distress being experienced, and assure the patient that she or he will remain present through the patient's suffering.
2. Expressive Suffering - Many times, patients do begin to cope more actively with their suffering by showing anger or thinking about alternatives, gaining more autonomy even though the source of the suffering is still present. The compassionate physician becomes more of a partner in this phase.
3. New Identity in Suffering- The patient suffering is transformed into a "new person" with a new meaning to the experience. The compassionate physician continues to listen, provide verbal support, and offer acceptance of the patient.<sup>(99)</sup>

Some of the suffering associated with a disease is readily understood to be a response to the disease itself. It can cause fear, despair, a profound sense of fatigue, anxiety about the future, and a sense of great futility and helplessness. To these, the physician and other healthcare workers should respond with caring and empathy and, where possible, counseling. Pain is a different kind of suffering and can be modified by changes in meaning, and therefore it is unique.<sup>(100)</sup>

Care of dying typically fails to take into consideration physical and emotional suffering and communication with the patient and family about goals of care. Palliative care focuses on relief of suffering, promotion on function, clarification of goals of care and support for patient and family caregivers, and aims for the best quality of life as determined by the patient and family.<sup>(101)</sup> Both palliative care and hospice programs exist across the United States and have a rightful place and play critical roles in end-of-life care.<sup>(102)</sup> Palliative care movements have improved end-of-life care for patients and their families. Palliative care takes into consideration the wishes of the patient in end-of-life care when there is no cure for the patient. Patients have the power to decide high quality dying for themselves, and how they would like to manage the end-of- life care that they would like to receive.

<sup>93</sup> Sinclair, Shane et al. “Sympathy, empathy, and compassion: A grounded theory study of palliative care patients’ understandings, experiences, and preferences.” *Palliative Medicine*, 31, 5 (2017), 444

<sup>94</sup> Eric Cassell, *The nature of suffering and the goals of medicine*. 29

<sup>95</sup> Eric Cassell, *The nature of suffering and the goals of medicine*. 35-36

<sup>96</sup> “Andre Comte-Sponville: A SMALL TREATISE on the GREAT VIRTUES. The Uses of Philosophy in Everyday life.” (Holt Paperbacks, Henry Holt and Company, LLC. New York, New York. 2001): 105

<sup>97</sup> David C. Thomamsa and Thomamsine Kushner. “Compassion: What Does It Really Mean? A Dialogue on Compassion and Supererogation in Medicine.”, 418

<sup>98</sup> Eric Cassell, *The nature of suffering and the goals of medicine*. (Oxford University Press, 2004), 273

<sup>99</sup> Charles J. Dougherty and Ruth Purtilo. “Special Section: Compassion: What Does It Really Mean? Physician’s Duty of Compassion”. *Cambridge Quarterly of Healthcare Ethics*, 4 (1995), 427

<sup>100</sup> Eric Cassell, *The nature of suffering and the goals of medicine*. 268

<sup>101</sup> Diane E. Meier. “Palliative Care Programs: What, Why and How?” 43

<sup>102</sup> Giovanni, Lisa A. “End-of-Life Care in the United States: Current Reality and Future Promise - A Policy Review.” *Nursing Economics* 30, no. 3 (2012), 127-128

When it comes to the end-of-life reform and improvement efforts, healthcare professionals must realize the power they have as individuals and as a profession. Healthcare professionals have an ethical responsibility to assist patients to achieve the care and life they want for their last days, and in many cases that may involve assisting them to die with dignity in a surrounding of their choice and their loved ones. Patients need to be honest and transparent about their advance care planning conversations with families and physicians. Talking about death should not be an uncomfortable feeling, but a simple matter, something expected and accepted. As Lisa A. Giovanni points out, “all healthcare professionals should strive to create an environment for patients where the philosophy of palliative care and hospice is understood.”<sup>(103)</sup> Goals would include increased knowledge about hospice and palliative care, greater symptom control for patients with end-stage diseases, improved advance care planning, better quality of life, and ultimately less money spent on achieving better outcomes for patients facing end-of-life illness and disease.<sup>(104)</sup>

## V. OVERCOMING BARRIERS TO FACILITATING A GOOD DEATH

In healthcare, “more” options do not necessarily translate into “better” healthcare. Death is inescapable, and the most satisfying option for both the patient and family is a peaceful death that is aligned with the values defined by the patient.<sup>(105)</sup> The goal of a peaceful death must be understood as an integral part of medicine. This can be done by admitting that every nonviolent death takes place as a result of an illness; illness and death cannot be separated. Aging, illness, and death cannot be separated.<sup>(106)</sup> The next section looks at diseases and values and the doctor-patient relationship.

### A. Understanding diseases and values – the doctor-patient relationship

Illness should not be seen as an enemy of life, but also as the necessary and inevitable means of death, to be accepted as much as death itself should be accepted. To reorient the goals of both scientific and clinical medicine away from an unbalanced bias toward a cure and the reduction of mortality, there should be an emphasis on care and comfort.<sup>(107)</sup> The cure will eventually run out, only caring will be possible – especially with the different kinds of chronic and degenerative diseases. We need medicine that understands its limits, and knows when it cannot affect a cure, emphasizes on the overall well-being of mortal creatures, with a greater emphasis on quality of life rather than length of life, on the relief of pain and suffering.<sup>(108)</sup> The future role of physicians should reflect the kind of shift mentioned, putting the first line of response to human mortality that puts a human face on medicine.

Medicine at the center is a humanistic profession devoted to the well-being of patients, the forces that make that happen is the changing needs of patients in an era of chronic disease and an aging population.<sup>(109)</sup> Just like physicians, patients can be biased toward a cure as well. After all, a sick person wants to get better, and for that reason may seek interventions that may not be beneficial to them.<sup>(110)</sup> Physicians find it troublesome to talk about death and how it should find a place in our self-conception.<sup>(111)</sup> There is already considerable pressure from physicians to be allowed to make judgments of medical futility themselves without having to ask patients or their families. Their goal is not to avoid a doctor-patient interaction, but to be spared the pressure of unrealistic patient demands. It is one thing to be asked by a patient or family to stop treatment and another to be asked to provide treatment of a kind they think is futile or useless, that they take to be unacceptable, a threat to their professional integrity.<sup>(112)</sup> The

<sup>103</sup> Giovanni, Lisa A. “End-of-Life Care in the United States: Current Reality and Future Promise - A Policy Review.” 132

<sup>104</sup> Giovanni, Lisa A. “End-of-Life Care in the United States: Current Reality and Future Promise - A Policy Review.” 133

<sup>105</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 207

<sup>106</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 208

<sup>107</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 209

<sup>108</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 210

<sup>109</sup> Eric Cassell, *The nature of suffering and the goals of medicine*. 15

<sup>110</sup> Eric Cassell, *The nature of suffering and the goals of medicine*. 112

<sup>111</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 39

<sup>112</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 215

sole way to behave beneficently toward another is to acknowledge and respect the self-determination of each, and every individual, the same holds for the relationship between healthcare providers and patients.<sup>(113)</sup> A Treatment regime should be designed with the particular patient in mind.

Since death will come to all, medicine must give a high place to creating those clinical circumstances in which a peaceful death is most likely. A peaceful death can be defined as one in which pain and suffering are minimized by adequate palliation, in which patients are never abandoned or neglected, and in which the care of those who will not survive is counted as important as the care of those who will survive.<sup>(114)</sup> We have reached a point where we need to find if we can create a 'peaceful death.' For this, we need to accept death and accept that the end-of-life is death. An accepted death, an alert, conscious death, and death supported by loving friends and family are ideals widely accepted today. There are many fears that such a death will prove elusive. If peaceful death is to be possible as a more widespread reality, then a fresh interpretation of death will have to be devised and put into place.<sup>(115)</sup>

When considering stopping or abating life-extending treatment, these stages need to be considered: Stage 1 - refusal to respond at all to health threats, even to seek diagnosis for medical symptoms or to engage in any kind of pre-symptomatic screening for the possible presence of disease; only palliative relief of symptoms sought – frequently chosen by the elderly who have already decided they are ready to die and some religious positions.<sup>(116)</sup>

Stage 2 – refusal to go beyond diagnosis or identification of a potentially lethal disease to any curative response to the condition; palliative relief of symptoms only.<sup>(117)</sup>

Stage 3 – refusal to accept any medical treatment, for curative or ameliorative purposes, that does not promise a high probability of success and a minimum of unpleasant side-effects.

Stage 4 - a willingness to accept any medical treatment that offers even a low probability of a successful outcome.

Stage 5 – an eagerness to pursue any medical treatment with even the remotest possibility of success.<sup>(118)</sup> Considerable skill on the part of the physician will be necessary to effect more formal embracing of the stage approach. Healthcare professionals will have to be willing to work with patients who deliberately refuse to choose treatments the physicians believe could benefit them. Families must also come to understand that they will have to overcome their reluctance to facilitate a peaceful death – which, if achieved, will benefit the patient as well as the family.<sup>(119)</sup> This is also where, Kolata pointed out in her article, "having difficult conversations" early on about end-of-life care with loved ones, talking to one's primary care providers about Advanced Care Plans that clearly state their end-of-life care preferences which, as rightfully recommended by Emily A Meier et al., *focuses on decreasing pain and suffering*, are highly advocated.<sup>(120)</sup>

Death has always been the inevitable outcome. At some point in every life, life-sustaining treatment will be futile. Thus the humane management of death is the final and perhaps most humanly demanding responsibility of the physician. When lethal illnesses and diseases are taught in textbooks, treatment strategies are emphasized; however, nothing is discussed as to how to address the situation if the treatment does not work, and the patient is dying. Death must come to all – not as an accident, not as a failure to treatment – it is inevitable – this needs to be addressed in medicine from the start.<sup>(121)</sup> This would help make it easier on

<sup>113</sup> Jos V.M. Welie. "Special Section: Compassion: What Does It Really Mean? Sympathy as the Basis of Compassion" *Cambridge Quarterly of Healthcare Ethics*, 4 (1995): 476

<sup>114</sup> Eric Cassell, *The nature of suffering and the goals of medicine*. 117

<sup>115</sup> "Special Supplement: The Goals of Medicine: Setting New Priorities. In Search of the Good Society: The Work of Daniel Callahan," S14

<sup>116</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 54-55

<sup>117</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 204

<sup>118</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 205

<sup>119</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 206

<sup>120</sup> Emily A. Meier et al. "Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue." *American Journal of Geriatric Psychiatry*, 24, 4 (2016): 276

<sup>121</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 207

the physicians to accept death as the likely cause of the illness, opening the way to peaceful death by choosing the combination of treatment and palliation of the accepted condition most likely to make it possible.

### **B. Education and facilitation of peaceful death**

Ethical dilemmas are associated with treating patients who are dying, and any interventions will not be beneficial.<sup>(122)</sup> Once a treatment has been categorized as medically futile, physicians must withhold or withdraw regardless of the wishes of the patient or family; this is a medical decision, not an ethical one, depends on the proper application of medical expertise.<sup>(123)</sup> Even while considering withdrawing or withholding treatments that would otherwise be non-beneficial/not achieve the desired medical goals, it is important to keep in mind that good pain management is extremely crucial, and no dying patient should have to endure excruciating pain - the patient should be kept as comfortable as possible. In this section, we look at a framework for decision-making, and identify gaps and make recommendations for a peaceful death.

It is a fallacy to think that medicine can cure anything, and the professional code is to prolong life. The physician is not obligated to fight death that the patient wishes for, or the death that is inevitable due to age or illness. The Hippocratic Oath gives priority to the person over the illness.<sup>(124)</sup> Physicians are constantly facing dilemmas addressing pain and suffering of dying patients. There is agreement that it is not right to kill or help patients kill themselves; major turmoil exists in the United States over euthanasia and physician-assisted suicide (PAS). There are also issues with euthanasia and palliative sedation in palliative care; however, there are differences, and the latter being preferred under certain circumstances.<sup>(125)</sup> Regardless of issues with interventions such as euthanasia and PAS, it has been recognized that there is a need to provide a better end-of-life care to patients who are dying - to die a peaceful death. There are two humane and legal and moral alternatives available that can be used in aiding patients - refuse life-sustaining treatment; and die with dignity – by managing pain.<sup>(126)</sup> Two characteristics of good death have been identified—1. Peaceful death – in palliative care it means dying without fuss, where patients slowly pass away without a death struggle. In other words, death accepted without fear.<sup>(127)</sup> 2. Die in one's sleep –when a person has lowered degree of consciousness – the person is in less consciousness when death takes place.<sup>(128)</sup>

According to *End of Life Care: An Ethical Overview*, one of the primary goals of palliative care is “relief of symptoms” – which is an option for those patients who are seriously or terminally ill to “focus on achieving the best possible quality of life, by emphasizing total and comprehensive care for all patient needs: pain and symptom management, spiritual, social, psychological, and emotional wellbeing.”<sup>(129)</sup> Although palliative care is not restricted to patients near end-of-life, unlike hospice care, and can be used in acute and long-term care setting; both palliative care and hospice care uses an interdisciplinary team of professionals including “doctors, nurses, social workers, psychologists, and others to provide comprehensive care according to the document.” However, traditional American medical practice focuses primarily on curing illnesses, causing symptom relief to be a secondary focus.<sup>(130)</sup> Therefore, many curative treatments for terminal illnesses “do not relieve physical suffering, and may not address emotional, spiritual, and psychological suffering at all” as highlighted by the document. The document also emphasizes the importance of palliative treatment in providing relief of suffering and pain and other symptoms, although it is still underutilized.<sup>(131)</sup>

<sup>122</sup> Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death*, 190

<sup>123</sup> David Kelly, *Medical care at the end of life. A Catholic perspective*, 138-139

<sup>124</sup> Henk ten Have and Jos Welie: “Euthanasia and medical power”, in Henk ten Have and Jos Welie: *Death and medical power. An ethical analysis of Dutch euthanasia practice*, 23

<sup>125</sup> David Kelly, *Medical care at the end of life. A Catholic perspective*, 118

<sup>126</sup> David Kelly, *Medical care at the end of life. A Catholic perspective*, 123

<sup>127</sup> Henk ten Have & David Clark (eds.), *The ethics of palliative care*. (Philadelphia, PA: Open University Press, 2002), 116

<sup>128</sup> Henk ten Have & David Clark (eds.), *The ethics of palliative care*, 118-119

<sup>129</sup> “End of Life Care: An Ethical Overview.” 18

<sup>130</sup> “End of Life Care: An Ethical Overview.” 19

<sup>131</sup> “End of Life Care: An Ethical Overview.” 16



Beckstrand and colleagues state, while pain control is not the only issue in palliative care, it remains a key component. While there is the objection to palliation on the grounds of Palliative Sedation Treatment (PST) being compared to slow euthanasia, many clinicians argue that palliative sedation does not necessarily mandate sedation to total unconsciousness, and suggest that PST can vary in terms of level, duration, and pharmacological characteristics. Moreover Beckstrand et al., point out “palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process.” It intends neither to hasten nor postpone death and integrates the psychological and spiritual aspects of patient care - by offering a support system to help patients live as actively as possible until death. The authors add that this also provides a “support system to help the family cope during the patient’s illness and in their bereavement, by using a team approach to address the needs of patients and their families - including bereavement counseling - that will enhance quality of life, and may also positively influence the course of illness.”<sup>(132)</sup> Some recommendations for facilitating a peaceful death include: Making it comfortable for the patient and family; Not allowing patients to die alone; Managing pain and discomfort; Knowing and following patient’s values/wishes for end-of-life care; Promoting earlier cessation or not initiating aggressive treatment when such care seems futile; Communicating effectively as a healthcare team.<sup>(133)</sup>

Hospice palliative care (HPC), Shannon Freeman and colleagues add, can be a good “person-centered approach that addresses the needs of the whole person, improves the quality of living and dying of persons facing a life-threatening illness.” HPC aims at the whole person, targeting to relieve suffering and improve the quality of living and dying, and helps empower individuals to gain control over their lives and manage pain and other symptoms more effectively, and it provides support to families and caregivers. HPC may empower and enable self-determination in preparation for, and management of, the dying process. Not only can HPC improve clinical care and family satisfaction, but it can also have a substantial economic impact on the costs of healthcare delivery.<sup>(134)</sup>

Barriers were identified in providing quality end-of-life care – especially in knowing when to stop treatment and allowing the patient to die with dignity, and communicating appropriately about limits of treatments, and end-of-life care goals between all parties involved.<sup>(135)</sup> It has been identified that educating all healthcare members about end- of- life care is important. Physicians most often will champion the initial conversation with patients and families, but nurses have a responsibility and professional ethics to be present for the patient and family after initial conversations take place.<sup>(136)</sup> It was also suggested that medical teams and communities need to talk openly about the limitations of medicine and treat death as a natural process, not the enemy. This way, there will be “less emphasis on interventions to prolong death and enhance or support effective care practices at the end-of-life to promote peaceful death,” as noted by Henk ten Have. Additionally, ten Have also recommended educational programs to be developed to educate healthcare providers about quality end-of-life care, initiating conversations between patient and families and team members about goals of treatment, quality of life, and palliative care. The author emphasizes that “further research is needed on better ways of communicating information to patients, patients’ families, and other members of the healthcare team, use of honesty, advocacy and compassion were recommended.”<sup>(137)</sup>

## VI. CONCLUSION

Palliation has always been a goal of medicine. Medical efforts are usually focused on eliminating the causes of disease (cure) or on preventing illness. However, for centuries, medicine has tried to control symptoms of diseases and alleviate the suffering of the patient.<sup>(138)</sup> Palliative care is related to a specific set of moral notions, such as “quality of life,” “human dignity,” “acceptance of

<sup>132</sup> C. Sepulveda et al. “Palliative care: The World Health Organization’s global perspective.” 94-95

<sup>133</sup> Renea L. Beckstrand et al. “Providing a “Good Death”: Critical Care Nurses’ Suggestions for Improving End-of-life Care”, 41-42

<sup>134</sup> Freeman, Shannon, et al. “Breaking Down Barriers: Hospice Palliative Care as a Human Right in Canada.” Educational Gerontology 39, no. 4 (2013):

<sup>135</sup> Giovanni, Lisa A. “End-of-Life Care in the United States: Current Reality and Future Promise - A Policy Review.” 130

<sup>136</sup> Renea L. Beckstrand et al. “Providing a “Good Death”: Critical Care Nurses’ Suggestions for Improving End-of-life Care”, 44

<sup>137</sup> H. ten Have: Palliative care. In: Hugh LaFollette (ed.): *The International Encyclopedia of Ethics*, 1

<sup>138</sup> H. ten Have: Palliative care. In: Hugh LaFollette (ed.): *The International Encyclopedia of Ethics*, 4

human mortality,” and “total care”<sup>(139)</sup> Palliative care is not only relevant for terminally ill patients such as cancer patients, but also patients suffering from Alzheimer’s disease, cardiovascular, neurological hematological and chronic illnesses.<sup>(140)</sup> The aim for any intervention at the end-of-life care should not only be to help people die peacefully with dignity, but to live until they die with their needs met as fully as possible and being in control of their end-of-life care treatment/interventions, and that is where hospice and palliative care, along with palliative sedation can play an important role.

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<sup>139</sup> Henk ten Have & David Clark (eds.), *The ethics of palliative care*, 72

<sup>140</sup> Cicely Saunders: “The evolution of palliative care”, *Patient Education and Counseling* 41 (2000), 8

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