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To the Graduate Council:

I am submitting herewith a dissertation written by Joseph R. Stackhouse entitled "The Appropriate Clinical Response to Patient Suffering." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Philosophy.

Glenn C. Graber, Major Professor

We have read this dissertation and recommend its acceptance:

J. Davis Allen, James O. Bennett, John R. Hardwig

Accepted for the Council: <u>Dixie L. Thompson</u>

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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We have read this dissertation and recommend its acceptance:

J. Davis Allen, M.D.

James O. Bennett, Ph.D.

John R. Hardwig, Ph.D.

Accepted for the Council:

<u>Anne Mayhew</u> Vice Provost and Dean of Graduate Studies

(Original signatures are on file with official student records)

The Appropriate Clinical Response To Patient Suffering

A Dissertation Presented for the Doctor of Philosophy Degree The University of Tennessee, Knoxville

> Joseph R. Stackhouse May, 2003

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With love and devotion to my wife, Mary Ann, whose support and encouragement of this project deserve my eternal gratitude, and to my daughter, Erin Lee Marie, and to my grandson, Justin Lawrence, for the great joy and happiness that they bring to me.

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Abstract

The starting point of my dissertation is a traditional goal of medicine, the relief of suffering. The central question that I dealt with is the appropriate clinical response to a patient's suffering. An underlying assumption in the answer that I provide is that a physician's clinical response must be guided primarily by the principles of beneficence and respect for patient autonomy. I argue that both principles require the physician to respond in a proportionate manner with medically appropriate care, which has the backing of relevant scientific and clinical data, <u>and</u> must be provided in a manner deemed acceptable by the patient.

Central to the process of providing medically appropriate care aimed at the relief of suffering is an understanding of suffering itself. To develop that understanding, I studied the works of Freud, Bakan, Frankl, and Cassell. I concluded that suffering is primarily an existential problem associated with the whole person, in contrast to physical pain, which is primarily a neurophysiological problem associated with the body. I define suffering itself as a state of emotion, consisting in an unrelenting tension between hope and despair, caused by a serious and unacceptable disruption in important personal matters. As Frankl put it, when one suffers, one perceives a gap between the way important personal matters are at the moment as compared to how such matters ought to be.

The matters are important because they involve something that the sufferer holds dear, while the disruption is unacceptable because the possibility of not overcoming that disruption is potentially devastating. The sufferer's hope derives from desire and belief

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that disruption will be resolved favorably, while the feeling of despair reflects the threat of being overwhelmed by the disruption

Although the intensity and duration of suffering vary with subjective factors and the particular circumstances, it follows that relief comes about in one of two ways. Either hope is fulfilled, in which case the sufferer no longer perceives a gap, or relief is a matter of genuine acceptance, as opposed to resignation. Genuine acceptance is the kind possible after adjusting to the death of a loved one, or the consequences of a divorce, or some other personal tragedy.

Since some patients hope for relief through physician-assisted suicide, I next examined that issue from the physician's perspective, and argue that physicians should not agree to such requests. I base my conclusion in part on a requirement defended by Pellegrino and Thomasma, which is that physicians must provide medically appropriate care in a proportionate manner. I developed their principle of proportionality with both a classical and a modern interpretation of that concept. Aquinas provides the basis of a classical interpretation of proportionality, while Gury and Knauer provide the basis of a modern interpretation.

Based on a classical version of proportionality, I argue that physician-assisted suicide is morally unacceptable for three reasons. One, it is contrary to the physician's duty to heal, which does not necessarily mean cure. The healer's commitment is to care for patients even when cure is not possible, or the patient has a poor quality of life, or death is imminent. This commitment reflects a long-standing legal, medical, and moral tradition that bars the practice of physician-assisted suicide. Two, it is contrary to the public good due to its inherent potential for abuse. I cite evidence from the Netherlands

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and from our own criminal justice system in relation to the death penalty in support of this claim. I also dispute Brock's claim that safeguards are an effective method of reducing the level of abuse in physician-assisted suicide to a level below that in other end-of-life care strategies. Third, I claim that physician-assisted suicide is contrary to the virtuous practice of medicine because it does not qualify as medically appropriate care. Due to this deficiency, physicians are led to substitute their own personal views about the worth of continued living, which exceeds the limits of their professional expertise. This deviation from established medical protocol goes beyond the particular case to the level of medical principle for all other patients similarly situated, without ethical warrant.

Based on a modern interpretation of proportionality, I argue that physicianassisted suicide fails Gury's version of that principle, which requires a predominance of good in the immediate outcome. Such results cannot be calculated in a case of physicianassisted suicide, because the immediate results of death are known only by the patient, if at all, after death. Physician-assisted suicide also fails Knauer's version, which requires that the net effect must be measured in the long run and on the whole, which are likewise unknown by the physician. Knauer also requires that there be no less harmful way of securing the value sought, in this case, relief of suffering. In the case of suffering, however, a less onerous method is available, namely, acceptance. Although acceptance is not possible for some patients and not appropriate for others, it is an avenue of relief in all cases of suffering.

Because suffering involves the whole person, I draw on the works of Frankl and Cassel to conclude that the appropriate clinical response to a patient's suffering is a holistic approach to patient care. From the individual's perspective, Frankl claims that

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resolving suffering depends on the meaning and value that we each give to our experience of suffering. From a clinical perspective, Cassell focuses on suffering as a psychological condition and offers a holistic response, consisting in two primary methods of relief. One is to guide patients to assign meaning to their medical condition, which often resolves the suffering associated with that condition. The other is to assist patients in developing a feeling of transcendence, which helps restore a sense of wholeness after injury to personhood. His approach has three goals. One is to define treatment plans in terms of a sick person, rather than in terms of a disease only. The second is to maximize the patient's function and not necessarily length of life. The third is to minimize the family's suffering as well as the patient's. In this respect, holistic medicine is centered in community, caring, compassion, and comfort, with a special emphasis on spiritual concerns. Its chief aim is inspire patients to view themselves as persons of value to be cared for, even at end of life when suffering can become unbearable.

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Chapter 1

Introduction

Any philosopher's argument which does not treat human suffering is worthless. For just as there is no profit in medicine if it does not expel the diseases of the body, so there is no profit in philosophy either, if it does not expel the suffering of the mind.

Epicurus

I. The nature of suffering.

Suffering is an inescapable part of the human condition.¹ Although the circumstances that give rise to suffering differ from person to person, suffering itself is a multidimensional cognitive experience that varies in intensity and duration. Suffering is also distinct from physical pain, despite how we often describe it with "pain language" as if suffering and physical pain were equivalent experiences.² For some, suffering is sporadic, unpredictable, and repeatable, while for others it is pervasive, relentless, and overwhelming. Because suffering is a subjective experience, however, a reliable and useful explanation of that phenomenon must derive in part from the individual's interpretation of their own suffering. In that case, what does each of us mean when we say that we suffer? What would such interpretations reveal about the nature of suffering?

As a prisoner at Auschwitz during WW II, Viktor Frankl knew first hand the personal suffering that results from "every possession lost, every value destroyed...hunger, cold, and brutality, hourly expecting extermination..."³ He drew on such experiences and those of his imprisoned comrades to claim that suffering is the experience of an unrelenting tension between hope and despair, caused by a serious and

¹Moseley, R. (1991), <u>Becoming a Self before God: Critical Transformations</u>. Nashville, Abingdon Press, p1; cf. Tournier, P. (1965), <u>The Healing of Persons</u>. San Francisco, Harper and Row, p. 143.

²Throughout, I retain the distinction between suffering and physical pain unless otherwise noted.

³Frankl, Viktor (1959), <u>Man's Search for Meaning</u>. New York, Pocket Books, p. viii.

unacceptable disruption in important personal matters.⁴ The matters in question are important and personal because they involve something that the sufferer holds dear, while the disruption is serious and unacceptable because the consequences of unfulfilled hope in overcoming the disruption are potentially devastating.

The sufferer perceives the disruption itself as an unacceptable gap between the way important personal matters are at the moment as compared to an ideal of how she believes they should be. With that perception comes the threat of despair as long as she views the gap between the "what is" and the "what should be" as unacceptable and potentially unbridgeable. Her hope in regard to these matters, on the other hand, derives from a desire and belief that the gap itself can and will be closed in a manner favorable to her.⁵ The tension between such hope and despair is unrelenting because the possibility of being overwhelmed by despair, along with the possibility of having her hope fulfilled, are both simultaneously ever-present and unyielding, and thus oppressive. The ever-present and unyielding oppressive tension between hope and despair gives suffering its form, which Viktor Frankl describes as a "state of tension between what actually is on the one hand and what ought to be on the other hand."⁶

Intensity and duration, however, are the qualities that give suffering its character. The character of suffering can vary with several personal factors that involve the sufferer alone. Such personal factors include the importance of the matters at hand, the intensity

⁴Frankl, Viktor (1986), <u>The Doctor and the Soul</u>. New York, Vintage Books, p. 107.

⁵ In claiming that desire and belief are necessary aspects of hope, I do not make a claim about the constitutive elements of motivational states. I merely borrow from Robert Stalnaker, who claims that desire and belief are "correlative dispositional states of a potentially rational agent. To desire that P is to be disposed to act in ways that would tend to bring it about that P in a world in which one's beliefs, whatever they are, were true. To believe that P is to be disposed to act in ways that would tend to satisfy one's desires, whatever they are, in a world in which P (together with one's other beliefs) were true." See Stalnaker, R. (1987), <u>Inquiry</u>. Cambridge, MA, MIT Press, p. 15. ⁶Frankl (1986), p. 108.

of the desire to resolve those matters and the ability to do so, the firmness of belief with respect to how, when, or even if the desired resolution will occur, and finally the consequences of the actual resolution.⁷ In other words, from the sufferer's perspective, the greater the desire to close the gap between the "what is" and the "what should be", the more firm the belief that the gap can and should be closed, the more grave the consequences and the more protracted the process of doing so, the more intense the suffering is likely to be.

Another factor that affects the character of suffering is the degree of uncertainty that always accompanies the experience. Because suffering means that something of grave importance persistently hangs in the balance, awaiting an unpredictable but passionately desired outcome, uncertainty is an inherent part of the experience itself. The intensity of suffering increases as the sufferer's control over the circumstances that led to the suffering decreases. Without that control, the intensity and duration of suffering (as well as its relief) then depend more on how persons in close relationship to the sufferer respond to her suffering. If those in close relationship can or should alleviate the suffering but fail to respond, their failure can magnify the uncertainty of the experience, which can unnecessarily prolong and intensify the suffering. Their failure puts the burden of relief back on the shoulders of the sufferer, which might amount to unjust abandonment, especially when there is little the sufferer can do to relieve her own suffering.

⁷Tournier (1965), pp. 143-155.

II. Relief of suffering.

The foregoing discussion on suffering raises a question about the nature of its relief, the answer to which might lead to a paradox. Given that suffering is the experience of an unrelenting, oppressive tension between hope and despair, which derives from contrasting perceptions of "what is" as compared to "what should be", another way of describing the experience is to say that suffering is essentially attitudinal, since perceptions shape attitudes.⁸ This suggests that relief of suffering occurs when the tension between the sufferer's hope and despair lessens or ceases altogether. In that case, relief may derive from a change in perceptions that affects the sufferer's attitude. In other words, relief of suffering corresponds to changes in perceptions of the gap between "what is" and the "what should be" such that a closing of the gap could occur merely by virtue of the adjustment in perceptions.

On the other hand, the gap also might close because the sufferer abandons her desire for the "what should be" and accepts the "what is" as the alternative. Acceptance in this sense, however, is not to be confused with despair where one gives up the *belief* that the "what should be" is attainable without giving up the *desire* for that particular outcome.⁹ Nevertheless, the consequences of acceptance can be positive or negative. If acceptance stems from an act of courage and self-determination, it can lead to wisdom and peace, which many view as a positive outcome. On the other hand, if acceptance stems from indolent or cringing resignation, it can lead to resentment and bitterness.

⁸Frankl (1986), p. 108.

⁹Frankl (1986), pp. 108 and 112.

Although such an outcome is perhaps just another form of suffering, many would view such a consequence in a negative light.

Even so, here is the paradox. Although total relief of suffering (complete closure of the gap) might reflect the fulfillment of hope with a r

ealization of the "what should be", total closure also might reflect a mere change in perception, or an adjustment in attitude, such that for the sufferer a gap no longer exists. After all, a gap no longer perceived is one that no longer exists for the sufferer, in which case, her suffering ends.¹⁰ Paradoxically, then, if suffering is essentially attitudinal, which is ordinarily under the control of the individual, and relief of suffering corresponds to a change in perceptions, a plausible argument is that the sufferer has a unique responsibility to relieve her own suffering merely by deliberately changing her perceptions.

It is doubtful that a victim of starvation would find such a claim at all persuasive, particularly if someone who could give her food here and now made the argument. She more likely would find the idea that she can eliminate her own suffering due to starvation merely by changing her own perceptions rather ludicrous, and instead justifiably insist on a duty that others have to relieve her suffering. This is not to deny that persons sometimes can and should relieve their own suffering. Despite that possibility, the concern in what follows is the extent to which observers ought to respond to the suffering

¹⁰ I argue that suffering would end in such cases even if the perception itself were erroneous. Consider the person dying from overexposure to the cold. Shortly before death, the sufferer often experiences a tremendous feeling of warmth, whereupon she might dismiss the previous threat to her life and no longer protect herself from the cold. In this case, although the perception is erroneous, the change in her perception about her body temperature might end her suffering from the cold. Of course, erroneous perceptions also can cause suffering. Consider the person who loses touch with reality and imagines that she will die soon from incurable cancer. Although her perception about her health and imminent death is wrong, the suffering it causes can be as real for her as it is for one who is indeed dying from incurable cancer.

of others, especially when they, as observers, are not responsible for the circumstances that gave rise to the suffering. The fundamental question concerns the moral imperative that mandates a response to the suffering of others, especially to those who seem unaware of their surroundings, such as a person numb from starvation or a comatose patient.¹¹

In part, the answer relates to the way in which an observer responds through the eyes of compassion to see the objectionable gap between the "what is" and the "what should be" in the life of the other, and thus perceive her suffering even when she herself cannot. Observing this gap connects one with the sufferer and inspires a compassionate response, which then provides motivation to close the gap for the other. This is the fundamental meaning of compassion, namely, to suffer with or alongside the other person, and "to experience feelings of pity and the desire to alleviate or prevent their suffering."¹²

Although a failure to act in such cases might constitute a moral failure, depending on the personal harm at stake, true compassion demands an active regard for the one who suffers. Perceiving a gap between the "what is" and the "what should be" in one's own life can lead to suffering, while perceiving such a gap in the life of another can lead to compassion. What remains are the important questions about what constitutes a morally responsible and effective compassionate response to suffering in the clinical setting. Although such questions often do not lend themselves to easy answers in any realm, in the clinical setting, they have a special moral significance. That significance stems primarily from the fact that persons often come to the clinical setting in search of relief

¹¹In view of the role that perception plays in suffering, can a person who is numb from starvation, or perhaps a comatose patient, suffer at all?

¹²Ruiz, P. O. and Vallejos, R. M. (1999), "The Role of Compassion in Moral Education." *Journal of Moral Education* 28(1), p. 7.

for their suffering. More importantly, physicians in their role as healers assume a duty to relieve suffering when they respond affirmatively to such requests for relief.

III. Appropriate clinical relief measures.

Because of its pervasiveness, inevitability, and consequences for human life, suffering often determines the moral status of individuals as well as that of our communities.¹³ In this sense, the human capacity to suffer (along with the capacity to experience happiness) can operate as a moral compass and measure of our actions insofar as those actions bring about suffering or happiness, usually measured in terms of harms or benefits.¹⁴ Based on this premise, right actions are those that bring about the most benefit or prevent the most harm, and wrong actions are those that have the opposite effect.

In the clinical setting, determining right courses of action on a measure of benefits versus burdens is a methodology that often informs medical care choices of both physicians and patients.¹⁵ The presumption is that such a measure determines "appropriate care" in all its phases, from care at the beginning of life throughout its course to care at the end of life. Determining appropriate care in the clinical setting is

¹³Loewy, E. H. (1991), <u>Suffering and the Beneficent Community</u>. New York, State University of New York Press, pp. 12-14.

¹⁴Burtt, E.A., ed. (1939), <u>The English Philosophers From Bacon to Mill</u>. New York, Random House, p.792. Jeremy Bentham is perhaps one of the earliest philosophers to make such a claim about the status of humans and the moral worth of their actions in terms of the benefits and harms produced by such actions. Bentham maintained that an act is right insofar as it can produce "benefit, advantage, pleasure, good, or happiness...[or if it can prevent] "mischief, pain, evil, or unhappiness to the party whose interest is considered..." On his view, an act is wrong on both counts if it has the opposite effect. This is the manner in which Bentham described his "principle of utility", which, by his account, communities and individuals could use to unravel the moral complexities of human life.

¹⁵President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. <u>Deciding to Forego Life-Sustaining Treatment</u> (1983). Washington, D. C., Government Printing Office, pp. 82-87. Medical care covers a wide spectrum of remedies and strategies irrespective of whether such care is simple or complex, natural or artificial, inexpensive or costly, usual or unusual.

thus a dynamic, mutual process shared by physician and patient (and by others, especially the patient's family).¹⁶

Motivated especially by the need to know and understand what is wrong with them, patients begin this process when they seek medical relief from some malady.¹⁷ The medical practitioner, who agrees to provide such relief, implicitly or explicitly promises to do so by means of appropriate medical care based on the traditional goals of medicine and the relevant scientific evidence supporting certain clinical guidelines. The goals of clinical medicine include the cure, restoration, or amelioration of disease or injury and the relief of suffering and pain. In this sense, relief of suffering is a core value of medicine and serves as a touchstone for a determination of appropriate care.¹⁸

A determination of appropriate care in a given clinical encounter occurs when the

medical practitioner¹⁹ and patient alike perceive the benefits of receiving such care as outweighing the associated burdens.²⁰ This approach to patient care merges two different analyses and conclusions into a third determination, the treatment plan. One analysis

¹⁶Pellegrino, Edmund D. (1983). "The Healing Relationship: The Architectonics of Clinical Medicine." <u>The Clinical Encounter: The Moral Fabric of the Physician-Patient Relationship</u>. E. A. Shelp. Boston and Dordrecht, D. Reidel Publishing Company, p. 162.

¹⁷Callahan, D. (1996). "The Goals of Medicine." *Hastings Center Report* Special Supplement (November-December), p. S9. Cf. Graber, Glenn C., Ph.D. et al. (1985), <u>Ethical Analysis of Clinical Medicine</u>, Urban and Schwarzenberg, Baltimore-Munich, p. 14; Zaner, Richard (1990). "Medicine and Dialogue." *The Journal of Medicine and Philosophy* 15(3), p. 314; Hardy, Robert C. (1978). <u>Sick: How People Feel About Being Sick and What They Think of Those Who Care for Them</u>. Chicago, Teach 'Em.

¹⁸In the following discussion of "appropriate medical care", the term "appropriate" applies to various procedures and treatment modalities that can range anywhere from the common-place to the rare, the inexpensive to the costly, the routine to the highly sophisticated, depending on the circumstances.

¹⁹Herein, I refer to all those who provide direct, professional patient care as "medical practitioners" or "caregivers" and reserve the title "physician" for those whose training and official sanction qualifies them to diagnose medical conditions and to prescribe specific forms of treatment. Where appropriate, I use titles other than "physician" for medical personnel who also diagnose conditions and prescribe treatment, such as "nurse practitioner" and "clinical psychologist". I use the more general term "caregiver" to indicate any person who provides care of any kind to the patient. As such, "caregiver" can include a wide range of persons, from family, friends, and hospital volunteers to compassionate strangers.

²⁰Council on Ethical and Judicial Affairs (1996-97), <u>Code of Medical Ethics</u>, Opinion 2.035. Chicago, American Medical Association, Chicago; see also Ayanian, J.Z., M.D., M.P.P., Landrum, M.B., Ph.D., et al, (1998), "Rating the Appropriateness of Coronary Angiography--Do Practicing Physicians Agree With an Expert Panel and With Each Other?" *NEJM* 338(26): 1903.

reflects the physician's *clinical* judgment of physiological or psychological benefits versus burdens, while the other analysis is the patient's *personal* judgment of benefits versus burdens. These judgments combine into the mutually agreed upon treatment plan. Although the judgments of both patient and physician overlap in some respects, each analysis includes other considerations and factors not part of the other's judgment.

More specifically, the physician bases her *clinical judgment* that certain care is appropriate on a combination of objective factors, including her education, training, clinical experience, and professional instinct, which she balances against scientific and clinical data, personal knowledge of her patient, and what her patient thinks is best in the circumstances at hand.²¹ David Thomasma refers to these factors as the medical indicators.²² In his view, the physician relies on such medical indicators to evaluate the patient's condition and to determine which care is appropriate for the patient. A clinical judgment of this sort generally reflects the clinical protocols suggested by professional standards and practice guidelines relative to the patient's condition, which are standards accepted by those who practice medicine within particular areas of medicine.²³ These medical specialists accept and follow such standards because they encapsulate

²¹Tanenbaum, S. J., Ph.D. (1993), "What Physicians Know." NEJM 329(17), p. 1269.

²²Thomasma, David C. (1986), "Philosophical Reflections on a Rational Treatment Plan." *The Journal of Medicine and Philosophy* 11: 157-165.

²³Although practice standards and guidelines are not without controversy, their popularity continues to increase. The AMA's 1993 Clinical Practice Guidelines Directory listed approximately 700 guidelines, whereas its 1999 Directory listed approximately 2000. In addition to physicians, various groups of medical professionals subscribe to and follow formal and informal practice guidelines, known by a variety of names. By whatever name known, practice guidelines tend to fulfill one of the requirements of evidence based medicine by focusing on utilization of patient services under specific conditions, especially when evaluating alternative treatment modalities and when professional knowledge needs guidance or is uncertain. Overall, designers of practice guidelines intend to promote high quality, appropriate, cost effective health care with reasonably objective criteria. See Hsu, J., M.D., M.B.A. (1998). "Assessing the Appropriateness of Medical Care." *NEJM* 339(20): 1241-1245; AMA Code of Medical Ethics (1996-7), Principle I, p. xiv; Field, M.J. and Lohr, K.N. (1992), <u>Guidelines for Clinical Practice: From Development to Use</u>. Washington, DC, National Academy Press, p. 2; Hirshfeld, E.B., J.D. (1991). "Should Practice Parameters Be the Standard of Care in Malpractice Litigation?" *JAMA* (November 27), p. 2886; Leape, L.L., M.D. (1990). "Practice Guidelines and Standards: An Overview." *Quality Review Bulletin* (February), pp. 42-44; AMA (1999). "Clinical Practice Guidelines Directory."

professional opinion about the effectiveness of a specific treatment modality. The supporting evidence includes the scientific and clinical data that suggests a benefit in terms of cure, amelioration, or comfort, as appropriate, with respect to a particular disease or ailment.²⁴ Aware that patients look to the medical profession with trust and hope for relief of their suffering and pain, physicians agree and expect to provide such benefits by rendering appropriate medical care that reflects proven professional opinion.

On the other hand, the patient's *personal judgment* that certain care is appropriate results from a different sort of evaluation than the physician's clinical evaluation. The patient usually weighs a wide variety of personal factors against the physician's recommended treatment.²⁵ In addition to the anticipated outcome and a simple desire to get well, such factors may include concerns about the treatment itself, a fear that the recommended treatment is unnecessary, or that treatment may cause financial burdens, lost time at work, or time away from family. Treatment might entail a period of recuperation unavailable to the patient, or might involve religious or cultural considerations, and so forth. Thomasma refers to these factors as the patient's preferential indicators, some of which might not even relate to the condition at hand.²⁶ The patient's resolution of such considerations, fostered by a feeling of trust in her physician's professional abilities and clinical recommendations, generally lead her to consent to that treatment which she considers appropriate.²⁷

²⁴Institute of Medicine (1990), "Clinical Practice Guidelines: Directions for a New Program," p. 38.
²⁵Graber (1985), p. 14.

²⁶Thomasma (1986), p. 160.

²⁷Pellegrino, E. D., M.D., Caplan, A., Ph.D., et al. (1998). "Doctors and Ethics, Morals and Manuals." *Annals of Internal Medicine* 128(7), p. 569.

Although some patients may reject the physician's clinical recommendation for various reasons, consent to treatment usually follows the patient's own determination that the benefits of receiving care outweigh the associated burdens.²⁸ With such consent, the practitioner then may render the care deemed medically appropriate and reflected in the treatment plan. From each of their own perspectives, both patient and physician deem certain care as appropriate and in the patient's best interest when each considers that care as more beneficial than burdensome. In other words, each has concluded that a particular care plan maps back to her respective goals. When these two different evaluations of appropriateness coincide, treatment usually proceeds with few conflicts. Conflicts cannot always be avoided, however. Given the differing perspectives of patient and physician, any given clinical encounter has the potential for conflict over choices and desired outcomes.²⁹ Conflicts in protocol might arise when the patient's and the practitioner's evaluations of the benefits and burdens of care diverge. The possibility of conflict increases dramatically as family members, significant others, and surrogates join the patient and practitioner in the process of measuring benefits and burdens.

Each participant's understanding of suffering often determines whether conflicts arise between physician and patient with respect to what constitutes appropriate care. Ideally, each participant in a clinical encounter grounds her view of appropriate care on her understanding of how to treat the underlying condition so as to relieve what is

²⁸Commission (1983), p. 88; Lynn, J., M.D. and Childress, J. F., Ph.D. (1986), "Must Patients Always Be Given Food and Water," in <u>By No Extraordinary Means</u>. Lynn, J., M.D., Bloomington and Indianapolis, Indiana University Press, p. 54.

²⁹With the advent of managed care, some would argue that a "third" perspective, that of the third party payor, enters the calculation along with the views of practitioner and patient. However, since payors seem willing to base reimbursement decisions on evidence of effectiveness, I assume that meeting the requirements of evidence based medicine will tend to satisfy the requirements of this additional perspective and do not give it specific attention herein. For a discussion of the third party payor's role in determinations of medical appropriateness, see Sharpe, V.A. (1997), "The Politics, Economics, and Ethics of 'Appropriateness'." *Kennedy Institute of Ethics Journal* 7(4), p. 340.

believed to be the suffering associated with that condition. Even in less than ideal clinical encounters, relief of suffering still remains a prime consideration of those involved in the decision making process.³⁰ As a result, how each party to the care process understands suffering has considerable influence on a measure of benefits and burdens, which largely determines the method of treatment chosen.

Conflicts and tensions about appropriate care can be numerous and problematic at all stages in the care process.³¹ These conflicts can revolve around a number of issues, including the physician's technical skills and clinical recommendations as well as the patient's preferences. Regardless of the underlying issue, however, conflicts about appropriate care in end-of-life situations differ from conflicts that arise in life-care situations in at least one important respect. In life-care situations, the conflict between physician and patient is usually a disagreement about how to cure or ameliorate the condition. By contrast, in end-of-life-care situations, where the condition is beyond cure, the conflict is often a more profound disagreement about suffering itself and how best to relieve it.

In life-care, relief of suffering often occurs as an indirect by-product of treating some underlying physical malady. In these situations, the primary focus is on malady rather than on suffering. Relief of the malady depends heavily on the physician's professional judgment, technical skills and clinical recommendations in relation to the

³⁰AMA <u>Code of Medical Ethics</u> (1996-97), p. 39; Lindholm, L. and Eriksson, K. (1993), "To Understand and Alleviate Suffering in a Caring Culture." *Journal of Advanced Nursing* 18, p. 1354. For a discussion of international support for relief of suffering as a goal of medicine, and other such goals, see Callahan (1996), pp. S1-S27.

³¹I use the term "life-care" to indicate those preventive and therapeutic measures rendered to those who are expected to continue living for the foreseeable future as a means of addressing their present medical condition. I use the term "end-of-life-care" to indicate those preventive and therapeutic measures rendered to those persons who are in the process of dying in the hopes that such care will ease or eliminate the physical, psychological, emotional, and spiritual burdens of the dying process.

malady rather than on an understanding of suffering per se. A consequence of this approach is that relief of the malady usually brings relief of the suffering, which is consistent with the patient's expectations of how relief will come about.³² If conflicts arise, they more often than not relate to either a physician's technical skills and clinical recommendations or to a patient's preferences, but rarely do such conflicts center on an understanding of the nature of suffering.

In end-of-life-care situations, on the other hand, the nature of the conflict often centers exactly on this issue. When cure or amelioration is no longer possible, as in endof-life situations, the focus of care changes from the underlying malady to suffering itself. Efforts aimed directly at relief of suffering then take center stage. In the process, conflicts that arise usually pivot on an understanding of suffering because the understanding of each party to the decision-making process in that regard has a direct bearing on which care choices are made. Ultimately, such choices determine the extent of relief. Authentic relief is more likely when end-of-life-care decisions are made with a proper understanding of suffering. In the absence of such an understanding, the physician's recommendations for relief may be no better, and perhaps even less efficacious, than the patient's own suggestions.

One consequence of the shift in focus from malady to suffering is that the need to relieve suffering itself at the end of life can put both physician and patient at a disadvantage. Most dying patients are at a disadvantage because they lack the necessary skills and experience to relieve their own suffering and must turn to the medical

 $^{^{32}}$ This may not be the case where the malady is permanent impairment or chronic illness. In these cases, some of the same considerations may obtain as in end-of-life-care where suffering becomes the focal point.

profession for healing.³³ As healers, most physicians are at a disadvantage because the profession itself does not yet have an adequate understanding of suffering per se.³⁴ Consequently, physicians must rely on their own personal and professional instincts and clinical experience to relieve suffering, especially at the end of life. This can be a disadvantage to the patient when the physician is professionally limited in this regard and, in some circumstances, might even cause harm to the patient. In such situations, the disappointment that follows for both physician and patient can lead to serious and sometimes irresolvable conflicts.

Some medical practitioners claim that a fundamental reason for this unfortunate consequence is that most physicians receive academic and clinical training in the conventional model of medicine only, which does not formally or intentionally foster a comprehensive understanding of the nature of suffering.³⁵ The conventional model encourages an understanding of the physiochemical aspects of suffering by focusing primarily on the body and only incidentally on the psychological aspects of disease and illness.³⁶ Paradoxically, this focus on the body frequently leads to the undertreatment of physical pain and chronic illness, which contributes to an increase in patient suffering.³⁷

³⁵Cassell, E.J. (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, New York and Oxford. Oxford University Press, p. 30; Coulehan, J. L. (1995), "Tenderness and Steadiness: Emotions in Medical Practice." *Literature and Medicine* 14.2: 223; Aring, C.D. (1958), "Sympathy and Empathy." *JAMA* 167, pp. 448-452.

³³Callahan (1996), p. S3.

³⁴Thomasma, D. C., Kimbrough-Kushner, T., et al. (1998), <u>Asking To Die: Inside the Dutch Debate About Euthanasia</u>. Dordrecht, The Netherlands, Kluwer, p. 213.

³⁶Morse, J.M. and Johnson, J.L. (1991). <u>The Illness Experience</u>, Sage Publications, p. 315; Callahan, D. (1998), <u>False Hopes</u>, Simon and Schuster, pp. 27-33; Osler, S.W. (1932). <u>Aequanimitas and Other Addresses to Medical Students</u>, <u>Nurses, and Practitioners of Medicine</u>, 3rd ed. Philadelphia, Blakiston's Son and Co., p. 33; Lief, H.I. and Fox, R.C. (1963), "Training for Detached Concern in Medical Students," in <u>The Psychological Basis for Medical Practice</u>. H. I. Lief, V. F. Lief and N. R. Lief. New York, Harper and Row, pp. 12-35.

³⁷Callahan (1996), pp. S11-12; Martino, A.M. (1998). "In Search of a New Ethic for Treating Patients with Chronic Pain: What Can Medical Boards Do?" *The Journal of Law, Medicine and Ethics* 26(4), pp. 332-349.

Such undertreatment reflects an inadequate understanding of and less than compassionate response to suffering itself, especially suffering caused by pain and chronic illness.³⁸

In treating disease and illness, conventional medicine pursues its traditional three goals of cure, amelioration, and relief of pain and suffering. On this model, physical pain and suffering are closely associated, if not synonymous,³⁹ such that suffering is viewed as primarily physical in nature. Its relief then becomes an indirect benefit of appropriate medical care.⁴⁰ In other words, on the conventional model, the immediate focus of care is the patient's underlying physical condition and not on suffering itself. The premise of conventional medicine is that suffering is an epiphenomenon of things gone awry in the body and that, if pain is relieved, so is suffering. Consequently, on this view, since the physician's understanding of suffering need not go beyond a physiological understanding of the body,⁴¹ traditional education in conventional medicine need not foster a comprehensive understanding of suffering. The unfortunate irony is that conventional medicine often falls short in the treatment of suffering because it does not take into account the psychological, social, and spiritual factors (as well as the underlying physical condition) that can cause a patient's suffering.⁴²

Given the different emphases on suffering in the care process, and despite the influence that patients and their families have on treatment outcomes in both life-care and

³⁸Goodman, E. (1999), "From Oregon, a call for compassionate care." <u>The Boston Globe</u>. Boston: 1; Bormann, D. and Hansen, K. (1997). "Improving Pain Management Through Staff Education." *Nursing Management* 28(7): 55-57; Editorial (1997). "Taking Better Care of the Dying." *ABA Journal* 83, p. 51.

³⁹Loeser, J.D. and Melzack, R. (1999). "Pain: An Overview." The Lancet 353(9164): 1608.

⁴⁰Jonas, H., Donhoff, C.M., et al. (1995). "Not Compassion Alone: Interview with Hans Jonas." *Hastings Center Report* (Special Issue), p. 48.

⁴¹Deeley, P.Q. (1999), "Ecological Understandings of Mental and Physical Illness." *Philosophy, Psychiatry, and Psychology* 6(2), p. 108.

⁴²Guzzetta, C.E. (1998), "Reflections: Healing and Wholeness in Chronic Illness." *Journal of Holistic Nursing* 16(2), p. 197.

end-of-life-care, a special responsibility to relieve suffering rests primarily with the physician as healer because it is to physicians that patients most often turn when they need healing.⁴³ By accepting the role of healer, the physician does more than merely confirm the validity of the patient's need and search for relief. As a representative of the healing profession, the physician also reinforces the view that relief of suffering is a traditional and valid goal of medicine.⁴⁴ The physician's acknowledgment and acceptance of her role as healer represents to the patient a professional ability to meet the patient's expectations of relief. In turn, by virtue of professional affiliation, one physician's claim of healing accrues to all other physicians who assume the role of healer.⁴⁵ Thus, the physician's self-representation as one who can heal constitutes a unique and distinctive obligation for all physicians to relieve patient suffering.

The physician's professional obligation to relieve suffering is unique, although not exclusive, because the purported ability to heal suffering presumably rests on expert knowledge gleaned from professional training and experience that exceeds an ordinary lay person's understanding. The purported ability to heal relies on, and indeed seems to demand, objective, verifiable evidence to support the method chosen or recommended for relief. The need for such evidence is especially critical when relief of suffering appears to take place only under the care of the physician. The profession often supports its claims about "what works" through the use of evidence based medicine.⁴⁶

⁴³Callahan (1996), p. S3.

⁴⁴Callahan (1996), p. S10.

⁴⁵Cassell (1991), p. 30. Cassell discusses the obligation of physicians to relieve suffering. I suggest that a similar duty comes about in the same way for all medical practitioners.

⁴⁶There is an appropriate place for experimental and investigative procedures or strategies in medicine, so long as they are acknowledged as such.

Evidence based medicine is the notion that treatment recommendations and clinical application of therapies and interventions are based on the strength of scientific and clinical data supporting their use.⁴⁷ Evidence based medicine represents the view that the medical profession, as a group of scientists, is dedicated to the use of theoretically and scientifically sound methods and procedures, frequently expressed in professional standards and practice guidelines endorsed by its members, aimed at the cure or ameliorate the patient's condition, or to provide comfort to their patients in their suffering.⁴⁸ In contrast to this premise of evidence-based medicine, there appears to be an absence of a comprehensive understanding of suffering by the medical profession.⁴⁹ With all due respect, this absence would suggest that the medical profession lacks the necessary foundation in some clinical encounters to assure patients whether relief of suffering is available. In other words, without formalizing and verifying its understanding of suffering and efficacious methods of relief, the medical profession falls short of its own reliance on evidence based medicine. This short fall allows for questioning the justification of relief measures, which in turn, exposes whether the medical profession can lay legitimate claim to its traditional status as healer of suffering. In other words, the crucial question is whether medicine makes an unsustainable claim about its unique ability to heal the patient's suffering.

⁴⁷Fontanarosa, Phil B., M.D. and Lundberg, George D., M.D. (1998), "Alternative Medicine Meets Science", *JAMA*, 280(18): 1618-1619. Although various meanings might be given to the notions of "what works" and "evidence based medicine", here I use these two terms interchangeably as the "conscientious, explicit, and judicious use of the current best evidence in making decisions about the care of individual patients". See Sackett, D.L., et al. (1996). "Evidence based medicine: What it is and what it isn't." *British Medical Journal* 312: 71-72; see also Gambrill, Eileen (1999), "Evidence-based Clinical Behavior Analysis, Evidence-based Medicine, and the Cochrane Collaboration." *Journal of Behavior Therapy and Experimental Psychiatry* 30, pp. 1-14.

⁴⁸Tanenbaum (1993), p.1268.

⁴⁹Thomasma, et al. (1998), p. 488.

In view of these concerns, a caveat seems in order. Questioning the skills of medical practitioners to relieve suffering is not meant to trivialize the personal knowledge and innate abilities of some clinicians who, from their own experience or from their work with patients, have learned first hand the meaning of suffering and how best to relieve it. In this regard, a special nod seems in order for physicians and nurses who work with patients suffering intensely with AIDS, terminal cancer, or chronic illness, or who have done work in third world countries where medical care is a rare commodity and unrelieved suffering the usual fare.⁵⁰ Nor is a question about the medical profession's understanding of suffering meant to underestimate the insight and wisdom of some patients regarding their own suffering as well as that of their families and friends. Although some patients may not fully understand the nature of suffering, the insights possessed by even the inexperienced in terms of how best to relieve their own suffering can be invaluable for the practitioner caring for such patients.⁵¹ Likewise, the wisdom of some physicians and nurses, especially the more seasoned veterans, has enormous application toward effective relief in particular cases. Nevertheless, questions regarding sustainable professional claims about the relief of suffering remain.

In addition to being unique, the physician's obligation to relieve suffering is also distinctive because, by reputation, tradition, and professional status,⁵² she exemplifies the kind of healer allegedly best able to relieve suffering through appropriate medical care.

⁵⁰Gore, D.M. (1998), "Descending Into the Pit." *The Spectator* 281(8887): 23-24. Gore describes his experience as a doctor in Soweto, South Africa where the medical facility personnel show little or no compassion toward the patients who present for treatment.

⁵¹Even without that understanding, a patient can know she is suffering and might very well know why, or can develop such insight as the suffering progresses. These qualifications enhance, rather than diminish, the need for the practitioner's understanding of suffering due to her role as healer.

⁵²Cassell (1991), p. 30.

In accepting the burden of healer, physicians need an objective and comprehensive understanding of that which they seek to heal, particularly suffering itself. In all such matters, moreover, the professional's understanding of suffering must exceed that of an ordinary lay person in order to fulfill the duties and responsibilities of the profession and to justifiably sustain the patient's hope for relief. Otherwise, professional attempts to relieve the patient's suffering might prove to be unpredictable, unsound or even potentially harmful. Such a consequence would seriously diminish the role of clinical healer and undermine the trust and hope of the patient. Hence, it seems paramount for the medical profession to develop a comprehensive understanding of the nature of suffering that is based on the scientific and clinical evidence of "what works". A better understanding of suffering will yield a better way of practicing medicine.

In view of the way in which relief of suffering underwrites medical care from the beginning to the end of life, the professional responsibility to relieve suffering clearly belongs to more than a few well-informed patients and physicians. That responsibility belongs to all practitioners, regardless of specialized knowledge, who by reputation and tradition allege an ability to relieve suffering.⁵³ Fulfilling this professional responsibility rests on the proviso that "medical treatments should be grounded in the best available scientific evidence" to ensure their effectiveness.⁵⁴ Consequently, it seems appropriate to ask whether authentic relief of suffering requires a proficiency grounded in evidence that exceeds the conventional norm for appropriate medical care. To meet that challenge, an authentic professional claim to relieve suffering demands a comprehensive understanding

⁵³Pellegrino, E. D. (1998), "Emerging Ethical Issues in Palliative Care." *JAMA* 279(19), pp. 1521-1522. As does Cassell, Pellegrino refers only to "physicians" as having a responsibility to relieve suffering. As noted above, I suggest that such a responsibility accrues to all medical practitioners who allege an ability to heal suffering. ⁵⁴Callahan (1996), p. S7.

of the nature of suffering, which can then provide for application of sound clinical methods to ensure satisfactory outcomes for patients who suffer. Otherwise, patients may be placing their hopes for relief of suffering in the hands of professionals who do not know what works in a clinical sense. Such a possibility calls for a different, expanded model of medicine.

IV. The holistic model of medicine.

In contrast to the conventional, scientific model of medicine that focuses primarily on the body, an alternative, expanded model of medicine would suggest that illness, rather than simply disease and physical ailments, ought to be the primary concern of medicine. Medical holism is a model of medicine that makes such a claim, based on the premise that human lives consist of a complex network of meanings, interests, relationships and beliefs.⁵⁵ On this view, illness results from some disruption in the complex interrelationship of physiological, psychosocial, spiritual and environmental factors in a person's life.⁵⁶ On the holistic model, the term "illness" refers to how "the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability."⁵⁷ The term "disease," on the other hand, is the way practitioners justifiably recast illness in biological terms according to the guidelines of medical education and training.⁵⁸ Nevertheless, the distinction between illness and disease is clear; illness reflects the patient's perspective, while disease reflects the

⁵⁵Deeley (1999), p. 108; Churchland, P.S. (1986), <u>Neurophilosophy: Toward a Unified Science of the Mind-Brain</u>, The MIT Press, p. 337; Taylor, Charles (1989). <u>Sources of the Self</u>. Cambridge, Harvard University Press, pp. 393-418; Wilson, E. O. (1998). <u>Consilience: The Unity of Knowledge</u>. New York, Alfred A. Knopf, pp. 96-124 and pp.164-180.
 ⁵⁶Freund, P. (1990). "The Expressive Body: A Common Ground for the Sociology of Emotions and Health and Illness." *Sociology of Health and Illness* 12: 463, 466, 470; E. J. Cassell (1991), pp. 32-33.

⁵⁷Kleinman, A. (1988). <u>The Illness Narratives: Suffering, Healing, and the Human Condition</u>. New York, Basic Books, p. 5.

⁵⁸Kleinman (1988), p. 5. For a similar treatment of the distinction between illness and disease, see Callahan (1996), p. S9 and Fulford, K. W. M. (1989). <u>Moral Theory and Medical Practice</u>, Cambridge University Press, Part III.

practitioner's perspective. Medical holism holds the view that, while disease may be the origin of an illness, it is only one of its aspects. Likewise, while physical pain may cause suffering, it is sometimes merely one aspect of the multifaceted personal experience called suffering, whose origin may stem from a variety of physical or nonphysical factors. A holistic model of medicine may offer a more authentic method for the relief of suffering.

The term "holism" refers to any system of parts that constitute a whole of some sort, the members of which share certain relational properties. Each part of the whole does not exist necessarily, but necessarily has at least one relational property with other members of the whole.⁵⁹ For example, it is not necessary for any particular family member to be a sibling, but of necessity, one cannot be a sibling without there being someone else who is also a sibling.⁶⁰ More precisely, the relational property (in this case "sibling") does not depend on how one describes the relationship of the members, but how the members in fact relate to one another. In other words, the relational properties of a holistic system go beyond mere description to the level of fact.

Many disciplines use the term "holism" in a distinct way to indicate an integrative and comprehensive understanding of whole systems with constituent linkages and continuities among the respective parts.⁶¹ For example, the life sciences often employ the parallel term "vitalism" to represent a holistic theory of a living organism. On this view, the organism has its many constitutive inanimate parts determined and enlivened by an

⁵⁹Esfeld, M. (1998). "Holism and Analytic Philosophy." *Mind* 107(426), p. 367.
⁶⁰Esfeld (1998), p. 370.

⁶¹Lawrence, C. and Weisz, G., eds. (1998), "Medical Holism: The Context," in <u>Greater Than The Parts: Holism in</u> <u>Biomedicine 1920-1950</u>. NY, Oxford University Press, p. 2.

autonomous vital component that both forms the relationship between those parts and also controls the life processes of the organism itself. The upshot is that the whole organic system is not reducible to nor can be fully understood in terms of its parts alone.⁶²

In the healthcare context, holism, or more precisely, medical holism, represents an approach to patient care where the practitioner focuses on the whole person rather than the patient's body and its diseases alone.⁶³ Such an approach might vary on a continuum that ranges from those practices outside the bounds of conventional medicine to a more conservative approach that complements standard medical practice. When considering practices outside the bounds of conventional medical holism as a radical alternative to standard patient care in that medical holism emphasizes preventive and therapeutic self-healing strategies to enhance one's own biological mechanisms.⁶⁴ For example, because naturopathy relies heavily, if not exclusively, on the body's own healing powers through a regimen of "natural foods, light, warmth, massage, fresh air, regular exercise, and the avoidance of drugs,"⁶⁵ it might be viewed as a radical form of holistic medicine.

When considering practices within the bounds of conventional medicine, some might view holistic medicine as a complement to standard medical practice. Medical

⁶³Robinson, G. C. (1939). <u>The Patient as a Person: A Study of the Social Aspects of Illness</u>. New York, The Commonwealth Fund. Although medical holism has roots deep in antiquity, Robinson was an early advocate for medical holism. For another advocate from the same period, cf. Peabody, F. W. (1925). "A Study of 500 Admissions to the Fourth Medical Service, Boston City Hospital." *Boston Medical and Surgical Journal* 193: 630. See also Williams, T. F. (1950). "Cabot, Peabody, and the Care of the Patient." *Bulletin of the History of Medicine* 24: 462-481. ⁶⁴Eskinazi, Daniel P. (1998), "Factors That Shape Alternative Medicine," *JAMA* 280(18): 1622.

⁶²Lawrence and Weisz (1998), p. 6.

⁶⁵Glanze, Walter D. et al., eds. (1992), <u>The Mosby Medical Encyclopedia</u>. New York. Penguin. Herbal medicine, which has roots in both the East and West, might also go outside the bounds of conventional medicine. For discussion of 17th century Western herbal medicine, see Tobyn, Graeme (1997), <u>Culpeper's Medicine: A Practice of Western</u> <u>Holistic Medicine</u>, Rockport, MA, Element Books, Inc., pp. 176-226.

holism can be an especially effective complement in this regard when it functions on the premise that appropriate medical care responds to patients as persons and in a manner that fully recognizes the need for integrating the many parts of their lives.⁶⁶ On this more conservative view of medical holism, a satisfactory integration of the varied parts of a patient's life tends to promote health, while a threat to such wholeness can lead to illness. The following encapsulates this more conservative goal for medical holism and its beneficial influence on patient care:

Holistic health, then, is a state of integration of the physical body and of the mental and emotional soul-self, in harmony with the spiritual self...The concept refers to the fact that the whole of a person is greater than the mere sum of his parts, and that there is an approach to the whole person who is ill, instead of merely to his parts or to his illness as if they were separate from the whole of him.⁶⁷

Despite the appeal of such rhetoric, it might be difficult for physicians to situate the patient as "person" in the way that even conservative medical holism requires. For instance, every patient has a genetic and experiential history that extensively shapes her current life-style, which in large measure might have led to the present physical ailment. As an example of two such ailments that often result from life-style, consider sexually transmitted diseases and alcoholism. The fact that a person's history can have such significant influence on her health status raises an important question about how much personal history a treating physician must learn to meet the requirement of medical holism to treat the patient as person. Such principles require that only when the physician

⁶⁶Alster, K. B. (1989). <u>The Holistic Health Movement</u>. Tuscaloosa and London, The University of Alabama Press, pp. 48-49. See also Gordon, J. S. (1996). "Alternative Medicine and the Family Physician." *American Family Physician* 54(7): 2205-2210.

⁶⁷Svihus, R. H. (1979). "On Healing the Whole Person: A Perspective." *The Western Journal of Medicine* 131(6): pp. 480-481.

learns a great deal about the patient as person can she construct a sound treatment plan.⁶⁸ Unfortunately, the current financial and time constraints on clinical practice render such a requirement difficult to achieve and perhaps untenable.

In addition to learning about the patient's personal history, another holistic way to situate the patient as person is to focus on the person's economic, social, or employment setting, since those aspects often play a significant role in whether there will even be a clinical encounter, not to mention the kinds of healthcare decisions made.⁶⁹ Those factors also frequently have both a direct and an indirect effect on a person's health.⁷⁰ Unfortunately, cultivating an awareness of the patient's circumstances in this sense sometimes has little effect on any preventive measures the physician would recommend because expecting patient compliance is unrealistic.

As an example of this last point, consider the patient who is a coal miner with severe breathing problems, a family of five to support, no other job skills or realistic employment alternatives, and no means to look for work in another locale. Disregarding any temporary medical care available for this patient, ultimately the person needs a change in work environment to realize any lasting health advantage. Imagine the miner's response to the physician's suggestion that he quit his job because of how working in the mine adversely affects his lungs and breathing. The suggestion seems pointless and

⁶⁸Bar, Bonnie, R.N., M.S. (1998), "The Effect of Holism on the Healthcare System," *Hospital Materiel Management Quarterly*, 20:1, p. 73. See also Principle Number 3 of the American Holistic Medical Association's Principles of Holistic Medical Practice, which states, "Holistic Physicians expend as much effort in establishing what kind of patient has a disease as they do in establishing what kind of disease a patient has."

⁶⁹Rosenberg, C.E. (1998), "Holism in Twentieth-Century Medicine," in <u>Greater Than The Parts: Holism in</u> <u>Biomedicine, 1920-1950</u>. C. Lawrence and G. Weisz. NY, Oxford University Press, p. 339.

⁷⁰The negative influence of socioeconomic factors on health has long been an issue for those concerned with public health matters. More recently, others have turned their attention to this crucial relationship; cf. Cecire, V. Ruth et al. (2000), "Urban Bioethics," *Kennedy Institute of Ethics Journal* 10(1): 1-20.

perhaps insensitive without simultaneously providing him a variety of socioeconomic remedies.⁷¹

The difficulties noted above might suggest that medical holism fails in the clinical setting as an effective and realistic approach to patient care because, in the face of inevitable suffering and death, it cannot deliver on the promise of "wholeness" as a reward for human striving.⁷² To put it another way, one might suggest that medical holism fails as a reliable patient care strategy because health itself is not something to be attained once and for all time, but is an ideal maintained more or less through a dynamic process of living and caring that has a lot of loose ends and many uncontrollable aspects. In this way, since wholeness is rarely the acknowledged goal by patient or physician, medical holism is not necessarily seen as the solution.

An interesting clue to answering such a criticism comes from William James, who modified simple holism with his notion of "someness" as a counter to what appear to be unrealistic claims about an integrated whole with interconnected parts. On James' account, to better understand the whole, he proposed a notion of "someness" where only some of parts of the whole connect with each other, while other parts do not connect at all.⁷³ In speaking this way, James expressed his version of a world view, but I believe his idea of "someness" has application in the clinical setting.

Consider "someness" in the life of a patient. On this view, because a person's life has parts, some of which are connected and others not, that life manifests itself in ways

⁷¹Brock, Dan W. (2000), "Broadening the Bioethics Agenda," *Kennedy Institute of Ethics Journal* 10(1), pp. 21-38. ⁷²Marty, M. E. (1994). "The Tradition of the Church in Health and Healing." *International Review of Mission* 83(329), pp. 227-243.

⁷³James, Wm. (1977). <u>A Pluralistic Universe</u>. Cambridge, MA, Harvard University Press, pp. 40-41.

that limit the attainability of wholeness. These limited connections also yield a partial set of meanings useful for interpreting and coping with disease and suffering. As a result, neither physicians nor followers of other vocations can heal everything or be all things to all people.⁷⁴ Thus, achieving wholeness with the help of only one healer may not be possible. Nevertheless, rather than refuting the wisdom of employing medical holism in the healthcare setting, these limitations suggest that a modified version of holism analogous to James' notion of "someness" might offer a less ambitious but more attainable approach to patient care, especially care aimed at the relief of suffering.

As a complement to standard medical practice, a modified version of medical holism acknowledges the efficacy of some nontraditional preventive and therapeutic measures, such as spiritual exercises, meditation, massage and healing touch therapy, and other such remedies. Relying on such alternative measures when the need arises gives full recognition to personal dimensions other than the physical aspects of a patient's life. In defending this modified version of medical holism, I claim that the appropriate way to relieve suffering in the clinical setting comes through a holistic approach to patient care where the practitioner must view the patient as a whole person with many needs--physical, emotional, and spiritual--rather than merely as a patient with physical needs only. Considering the nature of suffering in terms of hope and despair, viewing patients as whole persons makes it possible to meet their needs more fully, which in turn, makes it possible to relieve their suffering more effectively.

⁷⁴Kopelman, L. and Moskop, J. (1981). "The Holistic Health Movement: A Survey and Critique." *Journal of Medicine and Philosophy* 6(2), p. 226. See also Tillich, P. (1961). "The Meaning of Health." *Perspectives in Biology and Medicine* 5(1), p. 92

On the holistic model, the healer begins to relieve the patient's suffering by acknowledging a complexity of possible causes that stem from an underlying disruption in the patient's life. The healer and patient both are open to various methods of relief that depend in part on the specific disruption. The patient experiences relief through a complex healing process that ultimately repairs the disruption by restoring the patient's network of meanings, interests and relationships, or aids the patient in coping with permanent changes in that network.

To heal the patient in this holistic way requires a commitment to nonabandonment in all phases of care, especially at the end of life when suffering can be very intense and difficult to relieve.⁷⁵ Accepting such a commitment is crucial for all professional healers who promise to heal, especially for physicians and nurses because they are most often the primary care givers in the clinical setting. One effective way in which the physician or nurse fulfills a commitment to non-abandonment is by sustaining a compassionate presence with the one who suffers. Such an effort involves not only maintaining a physical presence, but also making oneself available "without an agenda, to be with them at times in silence, to be a nonjudgmental force in their lives, and to allow them the time and space...to heal."⁷⁶ In this way, the physician and nurse give deliberate attention to the physical, mental, emotional, and spiritual needs of the patient.

⁷⁵See Chapter 4 for a more developed concept of "non-abandonment" that incorporates Pellegrino's characterization of the patient-physician relationship as the healing relationship. In that context, within certain parameters, the same considerations given to terminally ill patients apply to chronically ill patients who have come to the end of their endurance. As a matter of note, my definition of "non-abandonment" does not exclude the very real possibility, and at times even necessity, of ending a patient-physician relationship before healing takes place. However, if the physician wants out, justice demands that she honor her professional promise to heal by exiting in a manner least harmful to the patient who is vulnerable.

⁷⁶Slater, Victoria et al. (1999), "Journey to Holism," Journal of Holistic Nursing 17(4), p. 373.

Sustaining a compassionate presence at times can be an enormous task. On the holistic model of medicine, it need not always be the duty of the physician or nurse alone to carry out that task. These practitioners can and often should call on other healthcare professionals, beloved family members, special friends, or members of the clergy, for example, to be this presence by becoming more directly involved in the healing process. Calling on others in this holistic way is perhaps even more vital when the primary focus is relief of suffering itself, as often happens at the end of life.⁷⁷ In calling on others for such assistance, the physician or nurse still orchestrates the attention that others give to the patient because engaging other co-healers does not spare either of the professional obligation to relieve the patient's suffering.

Although others might assist in the healing process, the holistic model of medicine acknowledges more fully the professional obligation to heal by expecting the professional healer to have a comprehensive understanding of suffering itself that exceeds the current norm for appropriate medical care allowed by the conventional model.⁷⁸ On the holistic model, the practitioner adopts an orientation to suffering in the clinical setting that promotes healing by considering the vital influence of many factors on the patient's illness, including the underlying physical ailment. With this orientation, the physician recognizes when and how others can promote healing and at times includes them in the healing process for that purpose. On the holistic model, the physician

⁷⁷Cohen, J.J., M.D. (1998). "Remembering the Real Questions." *Annals of Internal Medicine* 128(7): 564. Cf. Pellegrino (1983), p. 162.

⁷⁸Pellegrino, E. D. (1998), "Emerging Ethical Issues in Palliative Care," p. 1521.

promises to heal the patient with competent measures that address the patient's medically relevant needs in a way that remains consistent with the patient's goals and values.⁷⁹

Viewed holistically, a commitment to non-abandonment is thus a mutual undertaking between patient and physician that respects the values of each. Such mutual regard for the personal and professional values of each, however, is not without qualification. For instance, there are two moral agents acting within the healing relationship.⁸⁰ On the one hand, there is the professional who accepts an obligation to heal, but does not assume a concomitant obligation to act against her own personal and professional values to effect such healing. On the other hand, there is the patient who asks for healing, but retains the right to refuse the recommended care in that regard. Thus, a commitment to non-abandonment means that a physician's professional and moral obligation to render appropriate medical care does not preempt a patient's right to refuse such care if it is unwanted.

There are other ways in which a physician who is committed to non-abandonment honors her patient's wishes and values. For instance, such a physician would recommend medical care that is consistent with and respects her patient's conception of an acceptable life. Hence, this physician would not seek to preserve life at all costs by consigning her patient to a life sustained only by machines when that alternative clearly is not the patient's choice.⁸¹ Likewise, she would not leave her patient alone and isolated merely

⁷⁹Pellegrino (1983), p. 165.

⁸⁰Pellegrino, Edmund D., M.D. (1987), "Toward a Reconstruction of Medical Morality." *The Journal of Medical Humanities and Bioethics* 8(1), p. 13.

⁸¹Despite this claim, I will argue in Chapter 3 that non-abandonment does not include physician-assisted suicide.

because medical science can no longer do anything to cure or ameliorate the underlying medical condition so as to restore a level of daily functioning acceptable to the patient.

As another example, physicians committed to non-abandonment attempt to relieve unbearable and chronic pain with appropriate palliative measures, even at the risk of hastening the patient's death, provided the patient agrees. To deny the patient such measures merely because they hasten death reflects a false sense of obligation to preserve life at all costs, and exhibits a lack of compassion and disregard for simple comfort care. These are some of the many ways in which physicians can fulfill a commitment to nonabandonment while simultaneously honoring the patient's goals and values. To do otherwise is a professional failure in that it unjustly violates a professional agreement to heal the patient's suffering on the patient's terms.

On my account, the optimal forum to avoid such failure is the holistic model of medicine. Holism requires a comprehensive understanding of suffering itself, which in turn fosters reliance on a wide array of methods, procedures, and persons to facilitate healing of the patient's suffering in the clinical setting. In this sense, a holistic strategy better serves the patient's needs because it protects her values and dignity, which allows the physician opportunity to provide an authentic compassionate presence during the healing process and fulfill her professional commitment to non-abandonment in all phases of care, even at the end of life when healing seems illusive and impossible.

V. Holistic patient care at the end of life.

At the end of life, when medicine arrives at the crossroads where life-care must give way to end-of-life-care, troubling questions frequently arise about which interventions are appropriate, especially in regard to withholding or withdrawing

treatment or food and water. Even more troubling are questions about physician assisted suicide and voluntary active euthanasia, that is, prescribed death, as appropriate care to relieve patient suffering.⁸² In the absence of a comprehensive understanding of the nature of suffering, clinical recommendations about its relief are unreliable and unpredictable. Thus, successful transition from life-care to end-of-life-care might elude both physician and patient.

In end-of-life care, conventional strategies to cure or ameliorate the disease or ailment usually are no longer efficacious. Such efforts are frequently at odds with the patient's condition and seem to diverge in unacceptable ways from the patient's genuine needs and inevitable death. In sharp contrast to life-care where cure or amelioration is the focus and where relief of suffering hovers in the background as touchstone, end-of-life cases often have no ready answers with respect to the kind and extent of response needed. Perhaps, at the end of life, relief of suffering and pain is all medicine is able to do. To provide answers in end-of-life situations, relief of suffering and pain become the dominant goals and function as the decisional framework for patients, their families, and practitioners in making both personal and clinical judgments about appropriate care.⁸³ As a guiding principle, relief of suffering and pain become the direct aim of and very justification for specific care at the end of life.

⁸²The phrase "prescribed death" is meant to incorporate both "physician-assisted suicide" and "voluntary active euthanasia". Since my focus is on the healthcare setting, the term "prescribed" refers to the role that physicians perform in either scenario, namely, to prescribe the drug and dosage that results in death regardless of who ultimately administers that drug. The term "death" refers to the goal of ending the patient's life.

⁸³Loewy, E.H. (1992). "Suffering as a Consideration in Ethical Decision Making." *Cambridge Quarterly of Healthcare Ethics* (2), p. 139. Loewy makes the interesting point that relief of suffering, as a guide for decision making at any stage of medical care, operates more effectively than the traditional principles of beneficence, nonmaleficence, or respect for patient autonomy

In end-of-life-care, relief of suffering becomes the primary objective inasmuch as cure or amelioration of the disease is no longer a realistic goal. In such circumstances, how the physician and patient seek to relieve suffering may be determined by the understanding of suffering that each has. If viewed as synonymous with intolerable or unacceptable physical pain, as it may on the conventional model of medicine, then suffering may be viewed as tied to the body only. Thus, where pain management seems no longer effective, an emerging solution for the physician might be to prescribe death and for the patient to embrace death.⁸⁴ This prescription would operate on the assumption that, to get rid of the suffering one must get rid of the body. On the other hand, if the physician and patient adopt the holistic model, where emphasis is on the person situated in an intricate network of meanings, interests and relationships and where suffering is viewed as distinct from physical pain, solutions other than prescribed death may emerge.

Questions about the clinical efficacy of prescribed death rest on the notion that there is a distinction between suffering caused by physical pain and suffering caused by other factors. If suffering derived only from physical causes, one might argue reasonably that death of the body brings relief of suffering. On a physical basis alone, in the absence of the proper physiological mechanisms and sense organs, suffering seems impossible to experience. If, on the other hand, suffering is an inherent part of being itself, with many

⁸⁴Quill, T.E., M.D., Meier, D.E., M.D., et al. (1998), "The Debate Over Physician Assisted Suicide: Empirical Data and Convergent Views." *Annals of Internal Medicine* 128(7), p. 555. To supplement Quill's suggestion that death might be perceived as a benefit, in a discussion about such a benefit to the patient that may result from undergoing voluntary active euthanasia or physician assisted suicide in end-of-life-care, there may be two differing points of view: the practitioner's and the patient's. This possibility clouds the issue of whether death is a benefit to the patient and to what extent. A further complication derives from the controversy about the definition of death itself such that, in prescribing death, it is not clear what a physician prescribes. See also Youngner, Stuart, et al (1999), <u>The Definition of Death</u>, Baltimore, Johns Hopkins University Press. I note that the concept of "appropriate medical care" stated herein does not by itself preclude either procedure.

causes both non-physical and physical, it is unclear whether death brings relief of suffering because it is not clear that death is the end of being or merely a change in being, albeit a radical change.⁸⁵ If death is merely a change in being, there might not be any benefit from prescribed death other than relief of physical pain. In short, it is not clear that death is a benefit to the patient as a "being" as opposed to the patient as a "body."

The hypothetical claim that death relieves suffering--other than suffering from physical pain--lacks the support of scientific and clinical evidence. At best, the scientific and clinical evidence from a dead body itself is physiological silence. This lack, or absence, of evidence renders prescribed death a questionable medical benefit because such a remedy must rely on an inescapable but questionable metaphysical claim, namely, that suffering is of physical origin alone and, thus, ends with death of the body. However, in the context of evidence based medicine, the physician promises to render appropriate medical care, which is care that brings more medical benefit than harm to the patient, as evidenced by the scientific and clinical data. Consequently, since the alleged medical benefit of prescribed death is questionable due to its questionable metaphysical

A different remedy for the relief of suffering may emerge under the holistic model of medicine that emphasizes the situated life of the patient in a network of meanings and relationships. Consider how suffering itself results from a disruption in that network. In

⁸⁵Wildes, Kevin Wm., S. J. (1996), "Death: A Persistent Controversial State." *Kennedy Institute of Ethics Journal* 6(4), pp. 378-381. According to Wildes, death is not "merely a medical or scientific event. It is a cultural, moral, and often religious event." He claims that such views "shape how it [death] is understood and determine appropriate behavior."

⁸⁶AMA <u>Code of Medical Ethics</u> (1996-7), p. 6. I do not challenge a patient's belief that death will bring relief of suffering. I only question whether medical science ought to rely on such belief as justification for prescribing death.

an objective sense, suffering is a personal mode of being suspended in an unrelenting tension between hope and despair that the sufferer finds oppressive and unacceptable.⁸⁷ In a subjective sense, suffering is a psychological perturbance resulting from an interpretation of one's circumstances.⁸⁸ On either the objective or subjective basis of suffering, under the holistic model, it may be possible to restore or heal the underlying disruption in the patient's network of meanings and relationships, and thus, objectively, lift the experience of unrelenting oppression, and subjectively, heal the patient's psychological perturbance.⁸⁹ Thus, on the holistic model of medicine, in responding to the patient as person rather than as body, prescribed death may not emerge as the preferred solution to suffering because it may be viewed as inappropriate medical care. In other words, on the holistic model of medicine, prescribed death is simply not appropriate care because it does not address the patient's underlying condition.

On the objective basis of suffering--that suffering is a personal mode of being anchored in an experience of unrelenting oppression--to say that death relieves suffering is to say that death relieves oppression. For medicine to prescribe death as the solution to oppression assumes that death is efficacious in this regard. However, on evidence-based medicine, this may be a faulty assumption. On the subjective basis of suffering--that suffering is a psychological perturbance resulting from an interpretation of one's

⁸⁷Callahan (1996), p. S11.

⁸⁸Berenbaum, H., Raghavan, C., et al. (1999), "Disturbances in Emotion," in <u>Well-Being: The Foundations of Hedonic</u> <u>Psychology</u>. Kahneman, D., Diener, E. and Schwarz, N. New York, Russell Sage Foundation, pp. 267-281; Cassell, E. J., M.D. (1999), "Diagnosing Suffering: A Perspective." *Annals of Internal Medicine* 131(7): 532.

⁸⁹Wilkinson, R.G. (1996). <u>Unhealthy Societies: The Afflictions of Inequality</u>. London, Routledge, pp. 5-6; Williams, S.J. (1998). "Capitalising on emotions? Rethinking the inequalities in health debate." *Sociology* 32(1): 121-140; Lindholm, L. and Eriksson, K. (1998). "The Dialectic of Health and Suffering: An Ontological Perspective on Young People's Health." *Qualitative Health Research* 8(4), p. 525. I only suggest a link between psychological disturbances, illness, disease, and suffering, and that medicine could resolve patient suffering more satisfactorily if that link were included in developing treatment strategies. Thus, I do not suggest that medicine abandon the conventional approach altogether, or approach illness and suffering only on psychological terms.

circumstances--to say that death relieves suffering is to say that we interpret our circumstances after death, if at all, in a way that does not cause us to be perturbed. It also suggests that our circumstances after death, if any, and thus our interpretations, if any, bear no meaningful relationship to our physical life as a human. Such speculations might work well as personal judgments about suffering and death as appropriate care. However, personal claims about what perceptions, if any, we have after death are speculative because they lack the support of scientific or clinical evidence.⁹⁰ Without such evidence, all metaphysical speculations of this sort go well beyond the legitimate post mortem claims that medicine can make about the physiological condition of a dead body.⁹¹

Strong humanitarian or religious feelings might lead one beyond the scope of medical knowledge to claims about suffering and death. Frequently, humanitarian claims show an unwarranted emphasis on the body and suggest that the physiological aspects of our existence are the only source of human suffering. On that basis, the claim that death brings relief of suffering amounts to the claim that, once the body dies, suffering ceases as well. From a different perspective, religious claims commonly reflect the view that the after-life is a better life. The point is not to dispute such religious dogma or popular convention in this regard, but to emphasize that prescribed-death is an ambiguous

⁹⁰What happens after death has long been a favorite topic for speculation. For various philosophical perspectives on the concept of immortality, see Edwards, P., ed. (1997). <u>Immortality</u>. Amherst, NY, Prometheus Books. Although controversial, near death experiences might be a form of evidence that indicates the nature of our perceptions after death. For an account of near death experiences in both medieval and modern times, see Zaleski, C. (1987). <u>Otherworld Journeys</u>. New York, Oxford University Press. For firsthand reports of such experiences, see Moody, R.A. (1975). <u>Life after Life</u>. Covington, GA, Mockingbird, and Valarino, E.E. (1997). <u>On the Other Side of Life</u>, Insight Books. For children's accounts of near death experiences, Morse, M. and Perry, P. (1990). <u>Closer to the Light</u>. New York, Villard Books. For an investigation into near death experiences in the clinical setting, see Sabom, M., M.D., F.A.C.C. (1982). <u>Recollections of Death</u>. New York, Harper and Row. Concerning the controversy over near death experiences, see Kellehear, A. (1996). <u>Experiences Near Death</u>: <u>Beyond Medicine and Religion</u>. New York, Oxford University Press. Kellehear also does a comparison of reports made in the West with those made in the East. ⁹¹Engelhardt, H.T. (1996). "Suffering, Meaning, and Bioethics." *Christian Bioethics* 2(2), pp. 129-153.

medical benefit for the patient because the claim that it relieves suffering lacks scientific or clinical evidence. In other areas of medical practice, physicians generally restrict their prescriptions to those methods and strategies that are clinically or scientifically proven as efficacious. Thus, from a medical practice standpoint, extending the professional bounds of medicine to include prescribed-death as an alleged means to relieve suffering seems premature and ill-advised.

From an ethical standpoint, prescribing death as relief for suffering puts too much at stake because it constitutes a radical change to the practice of medicine.⁹² By tradition and professionally accepted ethical standards, medicine seeks to sustain life, promote health and relieve suffering.⁹³ Thus, the moral justification needed for a physician to deliberately cause, or assist in, a patient's death raises fundamental ethical questions about how far relief of suffering ought to extend in the practice of medicine.⁹⁴ If such justification turns on intolerable or worthless suffering, who should determine the threshold of tolerance or the value of suffering? Is the patient's judgment in this regard sufficient justification for the physician to prescribe death? Should a physician confirm the patient's judgment by reference to objective criteria? Are such determinations strictly a matter of public policy or should they be made at the bedside between physician and patient? Without answers to these and similar questions, prescribing death as appropriate medical care for the relief of suffering is without warrant.

⁹²Jonas (1995), p. 46. The following discussion leaves open the question of whether someone other than the physician might perform such acts without changing the character of medicine.

⁹³AMA Code of Medical Ethics (1996-7), p. 39.

⁹⁴Thomasma, et al. (1998), p. 213.

VI. Those who speak on behalf of sufferers.

In light of the above considerations, it is clear that medicine stands in need of an authentic understanding of suffering itself and how death might bring its relief before prescribing death as the remedy. An initial step toward achieving that understanding seems to require a consensus about what even counts as suffering. Yet, medicine does not have such a consensus,⁹⁵ which raises the question of whom to ask about suffering. Who can supply the missing components of a comprehensive understanding of the nature of suffering which can serve to build consensus regarding its relief?

Two groups well positioned to expand our collective understanding of suffering with their own descriptions and narratives are those who suffer and those who speak on their behalf.⁹⁶ Given the extent to which suffering is a constitutive element of human existence, however, those who suffer or have suffered are legion. Since obtaining useful accounts from such a multitude is impossible, representative empirical studies of personal experiences might be the better route. Likewise, since the number of qualified groups who speak on behalf of those who suffer are also many, obtaining useful information from this source also requires a limitation. In this regard, it seems appropriate to rely on the reflections of some physicians, nurses, psychologists, and bioethicists about the nature of suffering and how best to relieve it in the clinical setting.

Hoping to build on the work of those who know well the meaning of suffering, I intend to augment their accounts with my own views in the following explication and

⁹⁵Thomasma (1998), p. 488.

⁹⁶Scarry, Elaine (1985). <u>The Body in Pain</u>. New York, Oxford University Press, p. 6. Here, I borrow Scarry's point about pain.

analysis of the nature of suffering. I hope that result will reveal some helpful suggestions about the better responses to suffering in the clinical setting. My exposition begins with the premise that suffering is a personal experience that radically challenges us to make sense of what it means to be human.⁹⁷ Paradoxically, we meet that challenge best with a comprehensive understanding of what it means to suffer.⁹⁸ Acquiring that understanding by turning a rational eye to the personal experience of suffering demands guarding against trivializing or diminishing the emotional, spiritual, psychological and physical strength a person often needs to endure suffering.

To meet that demand, part of the strategy in what follows is to give a two-pronged account of the nature of suffering. One prong analyzes suffering as "personal experience" so as to uncover the subjective viewpoint, while the second prong analyzes suffering from the objective viewpoint as "observable condition". This second part seeks to account for how we share the experience of suffering and to explain our compassionate response to suffering, especially when those who suffer do not or cannot interpret their current experience as one of suffering.

Constructing such an account rests on the premise that suffering has morally weighty implications for medicine in all phases of patient care. The aim is to answer three fundamental questions: what is the nature of suffering, what does it mean, and what is the appropriate medical response in a clinical setting. In regard to the nature of suffering, the underlying theory is that suffering is an adaptive process triggered by the occurrence of undesirable events. As such, suffering is not an end state that lends itself to

⁹⁷Moseley (1991), p. 69.

⁹⁸Van Hooft, S. (1998), "The Meaning of Suffering." Hastings Center Report 28(5), pp. 13-19.

traditional methods of relief in the clinical setting as though it were a disease, but a process of coping that is itself a method of relief.

In regard to the meaning of suffering, the answer depends solely on the sufferer's own interpretation of the circumstances giving rise to her suffering and has a usefulness, if any, that she alone determines. This is not to suggest that suffering is so subjective that others cannot or should not attempt to influence its interpretation or outcome. Rather, whatever meaning suffering has for both sufferer and observer is ultimately one's own.

Finally, in regard to methods of relief, the appropriate way to respond to suffering in the clinical setting comes through a holistic approach to patient care. On this approach, the practitioner best views the patient as a whole person with many needs-physical, emotional, spiritual--rather than merely as a patient with only physical needs. Viewing patients in this way makes it possible to meet their needs more fully, which, in turn, makes it possible to relieve their suffering more effectively, that is, to restore as close as possible the patient's network of meanings, interests, and relationships. From a practical standpoint, following this strategy requires the practitioner to sustain a continuing compassionate presence with the one who suffers and a professional commitment to non-abandonment in all phases of care, especially at the end of life when suffering can be very intense and difficult to relieve.

VII. Conclusion.

Although the circumstances that give rise to suffering may differ from person to person, suffering itself is the experience of an unrelenting tension between hope and despair, caused by a serious and unacceptable disruption in important personal matters. Viktor Frankl described this ever-present and unyielding tension between hope and

despair as a "state of tension between what actually is on the one hand and what ought to be on the other hand." An implication of this view is that relief of suffering occurs when the tension between the sufferer's hope and despair lessens or ceases altogether. In the clinical setting, the patient and physician hope to effect relief of suffering through appropriate medical care. A determination of appropriate care in a given clinical encounter occurs when the medical practitioner and patient alike conclude that the benefits of receiving such care outweigh the associated burdens. In this two-pronged determination of appropriateness, however, there are two different analyses and conclusions that coincide. There is the medical practitioner's *clinical* judgment of "benefits versus burdens" and the patient's *personal* judgment of "benefits versus burdens", neither of which necessarily involve the same considerations or factors.

A consequence of the differing perspectives of patient and physician is that any given clinical encounter has the potential for conflict over choices and desired outcomes. However, conflicts about appropriate care in end-of-life situations differ from the conflicts that arise in life-care situations in at least one important respect. In life-care, the conflict between physician and patient usually is a disagreement about how to cure or ameliorate the condition, while in end-of-life-care, where the condition is beyond cure, the conflict is often a more profound disagreement about suffering itself.

Some medical practitioners claim that a conflict between patient and physician about how to relieve suffering at the end of life is due in part to the academic and clinical training of most physicians. Most physicians receive training in the conventional model of medicine, which does not formally or intentionally foster a comprehensive understanding of the nature of suffering. Because conventional training focuses almost

exclusively on the physiological and chemical aspects of disease and pain, many physicians trained under this model do not develop an understanding of suffering that goes beyond those aspects. Considering the essence of suffering as a perturbance of the emotions involving hope and despair, it is no wonder that these physicians might not have an understanding of suffering that exceeds the patient's, which often gives rise to conflicts between patient and physician about how best to relieve suffering.

The unfortunate consequence is that conventional medicine often falls short in its treatment of suffering because it does not take into account the psychological, social, and spiritual factors (as well as the underlying physical condition) that can cause a patient's suffering. This short fall allows for questioning the justification of relief measures, which in turn, exposes whether the medical profession can legitimately claim its traditional status as healer of suffering. In other words, without an adequate understanding of suffering, the crucial question with respect to conventional medicine is whether it makes an unsustainable claim about its unique ability to heal suffering, especially at the end of life where relief of suffering becomes the focal point of the care process.

In contrast to the conventional model of medicine that focuses primarily on the body, an alternative, expanded model of medicine would suggest that illness, rather than simply disease and physical ailments, ought to be the primary concern of medicine. Medical holism is a model of medicine that makes such a claim, based on the premise that human lives consist of a complex network of meanings, interests, relationships and beliefs. Medical holism holds the view that, while disease may be the origin of an illness, it is only one of its aspects. Likewise, while physical pain may cause suffering, it is

sometimes merely one aspect of the multifaceted personal experience called suffering, whose origin may stem from a variety of physical or nonphysical factors. Because medical holism considers a wider variety of causes with respect to suffering than conventional medicine, it may offer a more authentic method for the relief of suffering.

In the healthcare context, medical holism is an approach to patient care that varies on a continuum that ranges from practices outside the bounds of conventional medicine to more conservative approaches that complement standard medical practice. Medical holism can be an especially effective complement to standard medical practice when it functions on the premise that appropriate medical care responds to patients as persons and in a manner that fully recognizes the need for integrating the many parts of their lives. On this view, a satisfactory integration of the varied parts of a patient's life tends to promote health, while a threat to such wholeness can lead to illness. Considering the nature of suffering in terms of hope and despair, viewing patients as whole persons makes it possible to meet their needs more fully, which in turn, makes it possible to relieve their suffering more effectively.

To heal the patient in a holistic way, that is, to restore the patient's network of meanings, interests, and relationships, the practitioner must sustain a continuing compassionate presence with the one who suffers, especially at the end of life when suffering can be very intense and difficult to relieve. Compassionate presence means not only a physical presence with the person, but also making oneself available by giving deliberate attention to the physical, mental, emotional, and spiritual needs of a patient. While this compassionate presence need not always be the physician or nurse, these practitioners should orchestrate that attention. In keeping with this claim, other

professional healthcare providers, beloved family members, special friends, or members of the clergy, for example, can and often should be called upon to be this presence by becoming directly involved in the healing process, perhaps more so when the primary focus is relief of suffering itself, as it is in end of life care.

In end-of-life-care, relief of suffering is the primary objective of medical care inasmuch as cure or amelioration of the disease is no longer a realistic goal. In this circumstance, if suffering is viewed as synonymous with intolerable or unacceptable physical pain, as it may be on the conventional model of medicine, then suffering may be viewed as tied to the body only. Thus, where pain management seems no longer effective, an emerging solution for the physician might be to prescribe death and for the patient to embrace death. This prescription would operate on the assumption that, to get rid of the suffering one must get rid of the body.

A different remedy for the relief of suffering may emerge under the holistic model of medicine that emphasizes the situated life of the patient in a network of meanings and relationships. Consider how suffering itself results from a disruption in that network such that, it may be possible to restore or heal the underlying disruption in the patient's network of meanings and relationships, and thus, objectively, lift the experience of unrelenting oppression, and subjectively, heal the patient's psychological disturbance. Thus, in responding to the patient as person rather than as body, prescribed death may not emerge as the preferred solution to suffering because it does not address the patient's underlying condition.

From an ethical standpoint, prescribing death as relief for suffering puts too much at stake because it constitutes a radical change to the practice of medicine. By tradition

and professionally accepted ethical standards, medicine seeks to sustain life, promote health and relieve suffering. Thus, the moral justification needed for a physician to deliberately cause, or assist, a patient's death raises fundamental ethical questions about how far relief of suffering ought to extend in the practice of medicine. Without answers to these questions, prescribed death as appropriate medical care for the relief of suffering is without warrant. In keeping with professionally accepted ethical standards, the best clinical response to suffering, especially at the end of life, can be expressed as a compassionate presence moderated by a professional responsibility and commitment to non-abandonment in all phases of care.

Chapter 2

The Nature of Suffering

The fairest thing we can experience is the mysterious. It is the fundamental emotion which stands at the cradle of true art and true science.

Albert Einstein

I. Introduction.

An explicit theory of suffering derived from lived experience, when applied in the clinical setting, can provide a sound defense for various medical responses to patient suffering. Developing such a theory by analyzing an individual phenomenon like suffering, however, bears the inevitable risk of obscuring or forfeiting the personal dimension of that experience. Arthur Frank implicitly acknowledges such a risk when he describes suffering itself as that "most elusive quality" of the human condition.¹ Drawing on his own illness experiences, Frank claims that the suffering patients often endure in the clinical setting due to their illness resists articulation, while it simultaneously compels a response by the observer. According to Frank, an effective response to patient suffering demands an understanding that goes beyond the level of concept to that of lived reality. Without that level of understanding, those who respond run the risk of worsening the suffering.

Pellegrino makes a similar argument about a clinician's response to patient suffering. He claims that the practice of medicine commences "at the moment of clinical truth, when a decision is taken and an action initiated to heal or help a particular

¹Frank, Arthur W. (2001), "Can We Research Suffering?" *Qualitative Health Research* 11(3), p. 353.

patient."² Pellegrino characterizes this decision as an ideal that combines science and technology with a particular patient's preferences. In his view, such a combination is a crucial step in the healing process that enables physicians to meet the clinical challenge posed by the patient's suffering. Constructing such an ideal, however, begins anew each time a patient who suffers due to causes assessed as "medical" seeks relief for that condition from physicians.

In Kleinman's view, the physician's ability to relieve such suffering depends as much on a willingness to listen to the patient's story of pain and suffering as it does on educational and clinical skills. Kleinman emphasizes this point with his own story about a seven-year-old girl who had been badly burned.³ As a medical student, Kleinman's official job was to hold this little girl's hand during the painful, daily process of debridement. This reassurance was supposed to facilitate her treatment and healing. After several days of this routine, he was no longer able to tolerate either the process or his own impotence in consoling the little girl. Out of frustration, he finally asked her how she tolerated such pain, what the feeling was like of being so badly burned and of having to experience the awful treatment ritual day after day. Surprised by his openness and willingness to listen, she immediately stopped thrashing about and in direct, simple terms began to tell him. As Kleinman describes this poignant moment: "While she spoke, she grasped my hand harder and neither screamed nor fought off the surgeon or the nurse. Each day from then on, her trust established, she tried to give me a feeling of what she

²Pellegrino, Edmund D. (1983), "The Healing Relationship: The Architectonics of Clinical Medicine," p. 164, in <u>The Clinical Encounter: The Moral Fabric of the Physician-Patient Relationship</u>. E. A. Shelp, ed. (1983). Boston and Dordrecht, D. Reidel Publishing Company, pp.153-172.

³Kleinman, A. (1988). <u>The Illness Narratives: Suffering, Healing, and the Human Condition</u>. New York, Basic Books, p. xii.

was experiencing...the little burned patient seemed noticeably better able to tolerate the debridement."⁴

Kleinman's story calls attention not only to the healing power of a certain disposition on the physician's part, he also distinguishes between the "patient's experience of illness and the doctor's attention to disease..."⁵ In his view, physicians who listen more to illness narratives than to disease descriptions during patient visits sharpen their medical skills and the effectiveness of their responses to patient suffering. In this sense, the relationship between patient and physician can be the most reliable and, at times, the only mode of access to the personal dimension of suffering. Indeed, it is the primary care physician who claims a unique ability, backed by a particular education and special training, to listen to the patient's story of pain and suffering, and to respond with appropriate and effective measures of relief.⁶

Three clinicians who have employed just such a method as described by Frank and Kleinman to develop their respective theories of suffering are Sigmund Freud, physician and founder of psychoanalysis, David Bakan, clinical psychologist, and Eric Cassell, physician and bioethicist. Although these clinicians do not present a unified theory of suffering, all three begin at the point of "lived reality" as related to them by their patients. One explanation for this lack of unity might be that, as true scientists, each clinician focuses on the causes of suffering rather than on the experience itself. With this orientation, Freud describes suffering as frustrated desire, while Bakan explains suffering

⁴Kleinman (1988), p. xii.

⁵Kleinman (1988), p. xii.

⁶Finn, William F. (1986), "Patients' Wants and Needs: The Physicians' Response" in <u>Suffering: Psychological and</u> <u>Social Aspects in Loss, Grief, and Care</u>. Robert DeBellis, et al., eds. New York, The Haworth Press, p. 1.

as the psychic manifestation of a psychosocially disordered self. Cassell too defines suffering in terms of its cause, which he describes as a perceived loss of self. This theoretical focus on cause rather than on the nature of the experience itself leaves an intellectual gap that hinders the development of appropriate and effective measures of relief in the clinical setting.

To help close that gap, the following analysis highlights the personal dimension of suffering implied in the theories of Freud, Bakan, and Cassell, along with Frankl's insights. The view that emerges is that suffering itself is the experience of an unrelenting tension between hope and despair caused by the perception of a serious and unacceptable disruption in important personal matters.⁷ The disruption itself is an unacceptable gap between the way such matters are perceived to be at the moment as compared to how the sufferer believes they should be. With that perception comes the threat of despair, as long as the sufferer perceives the gap between the "what is" and the "what should be" as unacceptable and potentially unbridgeable. The matters in question are important and personal because they involve something that the sufferer holds dear, while the disruption is serious and unacceptable because the consequences of unfulfilled hope in overcoming the disruption are potentially devastating. The sufferer's hope in regard to such matters derives from a desire and belief that the gap itself can and will be closed in a favorable manner.⁸

⁷Frankl, V., M.D., Ph.D. (1986). <u>The Doctor and the Soul</u>. New York, Vintage Books, p. 107.

⁸ In claiming that desire and belief are necessary aspects of hope, I do not make a claim about the constitutive elements of motivational states. I merely borrow from Robert Stalnaker, who claims that desire and belief are "correlative dispositional states of a potentially rational agent. To desire that P is to be disposed to act in ways that would tend to bring it about that P in a world in which one's beliefs, whatever they are, were true. To believe that P is to be disposed to act in ways that would tend to satisfy one's desires, whatever they are, in a world in which P (together with one's other beliefs) were true." See Stalnaker, R. (1987), <u>Inquiry</u>. Cambridge, MIT Press, p. 15.

The tension between such hope and despair is unrelenting because the possibility of being overwhelmed by despair, along with the possibility of having hope fulfilled, are both simultaneously ever-present and unyielding, and thus oppressive. Combined with a fear of not being able to control the outcome, these factors give suffering its form, which Viktor Frankl described more concisely as a "state of tension between what actually is on the one hand and what ought to be on the other hand."⁹

II. Those who speak on behalf of sufferers.

A. Sigmund Freud.

1. Freud's theory of suffering.

Freud's concept of suffering is related to his theory of desire and the role it plays in the human psyche. Freud articulated the structure and function of the human psychological apparatus around the concepts of ego, superego and the id.¹⁰ In his view, the ego is the conscious sense of self that begins to evolve in infancy by virtue of an unavoidable confrontation with reality. Through such experience, the infant learns to identify, classify, and control its own many sensations of pain and emotional discomfort. This process of differentiation provides for the development of an ego-feeling, or psychological sphere of sensation separate from all other experience. Freud characterizes the ego as "something autonomous and unitary, marked off distinctly from everything else."¹¹ Ultimately, all experience that is not ego becomes object for the ego, which includes one's own body and other "ego-bodies", or individuals.

⁹Frankl (1986), p. 108.

¹⁰Freud, Sigmund (1961), "Civilization and Its Discontents." <u>The Standard Edition of the Complete Psychological</u> <u>Works of Sigmund Freud</u>. James Strachey and Anna Freud, eds. London, The Hogarth Press. XXI (1927-1931), p. 66ff. ¹¹Freud (1961), p. 66.

At the same time, instincts also begin to exert their influence on the infant's behavior and thought processes. Freud views two such instincts as pivotal in the ego's functioning.¹² One is the preservation instinct, or Eros, which concerns itself with growth, development, reproduction, and socialization that compels the individual to join into ever-larger units. The other is a contrary instinct that compels a kind of dissolution that returns the individual to a primeval, inorganic state, which Freud characterizes as the death instinct. These two instincts are mutually opposing factors that provide the psychic energy, or psychic tension, that gives rise to human functioning.

In Freud's view, the dominating, instinctual function of the ego is to identify and pursue objects of pleasure, and to defend against that which produces pain and unpleasure.¹³ Although this process begins in infancy, it ordinarily evolves into a more sophisticated process that eventually involves the superego and the id as two additional agencies of such psychological functioning. Both the superego and id are an unconscious part of the ego that shape and define the structure and quality of conscious experience.

The superego is a much more complicated aspect of the ego that develops during maturation as the internalization of external authority.¹⁴ The role of the superego is substantial. As the internal voice of authority, its job is to demand retribution from the ego for wrongdoing, to impose feelings of guilt, and to constrain the satisfaction of desire. The superego sustains the ego in a perpetual state of dependency on its decrees,

¹²Freud (1961), p. 118.

¹³Freud (1961), p. 67. At times, Freud uses the terms "pain" and "unpleasure" interchangeably to mean an unwanted experience that is the opposite of pleasure. At other times, he uses "pain" in an ordinary physical sense as a useful warning device. He also uses the term "unpleasure" to mean a state of affairs perceived as unwanted and to be avoided if possible. To maintain a distinction between physical pain and psychological unpleasure, I use these terms in their distinctive rather than their interchangeable senses.

¹⁴Freud (1961), p. 126-9.

irrespective of their rationality or severity, which continually affects the individual's emotional status and level of satisfaction.

As the other unconscious part the ego, the id is the source of desire that motivates behavior and structures thought processes. In Freud's view, desire is innate, irrational, spontaneous, and largely uncontrollable as long as it remains on an unconscious level.¹⁵ Because the id often has a deleterious effect on behavior, Freud developed psychoanalysis as a method of disclosing the id's hidden impulses to the conscious ego. The ultimate aim of such a process of reflection and self-inquiry is to reconcile the disclosed impulse with the requirements of the conscious ego. In this way, "by uncovering the hidden impulse, examining it, resolving its uncertainties and finding ways of integrating it into consciousness," the individual releases psychic energy "which has been tied up with the unconscious impulse so that it can be put at the disposal of the ego."¹⁶ Even with psychoanalysis, however, the ego never completely controls or eliminates unconscious, instinctual desire.

In developing psychoanalysis as a rational method of exploiting hidden impulses, Freud relied on the premise that we are innately desiring beings who engage in a

¹⁵Freud uses the term "unconscious mind" as opposed to the more modern term "subconscious mind" to denote the unconscious functioning of the id. Also, at times, Freud's meaning of "instinct" is not clear. For the most part, he uses it in the sense of an innate, unlearned behavior or behavior pattern that manifests itself in a fundamentally uncontrolled way analogous to hunger. On this view, while an individual might consciously exercise a level of control over a particular impulse, the impulse itself cannot be completely controlled or eliminated from one's motives. Thus, irrespective of an individual's awareness, all impulses influence behavior and thought processes to one degree or another. For a more detailed discussion of this point, see Freud's "Instincts and Their Vicissitudes," <u>The Standard Edition</u>, Volume 14. Many behavioral scientists now favor replacing the term "instinct" with the term "fixed-action pattern" to distinguish more clearly between the specific and rigid innate behavior of many animal species and the flexible behavior characteristic of humans. For a classic exposition of this last point, see Tinbergen, N. (1969). <u>The Study of Instinct</u>. NY, Oxford University Press.

¹⁶Frosh, Stephen (1997). For and Against Psychoanalysis. London and NY, Routledge, p. 90.

constant, life-long pursuit of pleasure as the dominant goal of life.¹⁷ He equates pleasure with happiness, and makes a finer point by characterizing its pursuit in two senses.¹⁸ In a broader sense, happiness is the absence of pain and unpleasure, while happiness in a narrow, genuine sense is a strong feeling of pleasure. In focusing on desire and pleasure as the defining characteristics of human behavior, Freud opposes a long-standing philosophical tradition that places greater value on the human capacity to reason.

In any case, Freud held the view that pleasure derives from the sudden gratification of pent-up instinctual desire, which has been frustrated to a high degree or has gone unmet for long periods. This sudden release of psychic tension yields a sense of satisfaction, the intensity of which varies according to the strength of the underlying desire. In Freud's view, the standard by which to judge all pleasure is love expressed in sexual union, because it combines both physical and spiritual elements in a way that leads to the greatest degree of happiness. The corollary, of course, is that a loss of love, or fear of such loss, has the opposite effect.¹⁹ Nevertheless, pleasure to any degree is possible only on an episodic basis, and thus more elusive than probable. Consequently, we often settle for the absence of pain and unpleasure, or pleasure in reduced measure.

Freud calls this innate, double-sided pursuit of pleasure the "program of the pleasure principle", which also must meet the demands imposed by the "reality principle", that is, life in the real world. These two principles define the level of happiness and the degree to which suffering can be avoided, which is a factor of realistic expectation and the level of independence that one develops. Complete independence

¹⁷Freud (1961), p. 76.

¹⁸Freud (1961), p. 76-7.

¹⁹Freud (1961), pp. 82; 124-6.

from the world, however, is not possible. We are not only part of that reality, because of our need to love and be loved, we are dependent on others, who are also part of the world.²⁰

Our only option is to alter the world in a way that satisfies our desires and enables us to avoid suffering in the alternative. Our success in that regard depends on our psychic energy and the use of effective defense mechanisms. On the emotional side, when events indicate that our efforts will succeed in terms of achieving our goals, there arises a feeling of hope, while "events that suggest our efforts are futile foster despair."²¹ On this view, hope and despair are not only opposite emotions, they are "intrinsically intertwined partners in the dance of desire, differing only in whether or not the object of desire is more or less likely to be reached."²² According to Freud, when our efforts fail and we lose the object of our desire, we experience suffering to one degree or another.²³

Freud claims that suffering is "nothing else than sensation; it only exists in so far as we feel it, and we only feel it in consequence of certain ways in which our organism is regulated."²⁴ On this view, suffering is a cognitive response that originates either with stimulation of a bodily sense organ, which is pain, or with the occurrence of a state of affairs perceived as unwanted, which is unpleasure. In this sense, suffering may or may not have a neurological component, but always involves emotion, especially the feelings of hope and despair.

²⁰Freud (1961), pp. 82; 101.

²¹Nesse, Randolph M. (1999). "The Evolution of Hope and Despair." *Social Research* 66(2), p. 429.

²²Nesse (1999), p. 431.

²³Freud (1961), p. 77.

²⁴Freud (1961), p. 78

Freud identifies three principal causes of suffering: pain and anxiety due to bodily decay or injury, the destructive forces of nature, and our relationships with others gone awry, especially the loss of love or fear of such loss. The latter is social suffering and the worst sort because, according to Freud, it is gratuitous, though no less inevitable.²⁵ Regardless of its cause, all suffering is an inevitable aspect of psychological functioning, which leads Freud to claim that prevention and alleviation depend on the specific cause of suffering.²⁶

For example, we never overcome decay and weakness of the body, nor completely protect against the superior forces of nature. As a result, there is little defense against the suffering caused by these factors. On the other hand, Freud appeals to the psychology of the individual as the basis of three specific methods of prevention and relief: distraction, substitution, and intoxication.²⁷ In no case, however, does Freud offer a cure for suffering, presumably because there is no cure for innate desire.

2. Assessment of Freud's theory.

Although current research in cognitive psychology does not support Freud's thesis that innate desire is the overriding principle of autonomous human behavior, it clearly shows that desire is a central motive in such behavior.²⁸ This lends support to Freud's argument that the satisfaction of desire is a matter of personal choice and learned

²⁵Freud (1961), p. 86.

²⁶Freud (1961), p. 78.

²⁷Freud (1961), p. 75.

²⁸For example, see Dunning, David, et al. (1995), "A New Look at Motivated Inference: Are Self-Serving Theories of Success a Product of Motivational Forces?" *Journal of Personality and Social Psychology* 69: 58-68.

behavior.²⁹ Experience shows that satisfaction depends on many factors, some more important than others. Our health status, our relationships with others, and place in society ordinarily are matters more important than, for example, the color of a room. Regardless of the particular matter involved, however, Freud claims that the frustration of desire involving such matters gives rise to an experience of suffering, while the intensity and duration of that experience vary with the degree of importance and level of frustration.

In other words, suffering is a subjective determination that results from a perceived state of dissatisfaction. Such an experience usually engenders hope for a favorable outcome in that regard, and a simultaneous fear that the gap in satisfaction will persist, or perhaps worsen, which engenders despair.³⁰ Because this tension between hope and despair varies in intensity and duration, depending on the underlying desires, beliefs, and general disposition of the sufferer, its resolution is uncertain and not entirely within the sufferer's control. As a result, this kind of mental angst is also oppressive.

In developing his theory, Freud distinguished between an experience of suffering and that of pain. He described suffering as a cognitive experience that may have neurological aspects, and pain as a neurological experience that may have cognitive aspects. Although pain can lead to suffering, Freud interpreted pain primarily as a warning sign that fosters survival and safety. This distinction differs from a traditional biochemical model of patient care that treats both suffering and pain as facets of a single

²⁹For a discussion of the role that desire has in relation to choice and behavior, see Edwards, Rem B. (1967), "Is Choice Determined by the Strongest Motive?" *American Philosophical Quarterly* 4(1): 1-7.

³⁰Sabini, John and Silver, Maury (1996), "On the Possible Non-Existence of Emotions: The Passions." *Journal for the Theory of Social Behaviour* 26(4), p. 395.

medical condition. As a result, traditional medical remedies that focus on relief of suffering often fall short.³¹

Though Freud takes up the issue of suffering caused by pain and disease, his primary focus is on the suffering caused by "the irremediable antagonism between the demands of instinct and the restrictions of civilization."³² In this sense, his professional aim is twofold. One is to dissect the psychological trauma in individual suffering brought on by the sublimation of desire, while the other is to examine the loss of individual happiness imposed by civilization.³³ He views the universal fear over the loss of love as the major contributing factor in such antagonism.³⁴ He claims that this fear develops very early in childhood in response to the demands of external authority. A child soon learns that a failure to comply with such demands not only jeopardizes the authority figure's love for her, a failure also threatens her safety and sense of security. As the child matures, the superego assumes the authority figure's role and perpetuates the fear, as does the family unit and the community at large. The end result is a diminished personal happiness.

By contrast, Viktor Frankl rejected this line of reasoning. Although trained in classic psychoanalysis, Frankl did not accept Freud's view that the main purpose of human existence is the "mere gratification and satisfaction of drives and instincts."³⁵ Neither did he agree with Freud's claim that personal satisfaction stems from the

³¹Cassell, Eric J. (1991), <u>The Nature of Suffering and the Goals of Medicine</u>. New York and Oxford, Oxford University Press, p. 30.

³²Freud (1961), p. 65.

³³Frosh, Stephen (1997), p. 5.

³⁴Freud (1961), pp. 124-26.

³⁵Frankl, Viktor (1959). <u>Man's Search for Meaning</u>. New York, Simon and Schuster, p. 164.

"reconciliation of the conflicting claims of the id, ego and superego, or mere adaptation and adjustment to the society and environment."³⁶ For Frankl, genuine happiness can be found only in "actualizing values and in fulfilling meaning" or purpose in life. As a result, Frankl transformed Freud's comparison between "what is" and "what should be" into a comparison between "what one has already achieved and what one still ought to accomplish, or the gap between what one is and what one should become."³⁷ Although awareness of this gap creates a certain tension involving hope and possible despair, Frankl viewed that tension as an inherent aspect of human nature and an indispensable step toward mental well-being."³⁸ In his view, suffering is a harbinger of mental health and thus a positive element in human existence.

Fankl's exception to Freud's theory of suffering aside, there is a potentially troubling aspect of Freud's theory as it may apply in the clinical setting to the question of physician-assisted suicide. Freud claims that satisfying desire is learned behavior. Given that imitation is a primary method of such learning, it follows that behavior motivated by desire is fundamentally imitative behavior.³⁹ In this light, consider the influence that physicians have achieved in the area of healthcare and in the community at large. Membership in a healing profession with a long history of effectively relieving pain and curing disease alone fosters that kind of influence. Such professional achievements have induced a general expectation and trust in physicians by society that exerts substantial influence on a particular patient's choice of medical care. The physician's influence

³⁶Frankl (1959), p. 164.

³⁷Frankl (1959), p. 166.

³⁸Frankl (1959), p. 166.

³⁹Lazar, Ariela (1999). "Deceiving Oneself or Self-Deceived? On the Formation of Beliefs 'Under the Influence'." *Mind* 108(430), p. 282.

leaves its mark on the patient's choice, even when the physician has not been explicit in her professional opinion about such choices.

More specifically, consider the physician's social stature and consequent influence in the context of physician-assisted suicide. Several studies indicate that a person's desire for suicide may be inspired by a role model who favors the practice, even though the role model has not committed suicide.⁴⁰ Given the role-model status of physicians, these results suggest that, as support for physician-assisted suicide grows among physicians, and as public awareness of their support increases, doctors may unwittingly influence the patient who is considering physician-assisted suicide. In some cases, physician-support of physician-assisted suicide may distort or perhaps unduly influence the patient's choice in that regard. To the extent that the patient's choice stems from such influence rather than from a careful consideration of the evidence, that choice relies on emotion and desire as opposed to sound reasoning. In such cases, the physician's agreement to assist also relies on emotion and desire. To the extent that physician-assisted suicide functions on emotion and desire rather than rational analysis, all else being equal, that practice is incompatible with the goals of medicine, and makes for bad medicine and poor social policy.⁴¹

On a more positive note, Freud's recommended chemical and meditative treatment methods that alter the perception of physical pain and mental angst may have practical value in the clinical setting. As one commentator remarks, the immediate aim of either approach recommended by Freud is relief of suffering, while the long-term goal is the

 ⁴⁰Livingston, Paisley (1992). <u>Models of Desire</u>. Baltimore, The Johns Hopkins University Press, p. xvi.
 ⁴¹Cassell (1991), p. 22.

development of a stronger sense of self and greater meaning to life.⁴² This suggests that the value of suffering is largely a subjective determination that depends on the patient's self-esteem, emotional disposition, and the transformational consequences posed for that individual. Such insight can aid the caregiver who must guide and assist the patient who struggles to resolve her suffering.

B. David Bakan.

1. Bakan's theory of suffering.

In his book, *Disease, Pain, and Sacrifice: Toward a Psychology of Suffering*, Bakan elaborates Freud's thesis that human suffering is an aspect of normal ego functioning with the claim that suffering itself is an affective response to the perception that one's biological or personal integrity is in doubt. The substance of his account is that disease, pain, and psychological disorders are the major factors that give rise to such a doubt about functioning or continued existence.⁴³ In his view, such doubt often leads to a state of mental anguish primarily in the form of anxiety and agony. The intensity and duration of such emotional pain depend on the circumstances, while its relief comes about either by repairing the loss of integrity or by sacrificing the offending part, which paradoxically might include the entire organism. Awareness of the latter possibility adds a degree of agony to physical or psychological disorders that often gives rise to a question about the meaning of life itself, which inevitably transforms the emotional pain of suffering into spiritual pain.

⁴²Baumeister, Roy F., et al. (1998). "Freudian Defense Mechanisms and Empirical Findings in Modern Social Psychology." *Journal of Personality* 66(6), p. 1081.

⁴³Bakan, David (1968). <u>Disease, Pain, and Sacrifice: Toward a Psychology of Suffering</u>. Chicago, The University of Chicago Press.

To explain, Bakan develops his theory of human suffering around the fundamental notion that every living organism exists and functions by virtue of certain biological, psychological and sociological processes and influences, which he designates with the term "telos". In its widest sense, "telos" refers to any level of goal-directed organization, system, or activity, regardless of its ultimate form.⁴⁴ Within an individual organism, for example, "telos" might refer to individual cells and their functioning, or to various bodily organs individually or collectively, or to the human psyche. It also refers to categories of organisms, such as the social unit to which humans belong. In all cases, however, it simply refers to that influence which determines form and function.

According to Bakan, the composition of biological entities consists in various levels of organization, or tele, arranged in a hierarchical order.⁴⁵ In any healthy organism, for instance, a dominant telos coordinates and manages the function of all lower level tele according to their form and function. To achieve that purpose, the dominant telos at a particular level of organization relies on a kind of communication with subordinate, lower level tele. As long as this relationship among the various tele remains intact, the system functions properly and the organism enjoys a state of equilibrium.

Bakan describes telic functioning in terms of an automatic, dynamic process that unfolds on an unconscious level, and is thus extraneous to a conscious mind and deliberate intervention. This qualification includes the conscious telos, or ego, which functions according to unconscious influences in addition to its deliberate purposes, as Freud

⁴⁴Bakan, p. 33.

⁴⁵Bakan, p. 33

explained in his analysis of desire.⁴⁶ According to Bakan, telic functioning is a continual reciprocal process of substances coming together at various levels and intervals into everlarger organic unities, and then splitting apart again. He denotes the fusion process with the term "telic centralization" and the fission process with the term "telic decentralization". Bakan argues that telic decentralization is essentially a loss of control by the dominant telos at a particular level of organization over lower tele within that system, which then function in a mechanical, uncontrolled manner that opposes the good of the whole.⁴⁷ Nevertheless, in a sense, all lower level tele remain in a constant state of decentralization to the extent that they remain subordinate to the dominant telos. Without a degree of constant instability within a particular biological organism, change would not be possible, nor could its systems function effectively as part of the total organism.⁴⁸ In a positive sense, then, telic decentralization is simply a normal adaptive process by which an organism functions, survives, grows, develops, or reproduces.

From a biological standpoint, however, telic decentralization does not always yield positive results. Because telic decentralization is a disruption in an organism's biochemistry, it can also manifest itself in a negative sense as disease and even death.⁴⁹ Cancer is an example of negative telic decentralization on a cellular level, while repression is an example of negative telic decentralization on a psychological level.⁵⁰ When telic decentralization manifests itself as disease, the resulting stress on the organism constitutes

⁴⁶Bakan, p. 39.

⁴⁷Bakan, p. 32.

⁴⁸Bakan, p. 40.

⁴⁹Bakan, pp. 38; 40; 51.

 $^{^{50}}$ Bakan, pp. 40; 43. It is not clear, however, that a similar disruption on a psychological level would invariably follow the same pattern as cancer cells on a physical level.

a basic threat to the biological and personal integrity of an organism.⁵¹ In other words, by its very nature, disease can raise a doubt about an organism's continued functioning or existence.

From a psychological standpoint, telic decentralization also manifests itself as pain, which is "among the most salient of human experiences [and] often precipitates questions about the meaning of life itself."⁵² Because pain is frequently a significant and unavoidable facet of survival, growth, development, reproduction, disease and death, it is ordinarily viewed as a physical phenomenon with collateral psychological aspects. Bakan alters this ordinary view by arguing that, because pain has no other locus than a conscious ego, it is fundamentally a purely psychological phenomenon.⁵³ With this alteration, he attempts to explain the demand for attention and interpretation that pain extracts from the ego, which is a subjective determination that becomes most urgent when pain is intense, intractable, and its cause obscure.⁵⁴

Not only must the ego assess the meaning of pain, it also must complete the task that pain imposes, namely, "to work to bring the decentralized part back into the unity of the organism."⁵⁵ A crucial step in that process is the psychological alienation of pain that transfers its locus "outside of me".⁵⁶ With this strategy, the ego regards the injured "part" as alien to itself, which is a psychological precondition that enables the subsequent repair

⁵¹Bakan, p. 44.

⁵²Bakan, pp. 57-9.

⁵³Bakan, p. 70.

⁵⁴Bakan, pp. 58-9; 64; 70-1.

⁵⁵Bakan, pp. 72-3

⁵⁶Bakan, p. 65.

or elimination of the injurious part, as appropriate, thereby reducing further injury.⁵⁷ In other words, should the need arise, the damaged part that has been rendered "not me" can be sacrificed without further damage to the "me" that remains.⁵⁸

Paradoxically, the "part" in need of sacrifice might be the entire organism. As Bakan explains it, there is an innate set of biological factors or conditions that triggers a complete surrender to decentralization by the dominant telos. When those conditions are met, change simply overwhelms the organism and it dies. In this sense, death is a kind of biological self-sacrifice that Freud explains in terms of a death instinct, while Bakan views it as the natural culmination of telic functioning for the sake of the larger biological telos to which the organism belongs. According to Bakan, death is an essential "genetic characteristic of each living organism" that serves the good of the species.⁵⁹ Moreover, he suggests that the illusion of personal immortality is perhaps the ultimate psychological ground for a sacrifice of the entire organism.⁶⁰

Ordinarily, a general awareness of one's own death as an inevitability causes no distress and is indeed crucial to survival and growth. On the other hand, a subjective interpretation of pain or disease as an immediate concern about continued functioning or existence can lead to an intense state of anxiety and agony.⁶¹ Such emotional pain is the substance of human suffering as described by Bakan. Nevertheless, there is an implied extension to his line of reasoning. In claiming that a perceived threat to biological and personal integrity often yields a mental anguish that is worsened by a simultaneous and

⁵⁷Bakan, p. 76.

⁵⁸Bakan, p. 79.

⁵⁹Bakan, p. 22.

⁶⁰Bakan, pp. 125; 127.

⁶¹Bakan, p. 80.

related concern about the meaning of life, Bakan implies that the true character of human

suffering is intense spiritual pain.⁶²

The following account of suffering given by Daniel Day Williams affords a way to summarize Bakan's own analysis in that regard.

We recognize suffering wherever living things or persons are shaped by something which moves them from their present state. Within this broad meaning of suffering, however, we have the experience of being acted upon in such a way that we know pain of body or mind. We ordinarily mean by suffering an anguish which we experience, not only as a pressure to change, but as a threat to our composure, our integrity, and the fulfillment of our intentions. All acute suffering has this character of threatening our self-direction, and therefore, implicitly, our being...In Heideggerian language, all acute suffering has the aspect of the threat of non-being.⁶³

2. Assessment of Bakan's theory.

Like Freud, Bakan grapples with suffering at its biological, psychological, and existential roots to discover and understand its causes as well as its value in human experience. While Freud identifies the major causes of suffering as a loss of physical or psychological status, Bakan identifies its primary cause as a threat to self posed by pain and disease. He also gives pain broader definition by adopting Freud's theme that human suffering is emotional and spiritual pain. Although on this view suffering can have both physical and psychological components, it is principally psychic in origin, and thus an experience that Bakan reserves to a conscious ego.

A consequence of this limitation is that patients who lack consciousness, such as those in a coma or vegetative state, do not suffer, at least in an ordinary sense. Although

⁶²Smucker, Carol, PhD, RN (1996), "A Phenomenological Description of the Experience of Spiritual Distress." *Nursing Diagnosis* 7(2). Bakan does not use the term "spiritual pain" in his discussion of suffering, although he considers suffering in relation to the meaning of life; e.g., ibid., p. 57.

⁶³Williams, Daniel Day (1969), "Suffering and Being in Empirical Theology", in <u>The Future of Empirical Theology</u>, Bernard E. Meland, ed. Chicago and London, The University of Chicago Press, p. 181.

such patients clearly have medical needs, their suffering might be described more fittingly with some other term. In any case, "suffering" is the appropriate descriptive term insofar as it indicates that a condition resulting in unconsciousness is inconsistent with a satisfactory quality of life for the ordinary person. Such conditions often elicit a compassionate response by the observer, who by the nature of that response "suffers" with and for the patient. In such cases, depending on the degree of compassion, perhaps "suffering" is a term that aptly describes the observer's condition as well as the patient's.

Given Bakan's view that suffering stems from a threat to self posed by disease and pain, it follows that those who lose their sense of self also lose the necessary cognitive basis for suffering, even though they may not lose consciousness. Some cases of Alzheimer's disease might provide an example. In such cases, when these persons lose their sense of an historical self due to memory loss, there is no longer a basis for perceiving the sort of threat that would give rise to suffering. At that point, it seems that "suffering" is a term that more accurately describes the patient's condition from an observer's standpoint, rather than the patient's perception and interpretation of pain or disease. Nevertheless, the traditional clinical imperative should remain focused on curing or relieving the patient's medical condition.

In regard to treatment modalities, the clinical value of Bakan's analysis concerns the explanation that he provides about the combined healing power of the human psyche and body. In his view, these aspects of human nature work in conjunction to combat the effects of disease and pain. With this approach, Bakan offers a model of healing that differs from traditional models of patient care, which tend to be mechanistic and reductive in structure. Due to their reliance on scientific data, traditional models also

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tend to marginalize the subjective aspects of pain and disease in favor of the physical aspects that are readily available and easily measured.⁶⁴

The limits of a traditional approach to patient care surface most often when caregivers must confront the subjective, experiential nature of illness in the form of suffering. One such limit stems from the view that suffering is essentially a physical phenomenon and by-product of pain and disease. By contrast, Bakan's analysis offers a more comprehensive view of suffering as a psychological mode of coping with the subjective interpretation of pain and disease, regardless of origin. More specifically, he defines suffering as a means of coping with trauma related to the self, which highlights the psychological value of suffering. With an additional emphasis on suffering as a necessary aspect of species survival, he also underscores its biological value.

Despite the advantage that Bakan's approach has over traditional models of patient care, he tends to generalize the value of suffering in a way that ignores the question about its value for particular persons. His claim that suffering is a natural way to cope with the subjective interpretation of pain and disease, and that death itself has an overall beneficial effect for a particular species, is an abstraction with little consolation for dying patients in the real world. Consider a young mother with terminal cancer, whose suffering stems not from her disease, but from the knowledge that her imminent death will devastate her small children and husband. In light of Bakan's goal to understand suffering from an existential perspective, his focus on the general at the

⁶⁴Darwin, Thomas J. (1999), "Intelligent Cells and the Body as Conversation: The Democratic Rhetoric of Mindbody Medicine." *Argumentation and Advocacy* 36, p. 35.

expense of the individual leaves a serious, though perhaps unintentional, theoretical gap in his analysis.

Applying Bakan's analysis to the question of physician-assisted suicide reveals yet another theoretical gap. Although he does not address the issue of assisted suicide, he evaluates the practice of suicide as a way to avoid unwanted suffering. Bakan objects to that practice on the premise that death is an innate characteristic of human nature that suicide arrogates to the will. Because suicide lacks psychological warrant, so too assisted suicide, which renders the physician's agreement unethical.

From a biological standpoint, however, it is not clear that Bakan's analysis prohibits such agreement. Consider his claim that, although pain and disease can be the immediate motivating factors in suicide, another factor can be the basic intuition that a biological inevitability currently unfolding on a subconscious level will soon culminate in death. Since patients who request assisted suicide may have a similar intuition, their requests might reflect no more than a resignation and voluntary surrender to the inevitable. Without some other reason to prolong the dying process, assisted suicide then becomes a biological issue related to the fatal consequences of pain and disease, rather than a moral issue about hastening death. The supporting argument then might be that the physician who complies with a patient's request for assisted suicide merely advances the natural process of dying, just as physicians often advance the natural process of giving birth.

As it now stands, Bakan's theoretical analysis of suffering does not provide a resolution of this conflict in application. Such a void raises another question as to how a patient might respond to imminent death in a less drastic but effective manner, were the

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clinician to offer assistance of a different kind. The need to consider alternative approaches stems from the fact that imminence alone is not a sufficient reason to hasten death. In that case, a physician's agreement to assist a patient's suicide requires another kind of justification, which Bakan does not provide.

C. Eric Cassell.

1. Cassell's theory of suffering.

The dilemma that physician-assisted suicide poses for the physician is also beyond the scope of Cassell's analysis of human suffering. He focuses on the patient's experience of suffering in a medical context, and explains the nature and meaning of that experience as rooted in our biology and inextricably linked to personhood. With this approach, Cassell follows both Freud and Bakan in rejecting the idea that disease and pain are more real and more important than the person who suffers due to such conditions. According to Cassell, the dependence of modern medicine on science and technology has led some physicians to make this sort of separation, which in his view is "one of the strange intellectual paradoxes of our times."⁶⁵ To counter that error, he explains the cause of suffering as a threat to personhood, which renders the experience itself a matter of subjective determination that does not lend itself to quantitative measure.

To explain the relationship between personhood and suffering, Cassell defines "person" as a "self-knowing identity that endures through time and is characterized in addition by aims and purposes, one of which is the preservation of the self that demands a

⁶⁵Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, pp. viii-ix; 33.

knowledge of a surrounding world that includes others."⁶⁶ Indeed, without others, there is no self. Despite this emphasis, however, Cassell argues that "self" is not synonymous with either mind or personhood itself. Rather, "self" is an aspect of "person" that involves a relationship with oneself, while different aspects involve relations with others and the surrounding world. In any case, an individual must wish to sustain a sense of personal identity over time, for without such desire and hope, a "threat to personhood" is devoid of all meaning.⁶⁷

In addition, Cassell holds the view that personhood evolves through a dynamic process in which both past experiences and plans for the future shape and define an individual's personality and character.⁶⁸ The ordinary setting for such development is the family, which lives in a particular community with its own social and cultural environment. Such an arrangement allows for a wide range of human experiences, including sex, love, happiness, and even suffering itself. In this setting, a healthy person functions in a fairly routine, predictable manner through a variety of roles, such as father, mother, brother, friend, doctor, and teacher. Lastly, to account for the human need to bond into groups and to pursue certain ideals and ideas larger than the person, Cassell notes the transcendent, spiritual dimension of personhood.

⁶⁶Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 26.

⁶⁷Cassell, E. J. (1991), "Recognizing Suffering", *Hastings Center Report* (May-June), p. 25.

⁶⁸Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, pp. 34-46. Cassell's discussion of "person" is taken from this section.

Cassell concludes that all aspects of personhood are susceptible to damage or loss, and thus can be the locus of suffering.⁶⁹ As a result, the specific causes of suffering vary and include "the death or suffering of loved ones, powerlessness, helplessness, hopelessness, torture, the loss of a life's work, deep betrayal, physical agony, isolation, homelessness, memory failure, and unremitting fear. Each [kind of experience] is both universal and individual. Each touches features common to us all, yet each contains features that must be defined in terms of a specific person at a specific time."⁷⁰ In Cassell's view, suffering is a mental response to the perceived loss or threat of loss in the physical, emotional, social, familial, or private realms of life. Sustaining such a loss brings about a radical and permanent disruption or unwanted changes in various realms of life.⁷¹

In describing the typical response to such changes, Cassell adopts a line of reasoning similar to Bakan's, and explains this response as suffering. As he explains it, suffering is a state of severe mental distress caused "by the actual or perceived impending threat to the integrity or continued existence of the whole person."⁷² With this focus on personhood, Cassell does not restrict the causes of suffering to the biological organism, "for persons...cannot be whole in body alone."⁷³ This expanded view allows Cassell to distinguish between suffering *per se* and physical pain. He claims that "there can be pain (or other dire symptoms) without suffering and suffering without such symptoms."⁷⁴

⁶⁹Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 43.

⁷⁰Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 44.

⁷¹Cassell (1991). "Recognizing Suffering," p.24-25.

⁷²Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 25.

⁷³Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 25

⁷⁴Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 25

Cassell adds to this description by explaining that suffering is a mental anguish involving a conflict between the emotions of hope and despair. He notes that, "In suffering, what can be seen is the loss of central purpose, marked by an aimlessness of behavior or reversion to behaviors that are primarily responses to immediate needs... Purposefulness, necessarily cohesive, fades. Suffering is the enemy of purpose, and the loss of central purpose is frequently seen in the suffering individual."⁷⁵ Since "purpose" implies a future and a corresponding hope in that regard, loss of purpose and loss of hope are dual aspects of the same psychological experience of suffering.

In this respect, Cassell agrees with the reflections of MacIntyre, who suggests that, "Hope is in place precisely in the face of evil that tempts us to despair, and more especially that evil that belongs specifically to our own age and condition...The presupposition of hope is, therefore, belief in a reality that transcends what is available as evidence".⁷⁶ Cassell blends MacIntyre's observations with his own by explaining suffering as a subjective response to a serious disruption or change in personal matters. In his view, "no one has ever questioned the suffering that attends the loss of hope."⁷⁷ Because this sort of disruption threatens to dissolve all hope regarding future plans, it inevitably raises the possibility of despair. For Cassell, this conflict between hope and despair, caused by the perception of an unwanted, radically changed future self, gives rise to a mental anguish that is the essence of suffering.⁷⁸

⁷⁵Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 30.

 ⁷⁶MacIntyre, Alisdair (1979), "Seven Traits for Designing Our Descendants." *The Hastings Center Report* 9, pp. 5-7.
 ⁷⁷Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 43.

⁷⁸Cassell, Eric J., M.D. (1999), "Diagnosing Suffering: A Perspective." Annals of Internal Medicine 131(7), p. 531.

2. Assessment of Cassell's theory.

Cassell continues Bakan's theme that suffering is a state of intense emotion involving a conflict between hope and despair, but adds a special emphasis on the role of personhood in that experience. Cassell explains personhood along the lines of Bennett, who argues that personhood is "actively formed rather than passively received...Unlike objects, which apparently can exist passively, persons must achieve their being..."⁷⁹ In Bennet's view, "there is more to being a person than simply being a living organism...[we humans] only become fully individuated persons in time, by means of social input and individual initiative--a process that is both relational and durational."⁸⁰

Because developing personhood is a dynamic process that involves both controllable and uncontrollable variables, the outcome is uncertain. Some uncontrollable variables include the surrounding circumstances and the role that others have in individual development. The competitive interplay between hope and despair as an inextricable part of such development adds to this uncertainty. Hope is a fundamental motivational force that drives human development, while a derailment in that process carries with it the possibility of despair. According to Cassell, the nature of this derailment is a perceived threat to the intactness or integrity of the person, which means that the possibility of suffering always looms in the background of human existence.

Yet, there are cases where a perceived threat to one's person does not result in suffering. For example, consider skydiving and car racing. By their very nature, participating in these sports constitutes a threat to self, which appears to meet the

⁷⁹Bennett, James O. (1999), "Selves and Personal Existence in the Existentialist Tradition." *Journal of the History of Philosophy* 37(1), p. 137.

⁸⁰Bennett (1999), p. 138.

conditions of suffering outlined by Cassell. The participants, however, more than likely would describe their experience as thrilling and not as suffering. It seems that those who participate in such sports do not perceive the threat to self as a radical, unwanted change in living. Instead, they either downplay the danger or actively court it, which enlivens the experience and enhances their sense of self.

Such consequences suggest that suffering is strictly a matter of subjective determination, which may have unwanted consequences in the clinical setting. Given that suffering stems from perception, which has an element of self-control, the assumption in the clinical setting might be that patients can reduce or eliminate their own suffering to a certain extent merely by changing their perception. Patients who do not take advantage of this option, despite the difficulty involved, may be held responsible for their own suffering by the caregiver, who may find it hard to resist the temptation to blame such patients.⁸¹

Blaming patients for their own condition is not exceptional among caregivers. The tendency to do so perhaps stems from a perceived connection between life style and ill health. Consider the connection between life style and alcoholism or drug abuse, a sedentary life style and coronary artery disease, unprotected sex and AIDS, smoking and lung cancer, overeating and obesity, and so forth. It is easy to understand how these perceived connections and others lure caregivers into blaming patients for their own illness.⁸² The primary motivation may be to lessen a sense of professional responsibility

⁸¹Kamisar, Yale (1998), "Physician-Assisted Suicide: The Problems Presented by the Compelling, Heartwrenching Case." *The Journal of Criminal Law and Criminology* 88(3), p. 1134.

⁸²Gunderman, Richard (2000), "Illness as Failure: Blaming Patients." Hastings Center Report (Jul-Aug), p. 8.

and to ease feelings of frustration or perhaps guilt, should the care provided fall short of its intended relief.

Blaming patients for their own condition can lead to worse consequences. Consider this tendency in the context of legalized physician-assisted suicide. One likely consequence of legalization is the acceptance of physician-assisted suicide as standard medical practice. The assumption that, in some cases, hastening death by suicide is an effective way to relieve suffering will foster such acceptance. Also fostering and reinforcing such acceptance will be the likely increase in patients' requests for assisted suicide following its legalization. In light of the caregiver's tendency to blame patients for their own condition, there is another likely consequence.

The suffering patient, who desperately wants relief from her suffering, but refuses the physician's offer of assisted-suicide, might be blamed for her own suffering. After all, by refusing an offer of standard medical care, albeit in the form of assisted suicide, "does not [the patient's] continued pain and suffering become her own decision and her own responsibility?"⁸³ The resulting psychological pressure brought on by this offer by the physician can unduly influence the patient's acceptance, more so when continued living creates greater hardship for her family or significant others that an earlier death would prevent. To the extent that such pressure coerces the patient's decision, her acceptance is less than voluntary, which renders both the offer and the assistance provided unethical.

For this reason alone, blaming the patient for her own illness, pain, or suffering is incompatible with the physician's professional goals of "promoting health, treating

⁸³Emanuel, Ezekiel J. (1997), "Whose Right to Die?" Atlantic Monthly (March), p. 79.

disease, and relieving suffering"⁸⁴ Blaming the patient also relies on a faulty assumption that risk-taking and bad health is strictly a matter of personal choice, rather than "the product of social and economic forces over which the [patient] may possess little knowledge, let alone control."⁸⁵ A multitude of factors, such as genetics, the environment, culture, and natural disposition, shape and inform our choices in both conscious and unconscious ways. To suggest that choices by definition are free from the influence of such factors is to misunderstand the human psychology of decision-making. Under these conditions, suffering is not an optional psychological state that the patient chooses. Rather, suffering is a natural response to threats involving the self that serves to motivate a defense in that regard. Suffering is a condition in need of resolution and not a reason to blame.

Although Cassell does not address the resolution or treatment of suffering in the clinical setting, his theory suggests that a theoretical understanding of emotion itself could provide the basis of an effective treatment plan aimed at relief of suffering. In a fundamental sense, all emotions are evolutionary coping mechanisms that provide subjective information "instrumental in guiding behavior required for self-preservation and preservation of the species."⁸⁶ Emotions are either positive or negative experiences, and always arise in connection with a disruption in goal-directed activity.⁸⁷ One very useful emotion that arises in connection with trauma involving the self is fear, because it

⁸⁴Gunderman (2000), p. 10

⁸⁵Gunderman (2000), p. 8.

⁸⁶Chapman, C. Richard and Gavrin, Jonathan (1993), "Suffering and Its Relationship to Pain." *Journal of Palliative Care* 9(2), p. 6.

⁸⁷Sabini, John and Silver, Maury (1996), "On the Possible Non-Existence of Emotions: The Passions." *Journal for the Theory of Social Behaviour* 26(4), p. 394.

fosters adaptation and survival. Given Cassell's view that suffering involves fear about the self, the appropriate clinical response to suffering must address such fear by identifying those coping strategies proven effective in protecting the patient's sense of self.

To that end, some empirical findings show that counterfactual thinking is a common response to unfavorable or traumatic events involving the self that can be effective in yielding positive results.⁸⁸ Such thinking involves a repeated mental review of the actual event, along with the visualization of alternative outcomes for comparative purposes. One kind of visualization is an upward comparison, which reflects ways in which the actual event "could have been better." The purpose is to prevent similar results in the future, which helps the sufferer feel more in charge and self-confident despite the negative event. Another kind of visualization is a "downward comparison" that yields a different outcome that reflects ways in which the actual outcome "could have been worse." The imagined results boost the sufferer's self-image and attitude about the actual outcome.

To illustrate the latter kind of comparison, a woman who has a breast removed due to cancer often compares herself with other women who have had both breasts removed for the same reason. Such comparisons are a mild form of "downward comparison" that promotes acceptance of the situation. Although some might view this strategy as a way to find satisfaction in the suffering of others who are worse off, such an interpretation misses the point. The purpose of this comparison is not to delight in the misery of others, but to resolve unfavorable changes of the self by imagining how things

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⁸⁸Baumeister, et al. (1998), p. 1081.

could have been worse. The condition of those who are indeed worse off acts as the catalyst for a positive modification in her initial response to her own trauma. The results of imagining worse case scenarios may serve to "bolster self-esteem, minimize emotional distress, and thus facilitate mental health and adjustment."⁸⁹

Regardless of which comparison the sufferer makes, however, these same studies also show that effectively coping with trauma related to the self, such as serious illness or job loss, depends on self-image. Those with high self-esteem tend to benefit from counterfactual thinking, while such thinking provides little relief for those with low selfesteem. Because those with high self-esteem tend to focus on their ability to bring about favorable outcomes, that approach serves to strengthen the ego and produce an overall positive attitude about the trauma. On the other hand, those with low self-esteem tend to focus on the part they had in causing the event, which often leads to feelings of regret and self-blame, especially in situations involving shame. This suggests that, because suffering is a complex phenomenon related to fears about the self, it requires individualized treatment that gives special attention to the patient's level of self-esteem.

An additional factor in resolving traumatic events involving the self concerns the sufferer's experience in such matters. In true Freudian style, for example, psychologist Erik Erikson claims that managing such events is an essential and inescapable part of ego development. In Erikson's view, ego development is a dynamic process that spans the entire life cycle, and follows an ordered sequence that roughly corresponds to specific

⁸⁹Baumeister (1998), p. 1106.

age periods.⁹⁰ The physiological maturation and accompanying psychosocial demands of each period give rise to a 'crisis' of ego, or turning point in life. The manner of resolving such a crisis at one stage shapes and determines the manner of resolution at future stages. A positive resolution at one stage strengthens the ego and increases the likelihood of a positive resolution at the next stage, and vice versa. Hence, the key to an effective resolution of a current experience of suffering may require confronting and resolving buried issues of self-esteem.

Given the extent to which one's sense of self and suffering are inextricably related, the actual or potential kind of loss related to the self also may affect the quality of suffering. Regarding those kinds, Peretz identifies four types of loss involving the self that can be either permanent or temporary losses.⁹¹ First is the loss of a loved one or significant other through physical separation, divorce, or death. The second kind includes physical, social, financial, and role-related losses. The third category concerns loss of external objects, such as money and personal property. The final category includes developmental losses that are an aspect of maturation and aging. Whether the suffering associated with each kind of these losses is of a different quality warrants further research.

In the interim, there is evidence to suggest that a common response to losses involving the self is grief.⁹² In such cases, a clinical strategy that aims at relief of

⁹⁰See for example, Erikson, Erik (1963), <u>Childhood and Society</u>. New York, Norton; see also Erikson (1982), <u>The Life</u> <u>Cycle Complete: A Review</u>. New York, Norton, p. 268.

⁹¹Peretz, David (1970), "Development, Object-Relationships and Loss", in <u>Loss and Grief</u>. B. Scheonberg, A. C. Carr, D. Peretz and A.H. Kutscher (eds.). London, Columbia University Press, pp. 3-19.

⁹²Robinson, David S. and McKenna, Hugh P. (1998), "Loss: An Analysis of a Concept of Particular Interest to Nursing." *Journal of Advanced Nursing*, p. 781.

suffering ought to rely on the view that suffering is a kind of grief. According to Freud, grief itself is a psychological process of separation through which the bereaved person gradually withdraws emotional attachment from the lost object or deceased loved one.⁹³ In a similar vein, Kubler-Ross explains the grief of terminally ill patients as a mode of expression in advance of the loss.⁹⁴ In her view, such grief is an integrative process by virtue of which an individual psychologically adapts to an anticipated loss. She describes one aspect of this adaptive process as "preparatory grief", which unfolds in stages, beginning with denial, eventually progressing to anger, then on to bargaining, depression, and finally acceptance.

Other research adds to Kubler-Ross' theory of adaptation to loss and suffering. One such study uses a definition of suffering as "a highly emotional response to that which was endured, to the changed present, or to anticipating the altered future..." due to illness and injury, and identifies a common, five-step response to such threats involving the self.⁹⁵ According to the results of this study, a feeling of having to endure the injury is characteristic of the first three stages, while a feeling of suffering due to the injury is characteristic of the last two stages.

At the onset of illness or injury, the injured person becomes keenly vigilant about that which has happened, observing the consequences, feeling overwhelmed, struggling to maintain emotional control, and readily accepting assistance from others to ward off the danger. During the second stage, however, depending on the seriousness of the injury

⁹³Freud, Sigmund (1961), "Mourning and Melancholia." <u>The Standard Edition</u> Vol. 14, p. 255.

⁹⁴See for example, Kubler-Ross, Elizabeth (1969), <u>On Death and Dying</u>. New York, Macmillan.

⁹⁵Morse, Janice M., Ph.D. (1997), "Responding to Threats to Integrity of Self." *Advances in Nursing Science* 19(4), pp. 21-36.

or illness, such persons begin to lose their hold on reality and perceive the world as changed and hostile. Their perception often motivates a desire to "anchor" onto a significant other, who can act as a buffer and provide a sense of protection. At this stage, such persons often describe their experience as having to endure the trauma, rather than as an experience of suffering, which gives rise to a determination to survive. Injured persons enter the third stage of adaptation as they develop goals beyond the level of endurance and mere survival. Once the injured person grasps the implications of the physical changes and loss of function, such persons still experience the need to endure their trauma, but they begin to fear the isolation that injury can produce. Such recognition can signal the beginning of acceptance, which can lead to a renewed desire for living and eventual restoration of the damaged self.

While this study shows that, during the first three stages of adaptation, injured persons often interpret their injury as an endurance test, it shows that, during the fourth phase, they begin to interpret their injury primarily as an experience of suffering, which they express as grief over the loss sustained. This interpretation leads to a deeper appreciation of reality, which sets the stage for a resolution of guilt feelings that injured persons may experience in relation to the cause of their injury. Such frank appraisal indicates that the personal aspect of healing has begun. As a result, the primary focus during this fourth phase is on piecing reality together in a way that allows such patients to regain their integrity of self.

For some individuals, progressing to the fifth and final stage of adaptation does not occur until a certain amount of suffering has been endured. According to the study above, once these individuals perceived that they had "suffered enough and were able to

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accept their changed reality, they left suffering and gained new insights and appreciation for life as a reformulated self."⁹⁶ Their subjective determination about the necessary length of their suffering marked the beginning of the final stage of adaptation, where the injured person learns to live with an altered view of self.

It would be a mistake to interpret such results as though progression from one stage to the next comes about simply with the passage of time, and that achieving acceptance and a renewed sense of self is a given or happens to everybody. Adapting to loss and resolving the associated suffering depends on many factors, including the extent of the loss, an ability to provide self-comfort, and the role of others, especially the caregiver.⁹⁷ The caregiver fosters adaptation primarily by cultivating the injured person's trust and confidence, which is an additional demand of providing comfort and skilled care. Because suffering is a complex form of grief, especially in a case of terminal illness or injury, its resolution is not always possible.

Despite such uncertainty, suffering is a phenomenon that lends itself to strategizing and intervention in the clinical setting.⁹⁸ One method of patient care that aims at helping patients and their families come to terms with grief is the Wright, Watson, and Bell model of Advanced Family Systems Nursing Practice.⁹⁹ This model functions on the premise that, although certain aspects of grief can end, others remain, because a sustained loss becomes an ever-present part of the sufferer's life. Given this premise, the goal for the patient and family is not to be rid of grief, but to develop a

⁹⁶Morse (1997), p. 23.

⁹⁷Morse (1997), p. 30.

⁹⁸Morse (1997), p. 34.

⁹⁹Wright, L.M., et al. (1996), <u>Beliefs: The Heart of Healing in Families and Illness</u>. New York, Basic Books.

relationship with that grief and the loss that spawned it. Based on an interconnection between beliefs, stories, and illness, one of the ways in which the caregiver aids the patient in this way is by opening a communication context that frees the patient to identify, challenge and modify the beliefs that constrain and hinder adjustment to the consequences of loss.¹⁰⁰ With this approach by the clinician, "[patients] who are suffering in loss...can be guided into finding a fitting place in their lives for a relationship with grief."¹⁰¹

In acknowledging a clinical need to facilitate candid communication between caregiver and patient, it is as though the Wright-Watson-Bell model of patient care accepted as its motivating principle Arthur Frank's claim that the suffering endured by patients in the clinical setting resists articulation. With its focus on communication, this model seeks a level of understanding between patient and caregiver that addresses Frank's major concern. Frank argues that an effective response to suffering demands an understanding that goes beyond the level of concept to that of lived reality. In his view, achieving that kind of understanding enables the caregiver to avoid worsening the patient's suffering.

Reflecting a similar concern, another clinical approach to suffering operates on the premise that coping with grief and regaining integrity of self is an oscillating process, "whereby the grieving individual at times confronts, [and] at other times, avoids the

¹⁰⁰Wright, L.M., et al (1996), p. 22.

¹⁰¹Moules, Nancy J. (1998), "Legitimizing Grief: Challenging Beliefs that Constrain." *Journal of Family Nursing* 4(2), p. 165.

different tasks of grieving."¹⁰² In this sense, grieving is a necessary part of adaptation to loss, and does not have to be managed in a relentless manner "at the expense of attending to other tasks that are concomitant with loss."¹⁰³ On this approach, the resolution of suffering becomes a mutual challenge for both patient and caregiver that in part depends on the meaning and value of suffering. The theories discussed above suggest that, as a state of emotion involving hope and despair, suffering has a specific content and purpose, and thus always has meaning. The patient's challenge, however, is to specify the meaning and value of her own suffering, while the caregiver's challenge is to assist the patient in achieving that goal.

III. The meaning and value of suffering.

The results of recent studies in the area of human behavior suggest that finding meaning for a loss that challenges an individual's sense of self is part of a dynamic process of coping and adjustment that involves not one but two significant issues.¹⁰⁴ One issue is the need to make sense of the loss, while the other issue is the need to find some benefit to the loss. Although related, these issues are distinct and independent such that the resolution of one does not necessarily result in a resolution of the other. One study, for example, indicates that people who cannot make sense of their loss may yet

¹⁰²Stroebe, Margaret and Schut, Henk (1999), "The Dual Process Model of Coping with Bereavement: Rationale and Description." *Death Studies* 23, p. 197.

¹⁰³Stroebe and Schut (1999), p. 220.

¹⁰⁴ Christopher G. and Nolen-Hoeksema, Susan (2001), "Loss and Meaning," *American Behavioral Scientist* 44(5), p. 726.

experience satisfaction and relief by finding some benefit to their loss, most commonly a "growth in character, a gain in perspective, and a strengthening of relationships."¹⁰⁵ The results of other research suggest that, although some people may not find any such benefit, they can readily make sense of a loss when it is predictable, that is, "a logical consequence to some set of behaviors or factors," as when a family member dies of old age.¹⁰⁶ These results also indicate that making sense of a loss is more likely when it is consistent with the sufferer's worldview or perspective on life, or when the individual's religious or spiritual beliefs provide a reason for the loss that science and logic cannot explain.¹⁰⁷

The religious and spiritual aspect of suffering is also a chief concern for Engelhardt, who claims that secular bioethics is "imprisoned" in the world of human experience in healthcare, and is thus unable to address metaphysical questions about the ultimate meaning and value of suffering.¹⁰⁸ He argues that secular bioethics cannot give any transcendent meaning to suffering because it lacks a metaphysical perspective. Without that perspective, Engelhardt concludes, modern secular bioethics at best concerns itself only with the various options of confrontation and the mechanics of endurance. Beyond the essential characteristics of those options and mechanics, secular bioethics has nothing normative to say about the meaning and treatment of suffering. Because this deficiency leaves a silent void in the secular world, Engelhardt relies on a religious context to find the meaning and value of human suffering.

 ¹⁰⁵Nolen-Hoeksema, Susan and Larson, J. (1999), <u>Coping with Loss</u>. Hillsdale, NJ, Lawrence Erlbaum, pp.145-50.
 ¹⁰⁶Davis and Nolen-Hoeksema (2001), p. 731.

¹⁰⁷Davis and Nolen-Hoeksema (2001), p. 732.

¹⁰⁸Engelhardt, H. Tristram (1996), "Suffering, Meaning, and Bioethics." Christian Bioethics 2(2), pp. 129-153.

In that same vein, the story of Job is a familiar example of how to understand gratuitous suffering and the struggle between innocence and power, virtue and injustice.¹⁰⁹ According to the Biblical narrator, Satan complains to God that Job's morally upright behavior is nothing but a shallow expression of his wealthy extravagance. Satan suggests that, should God strip Job of his possessions and children, inflict him with an incurable disease and untreatable sores, and torment him with isolation and abandonment, Job will curse God.

God indulges Satan's challenge and allows Satan to inflict Job with these and other losses that eventually plunge Job into bitter suffering. Out of his innocence and virtue, Job protests to God that his suffering is undeserved, and furiously demands an accounting from God for such an injustice. After Job repeatedly asserts this demand, God finally replies in a way that enables Job to understand that God cannot be held to our standards of justice. For the modern reader, Job imparts the lesson that suffering is a mystery whose meaning cannot always be discerned.

For this reason, Pope John Paul II focuses on the mysterious nature of suffering in his encyclical, "On the Christian Meaning of Suffering," and claims that we can pierce some of that mystery by finding meaning and value in suffering.¹¹⁰ In John Paul's view, when we symbolically unite our suffering to the suffering of Christ out of love, our selfconsecration makes each of us like Christ, by virtue of which we participate in his ongoing salvific mission. In other words, human suffering has meaning and value because it can be redemptive. In defending his thesis about the value of vicarious human

¹⁰⁹Ozick, Cynthia (1998), <u>The Book of Job</u>. New York, Vintage Books, p. xv.

¹¹⁰John Paul II (1984), "On the Christian Meaning of Suffering." Vatican City.

suffering, John Paul defines suffering itself as the deprivation of a good in which we ought to share, regardless of whether we cause our own deprivation or are innocent in that regard. For example, health is the good and disease the deprivation; companionship the good and loneliness the deprivation. He mentions many other causes of suffering, including death, persecution, hostility, abandonment, remorse, nostalgia, mockery, scorn, unfaithfulness, ingratitude, natural disasters, epidemics, catastrophe, upheaval, war, famine, and so on. Although we experience suffering as physical or spiritual pain, sometimes the experience itself makes the two indistinguishable.

John Paul concedes that, in view of God's creative power and fatherly love, suffering raises important questions about God's relationship to his children on earth. Although some theodicies explain human suffering as God's just punishment for sins, John Paul argues that the Book of Job challenges such a notion by showing that God is the creator of all that is good and not the source of evil. Thus, God is not the source of suffering. While John Paul acknowledges that suffering connected with a fault often has meaning and value as punishment to convert and strengthen the transgressor, he also notes that much suffering is innocent. For this reason, he claims that Jesus Christ, who overcame undeserved suffering through love in his divine mission of salvation, is the best model for understanding suffering alongside an omnipotent and loving God.

For John Paul, Christ gives meaning and value to suffering in two ways. One is by giving us hope of eternal life through his own personal suffering, while the other is by initiating the eventual obliteration of all suffering, especially death. In carrying out his mission, Jesus also shows us the fitting response to suffering through his love and compassion for the suffering of others. By virtue of his own compassion, Jesus healed

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the sick, consoled the afflicted, fed the hungry, cured the blind and deaf, and three times, restored the dead to life. John Paul argues that, through such compassion, Christ raised human suffering to the level of redemption.

Consequently, through a loving union of our suffering with that of Christ by an act of our wills, we share in his redemptive mission. Although John Paul acknowledges that Christ has already accomplished redemption, in the realm of love, redemption is constantly being accomplished. On this view, Christ achieved redemption completely and to the limit, but did not bring it to a close. According to John Paul, Christ paradoxically continually opens himself to every human suffering, which provides us opportunity to unite our sufferings with love to him and thus to his redemptive work.

Although he explains human suffering in terms of its redemptive value only, John Paul makes it clear that we should neither seek out suffering, nor be passive toward the suffering of others. Rather, he claims that we must see the face of Christ in the sufferer, even in those whom we think deserve their suffering. In his view, our commitment to Christ compels us to respond to suffering with love, which has no place for selfrighteousness in regard to the suffering of our neighbor. We, the 20th century Samaritan, stop by the side of the road, not out of curiosity, but out of availability, sensitivity, and willingness to be effective in our help. According to John Paul, the purpose of suffering in the world is to release love, to give birth to works of love, and to transform both the giver and the sufferer into a civilization of love. Because of our mutual need for care and understanding, there is solidarity among those who suffer. Because of Christ's constant concern and love for each of us, there is also solidarity with him, who suffers with us

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each time we suffer. For this reason, John Paul claims that all suffering is holy and deserves reverence.

From this perspective, suffering calls forth the virtue of perseverance in whatever disturbs us, just as Christ bore his sufferings. John Paul claims that the image of Christ as obediently accepting his own suffering, which led to his eventual triumph, is reason enough for those who wish to imitate Christ to believe that suffering will not get the better of us nor deprive us of our dignity. He also claims that our immediate response to suffering is invariably one of protest, but our love both for Christ and for others compels us to discover anew the meaning to suffering, not on a human level, but on the level of Christ. On that level, suffering in the world unceasingly calls for the response of love as the most effective antidote to hatred, violence, cruelty, contempt for others, and insensitivity. In short, through his own life and love, Christ taught us both to do good with our own suffering and to do good to those who suffer. In this double respect, according to John Paul, Christ completely reveals the meaning and value of suffering.

Those who reject John Paul's theological approach to human suffering might suggest that his interpretation does not address the personal dimension of suffering.¹¹¹ By assigning a supernatural meaning to suffering, he implies that individuals suffer primarily for the benefit of others, regardless of whether they acknowledge that substitution. Such a critique seems a bit extreme, however, and inconsistent with John Paul's meaning. Despite the limited appeal that his interpretation of human affliction might have, he merely claims that suffering can be understood in a Christian sense as

¹¹¹Kane, Paula (2002), "She offered herself up: The Victim Soul and Victim Spirituality in Catholicism." *Church History* 71, pp. 106-107.

redemptive, provided those who intend to make reparation for others in this way voluntarily embrace their suffering. On this view, "Obedient submission to suffering, rather than the suffering itself, is the redemptive act, in imitation of Christ's acceptance of God's will."¹¹² In claiming that voluntary obedience enables one to make amends for one's own sins as well as the sins of others, John Paul underscores the individual's search for God and meaning itself in the experience of suffering, and offers a way to understand that experience so as to discover both.¹¹³

To elaborate on John Paul's claim that some persons experience suffering as spiritual pain, one hospital chaplain observes that some patients describe their spiritual pain to him as a sense of shame, of having been found out, of having been exposed. As this chaplain notes, such patients conclude, "through their own self-judgments, that there is something wrong with them at their core."¹¹⁴ Such an observation is consistent with a "standard philosophical analysis of shame as an emotion of reflected self-assessment. According to this analysis, the subject of shame thinks less of himself at the thought of how he is seen by others."¹¹⁵ In other words, the person who feels shame views herself and the mistake as one and the same, whereas feeling guilty implies only that one has made a mistake.

For example, Sartre claims that shame often accompanies the recognition that "I am as the Other sees me," by virtue of which, "I am put in a position of passing judgment on

¹¹²Kane (2002), p. 83.

¹¹³Vicarious suffering is not unique to Roman Catholic theology. See Kane (2002), p. 85, where she notes that "Hasidic Jews speak of a *zaddik*, for example, as a righteous man who embodies the Torah but who also partially bears the sins of his generation." See also Girard, Rene (1986), <u>The Scapegoat</u>. Baltimore, Johns Hopkins University Press, for a discussion of vicarious suffering as both a social and religious practice.

¹¹⁴Satterly, Lamont (2001), "Guilt, Shame, and Religious and Spiritual Pain." *Holistic Nursing Practice* 15(2), p. 35.
¹¹⁵Velleman, J. David (2001), "The Genesis of Shame." *Philosophy and Public Affairs* 30(1), p. 28.

myself as an object, for it is as an object that I appear to the Other."¹¹⁶ For Sartre, becoming an object for another undermines one's ability to freely engage in selfdefinition, and results in a negative self-assessment based on an assumed character flaw that may or may not be the case.

Bernard Williams develops the concept of shame with a slightly different emphasis than Sartre by claiming that "the root of shame lies in exposure...in being at a disadvantage [due to] a loss of power."¹¹⁷ The nature of this exposure is a sense of having revealed to others an inconsistency between our inward, private self and the outward, public self. For one to feel shame in such circumstances, however, the exposure must be unintentional. Such an unintentional exposure is a failure to manage our private matters in a way that compromises our ability to maintain our public persona, the consequence of which is a loss of personal power and control that puts us in a socially untenable position.¹¹⁸ This interpretation of shame suggests that some patients, who have been stripped of their accustomed social standing by disease, pain, or illness, might perceive their revised medical status as a loss of control and an occasion for feeling shame. To borrow from Sartre, perhaps these patients view their own medical status as an unintentional public "confession" of an inability to be the person they intend and want to be, which causes them to feel "ashamed of themselves."¹¹⁹ This might account for the chaplain's observation that some patients describe their spiritual pain as a feeling that

¹¹⁶Sartre, Jean-Paul (1956), <u>Being and Nothingness</u>, Hazel E. Barnes, trans. NY, Philosophical Library, p. 222.

¹¹⁷Williams, Bernard (1993), <u>Shame and Necessity</u>. University of California Press, p. 220.

¹¹⁸Velleman (2001), p. 40.

¹¹⁹Sartre (1956), p. 261. Sartre explains shame as a "confession" of not living on one's own terms, but on terms that others have defined. In such cases, according to Sartre, what we feel is "ashamed of ourselves."

"there is something globally wrong with them, as opposed to their doing some specific thing wrong."¹²⁰

Perhaps the antidote for such spiritual pain is unconditional love, which acknowledges the sufferer's worthiness despite her perceived shamefulness. Such a suggestion seems plausible in light of several studies that show "people who appear to be ashamed of themselves and to feel deficient are seeing themselves as worse off than others."¹²¹ Still others suggest that the most effective antidote to shame is humility, which "preempts this sense of being compromised by deflating our pretensions and thereby rendering our [public persona] consistent with the criticism that we face. Feeling humbled is thus an alternative to, and incompatible with, feeling humiliated or ashamed."¹²² In short, perhaps the best defense against the perceived shame of disease, pain, or illness consists in accepting a revised sense of self, which may restore a sense of personal control and power.

Nevertheless, "shame itself is far more limited in its unique association with psychological distress" than feelings of guilt.¹²³ For example, patients often interpret suffering due to their medical condition as religious pain, which usually means that the patient feels "guilty over the violation of the moral codes and values of his or her religious tradition."¹²⁴ This description is consistent with both an ordinary and a clinical definition of guilt as "the dysphoric feeling associated with the recognition that one has

¹²⁰O'Connor, Lynne, Berry, Jack W., and Weiss, Joseph (1999), "Interpersonal Guilt, Shame, and Psychological Problems." *Journal of Social and Clinical Psychology* 18(2), p. 185. This way of describing shame is a common definition used in studies of that experience.

¹²¹O'Connor, et al. (1999), p. 199.

¹²²Velleman (2001), p. 43.

¹²³O'Connor, et al. (1999), p. 199.

¹²⁴Satterly (2001), p. 32.

violated a personally relevant moral or social standard."¹²⁵ Whether the transgression is egregious or minor, recent or remote, the person who feels guilty often perceives her behavior as disappointing to God or some higher being. In these circumstances, the emotion that most closely characterizes religious pain is fear, which arises in anticipation of the punishment to be meted out at the moment of reckoning.¹²⁶ A feeling of guilt and the need to make restitution for moral wrongdoing may explain why some patients feel the need to suffer for a time before moving on to the resolution stage. Perhaps the sensitive caregiver can help such patients find a quicker resolution of their guilt feelings, which should facilitate their recovery and ability to cope with their medical condition.

However that may be, Viktor Frankl argues that each of us must determine the meaning and value of our own suffering. In his view, not all suffering is pathological, and at a fundamental level, it may be a sign of mental health. He claims that "suffering may well be a human achievement, especially if the suffering grows out of existential frustration."¹²⁷ On this view, a person's "concern, even his despair, over the worthwhileness of life is a *spiritual distress* but by no means a *mental disease*."¹²⁸

According to Frankl, we resolve spiritual distress by finding meaning and value to life, which in turn, gives meaning and value to suffering, but not the reverse. Life does not have meaning and value because we assign meaning and value to suffering. Nevertheless, "we may well find meaning through suffering, and its even possible that we

¹²⁵Kugler, K. E., and Jones, W. H. (1992), "On Conceptualizing and Assessing Guilt," *Journal of Personality and Social Psychology* 62, pp. 318-327.

¹²⁶Satterly (2001), p. 32.

¹²⁷Frankl (1959). <u>Man's Search for Meaning</u>, p. 162.

¹²⁸Frankl (1959), p. 163.

would not have found it otherwise."¹²⁹ Unlike some existentialist philosophers, however, such as Sartre, who claim that the challenge of life is to endure its meaninglessness and absurdity, Frankl claims that the main challenge of life is "to bear [one's] incapacity to grasp its unconditional meaningfulness in rational terms."¹³⁰ Thus, we can understand the meaning of our own suffering only to the extent that we understand the meaning of our lives. Frankl concludes that, for better or for worse and at any moment, we must decide the meaning of our lives.¹³¹

IV. Conclusion.

As the above analysis shows, suffering is a psychological rather than a physical phenomenon. Although suffering may be the effect of physical pain, suffering and pain are distinct experiences. Suffering itself is a state of emotion that consists in an unrelenting and oppressive tension between hope and despair. There are many specific reasons in the clinical situation why persons suffer, including pain, loss of function, disability, chronic illness, failure to find symptomatic relief, the complexity of a particular treatment modality, an unfavorable prognosis, the financial cost of treatment, and the effects of disease, to name a few. In this sense, suffering is an experience of grief over an actual or anticipated loss of self, while the feeling of personal disintegration varies with the magnitude of the loss and the disposition of the sufferer. The ultimate cause of all suffering, however, is the distress that arises in connection with a disruption in the way important personal matters are perceived to be the moment as compared to how it is perceived that such matters ought to be. From this individual perspective,

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¹²⁹James O. Bennett, personal conversation.

¹³⁰Frankl (1959), p. 188.

¹³¹Frankl (1959), p. 191.

Frankl claims that a crucial step in resolving such a disruption is the meaning and value that each must give to her own experience of suffering.

From the caregiver's perspective, on the other hand, Cassell claims that there are two primary ways to relieve suffering in the clinical setting. One is to guide the patient to assign meaning to the patient's medical condition, which often resolves the suffering associated with that condition. The other is to assist the patient in developing a sense of transcendence, which is most effective in restoring a sense of wholeness after injury to an individual's personhood. To that end, he offers three specific goals of patient care that aim at reducing or minimizing the patient's suffering.¹³² The first goal is to define all diagnostic or therapeutic plans in terms of the sick person, rather than in terms of a disease. The second goal is to maximize the patient's function and not necessarily the patient's length of life. The third goal is to minimize the family's suffering as well as the patient's suffering, although Cassell offers no discussion of how to resolve a conflict between these two goals.

The fundamental notion behind Cassell's approach is that physicians and other caregivers must focus on fostering the best interests of the sick person rather than on merely treating a disease. Sick persons usually know better than others what their best interests are, what aspects of function matter most to them, and when they are suffering. Cassell's approach acknowledges the clinical need to include such knowledge as a vital element in treating the patient's suffering. Doing so requires working more closely with patients and their families than is customary in traditional medical practice. Cassell's holistic approach is an alternative that seeks to minimize such a limitation.

¹³²Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. 241.

In light of Frankl's claim that patients must decide the meaning to their own suffering in terms of the meaning to their lives, a holistic approach to patient care raises a question about the appropriateness of physician-assisted suicide as a form of medical care. Chapter 3 discusses that issue from the physician's perspective, while Chapter 4 discusses it from the patient's perspective.

Chapter 3

Physician-assisted Suicide and Proportionate Medical Care

In our time...it is the physician who exercises the cure of souls.

Soren Kierkegaard Judge for Yourselves

I. Introduction.

According to the discussion developed in Chapter 2, suffering itself is a state of emotion involving an unrelenting tension between hope for "what should be" and possible despair over "what is", while its relief comes from an elimination or reduction in that tension. It follows that there are two avenues of relief. On the one hand, relief corresponds to the realization of a desired outcome that represents fulfillment of the sufferer's hope. On the other hand, relief also corresponds to a change in the tension between hope and despair that reflects the sufferer's acceptance of the situation. In acceptance, the gap between the "what is" and the "what should be" closes because the sufferer relinquishes or modifies the desire and belief about a certain kind of outcome. In place of the originally desired outcome, she accepts an alternative view such that a gap in her expectations no longer exists. In either case, however, because the sufferer no longer perceives a gap between the "what is" and the "what should be", she experiences relief.¹

Acceptance is not to be confused with giving in to despair, which does not bring relief. In despairing, the sufferer merely gives up the *belief* that "what should be" is attainable without giving up the *desire* for that outcome.² Confusing acceptance with despair is due primarily to the manner in which acceptance can have either positive or

¹Frankl, V., M.D., Ph.D. (1986). <u>The Doctor and the Soul</u>. New York, Vintage Books, p. 108. ²Frankl (1986), pp. 108, 112.

negative results for the sufferer. Positive results occur when acceptance derives from courage and self-determination, which can lead to wisdom and peace. Negative results occur when tolerating a particular situation or outcome derives from indolent or cringing resignation, which can lead to resentment and bitterness. Such an attitude is often perceived and described in terms of despair, when a more accurate description would be as a different form of acceptance. In any case, relief of suffering follows either from having hope fulfilled or from acceptance, but never follows despair.

Regardless of how one finds relief, suffering itself remains an inescapable part of the human condition, and in some cases, is nothing less than unmitigated misery. Compassion for those who must endure such misery often motivates efforts to help them find relief. Such a response by the observer at times can become a natural duty based on the dignity of human beings: "We have only to imagine ourselves the victims of severe cold, hunger, or thirst to believe suffering of that kind should be eradicated."³ The medical profession itself long ago expressed this kind of compassionate regard for others in adopting the relief of patient suffering related to disease and illness as one of its professional goals.⁴ Given that ideal, compassion and a benevolent regard for others often motivate the individual physician to accept the healer's role and accompanying duty to relieve medically relevant suffering within limits.⁵

When cure is attainable in the ordinary course of medical practice, the strain on the healer's ability and duty to relieve suffering is manageable. When cure or restoration

³James, S. (1982). "The Duty to Relieve Suffering." *Ethics* 93: 4021.

⁴Cassell, E. J. (1991). <u>The Nature of Suffering and the Goals of Medicine</u>. New York and Oxford, Oxford University Press, p. 31.

⁵Pellegrino, Edmund D. (1983). "The Healing Relationship: The Architectonics of Clinical Medicine." <u>The Clinical Encounter: The Moral Fabric of the Physician-Patient Relationship</u>. E. A. Shelp. Boston and Dordrecht, D. Reidel Publishing Company, p. 163.

to an acceptable level of functioning is no longer possible, however, the patient and physician must confront a permanently altered or shortened life for the patient with methods of relief that aim at "amelioration, adaptation, or coping."⁶ In such cases, relief becomes a difficult challenge for both patient and physician that can intensify as the outcome for the patient becomes more undesirable and the associated suffering more unbearable.⁷ When all efforts fail to achieve the intended goal, despite the physician's technical skill, both patient and healer approach the limits of medicine to relieve human suffering caused by illness and disease. Although this failure can happen any time during the care process, it is especially tragic at the end of life on those occasions when the patient suffers unbearably.

In such cases, poor health and impending death frequently cause some terminally ill patients to look beyond the confines of traditional medicine in search of alternative methods of relief. In their search, some patients come to believe that hastening their own death by suicide is the most effective way to relieve suffering. To fulfill their hope in this way, they ask their physicians for assistance in ending their lives. In light of the physician's professional duty to relieve medically relevant suffering, the question arises as to whether that duty includes causing the patient's death, either directly, as in the case of active euthanasia, or indirectly, as in the case of physician-assisted suicide. Could physician-assisted suicide be a "good of last resort"?

If the duty to relieve suffering does not extend as far as causing or hastening death, what alternative methods of relief are available? Which ones, if any, should the

⁶Zaner, R. (1990). "Medicine and Dialogue." *The Journal of Medicine and Philosophy* 15 (3), p.311.

⁷Thomasma, D. C. and Graber, G. C. (1990). <u>Euthanasia: Toward an Ethical Social Policy</u>. New York, The Continuum Publishing Company, p. 193.

physician offer to the terminally ill patient who has requested assisted suicide, and in what circumstances? Would such an offer represent an acceptable or an offensive kind of paternalism? If the duty to relieve suffering includes causing the patient's death, then, from within the traditional medical model where the ethical focus is on patient welfare, on what grounds would a physician refuse a patient's voluntary request for assisted suicide?

The difficulty in answering such questions highlights the moral complexity surrounding the issue of causing a patient's death, either directly or indirectly. To some, a physician's refusal to provide such assistance, particularly in the case of physician-assisted suicide, might seem ethically indefensible, inasmuch as relief of medically relevant suffering is a traditional goal of medicine and death is presumed to end all suffering. Such difficulty intensifies when the goal of relieving suffering conflicts with the goal of relieving pain and extending life. In such cases, since acting in the patient's best interest includes honoring her right to self-determination, it might appear that the physician has the option, if not a duty, to comply with a patient's request for assisted suicide. Proponents of causing the patient's death often employ this line of reasoning in two different but connected arguments to support their position. One is the argument from autonomy, and the other is the argument from mercy.⁸

According to the argument from autonomy, the right to self-determination extends to the process of dying as well. On this view, "if a terminally ill person seeks assistance in suicide from a physician, the physician ought...to provide it," on condition that the

⁸Battin, Margaret P. (2000), "On the Structure of the Euthanasia Debate: Observations Provoked by a Near-Perfect For-and-Against Book." *Journal of Health Politics, Policy and Law* 25(2): 415-430.

request is voluntary and rational.⁹ Similarly, according to the argument from mercy, "No person should have to endure pointless terminal suffering. If the physician is unable to relieve the patient's suffering in other ways acceptable to the patient and the only way to avoid such suffering is by death, then death may be brought about."¹⁰ Based on such reasoning, proponents of physician-assisted suicide claim that a fundamental respect for patient autonomy and the demands of beneficence justify the physician's participation in assisting a patient's intentional death.

On an alternative view, however, neither respect for patient autonomy nor beneficence justifies assisting a patient's suicide. The alternative view is that physicianassisted suicide is a disproportionate and unethical medical response to a patient's suffering, and as such, must be rejected by the physician. As the following analysis shows, this conclusion relies on a classical and a modern interpretation of proportionality. Both interpretations originated in the context of double effect reasoning as a way to resolve certain kinds of moral conflicts. Thomas Aquinas provides the basis for a classical interpretation of proportionate reason, while the works of Jean Pierre Gury and Peter Knauer take on that role in regard to a modern interpretation.

Although proportionate reason is a common element in both a classical and a modern account, it has a very different meaning in each. According to the classical view as originated by Aquinas, proportionality expresses a relationship between an act and its end, or the reason for acting.¹¹ On this view, however, the end does not justify the

⁹Battin (2000), p. 417.

¹⁰Battin (2000), p. 417.

¹¹Johnstone, B. V., C.SS.R. (1985), "The Meaning of Proportionate Reason in Contemporary Moral Theology." *Thomist* 49(2), p. 228. Aside from the controversy over the meaning of proportionate reason, the principle of double

means. For Aquinas, the moral status of any act is a measure of how well it promotes our ultimate destiny, which he defines in spiritual terms. In his view, those acts that promote our spiritual destiny are obligatory, while those that are neutral with respect to that destiny are permissible, and those that oppose our spiritual destiny and welfare are morally impermissible. Ultimately, Aquinas argues that acts are "proportioned to the end" in this spiritual sense to the extent that they conform to the requirements of charity, which is the overarching principle of all human affairs.¹²

By contrast, both Gury and Knauer define proportionality in terms of a net gain in values over disvalues, or evil, in the outcome.¹³ On a modern view, proportionality means that the good effect must be "important enough to justify the bad upshot."¹⁴ Hence, in some cases, the end can justify the means. With a focus on "outcome" as the basic unit for moral evaluation, modern interpretations of proportionality have evolved into a distinct moral theory known as proportionalism, which is fundamentally incompatible with the meaning that Aquinas developed for that term.¹⁵ Such incompatibility stems in part from the fact that modern proportionalism does not recognize exceptionless norms, whereas classical proportionalism does recognize such norms.

Despite this general contrast, the following analysis shows that physician-assisted suicide is a disproportionate medical response to patient suffering on either a classical or

effect itself is not without controversy. For example, see Graber, Glenn C. (1979). "Some Questions About Double Effect." *Ethics in Science and Medicine* 6: 65-84; cf. Boyle, J. M., Jr. (1991), "Who is Entitled to Double Effect." *The Journal of Medicine and Philosophy* 16.

¹²Johnstone (1985), p. 230.

¹³Johnstone (1985), p. 228.

¹⁴Quinn, Warren S. (1989), "Actions, Intentions, and Consequences: The Doctrine of Double Effect." *Philosophy and Public Affairs* 18(4), p. 334.

¹⁵Finnis, John (1998), <u>Aquinas: Moral, Political, and Legal Theory</u>. Oxford, Oxford University Press, p. 139.

modern interpretation of proportionality. Based on a classical view, the physician's agreement to assist a patient's suicide is morally impermissible for three reasons. First, not only does such assistance contribute to the killing of an innocent person--a moral wrong in itself--it also violates the healer's duty to care for human life with medically appropriate care relevant to the patient's quality of life and medical condition. Second, the physician's participation establishes physician-assisted suicide as a medically acceptable social practice, which, due to its inherent and unavoidable potential for abuse, perpetuates harm to the common good. Third, despite the autonomous nature of a patient's request for assisted suicide, the physician's agreement relies on her own subjective evaluation of that patient's quality of life as warrant for her professional decision to provide that assistance, which exceeds the physician's expertise and abandons the virtuous practice of medicine.

Based on a modern interpretation of proportionality consistent with Gury's account, physician-assisted suicide is morally impermissible because a predominance of good in the immediate outcome is unknown and incalculable. The net effect of death in relation to patient suffering is unknown, because no one, including the physician, knows what happens after death, except possibly the patient, after death. From the physician's perspective, this lack of knowledge rules out the possibility of calculating the immediate net effect of physician-assisted suicide, which eliminates the clinical basis of physician-assisted suicide as an alleged way to relieve suffering.

Lastly, based on Knauer's account, physician-assisted suicide fails as a proportionate medical response for two reasons. First, the long-term consequences of causing an intentional death are self-defeating in terms of a right to self-determination.

Physician-assisted suicide carries an inherent and unavoidable potential for abuse with respect to vulnerable members of society, especially during terminal illness, which often intensifies vulnerability in the extreme. Given a general vulnerability of all members of society, physician-assisted suicide in the long and on the whole serves to undermine rather than ensure a right to self-determination. Second, there is a less onerous method of relief available, namely, acceptance. Although difficult to achieve for some patients, acceptance is more likely to occur when the physician's efforts in that regard center on treating the whole person with holistic medical care.

To defend this line of reasoning, the following analysis relies on the premise that double effect reasoning is a long-standing tradition in clinical practice that has particular relevance to the care of terminally ill patients. Care at the end of life often raises issues concerning relief of suffering, unavoidable harm, and conflicts between the principles of beneficence and respect for patient autonomy. Resolving such conflicts often calls for double effect reasoning, which easily lends itself to the question at hand about physicianassisted suicide. In making that application, the following analysis adopts the physician's perspective rather than the patient's, and develops in two stages.

The first stage is to explore proportionality in the context of medically appropriate care as advanced by Pellegrino and Thomasma, the results of which indicate a need to elaborate on their reasoning in that regard. To that end, the second stage is to explain proportionality in a classical sense as posited by Aquinas, and in a modern sense as posited by Gury and Knauer. During the process, the explanation shows that physicianassisted suicide, as a medical procedure, fails to meet the requirements of either interpretation of proportionality. As a by-product of this analysis, the arguments from

autonomy and from mercy fail to justify physician-assisted suicide, because neither considers the way in which beneficence and respect for patient autonomy must work in conjunction to promote the patient's best interests.

II. The first stage: proportionate medical care.

A. Beneficence, autonomy, and a rational treatment plan.

From the physician's perspective, the ethics of assisted suicide as an alleged form of medical care that relieves suffering depends on whether physician-assisted suicide is appropriate medical care. To qualify as such care, physician-assisted suicide first must meet certain scientific and clinical standards, just as other forms of medical care deemed appropriate comply with certain standards. This technical determination occurs both formally and informally through a dynamic, complex process that employs a number of criteria derived from several sources. Included among these sources, for example, are the sciences, published practice guidelines, institutional and legal standards, and an everevolving professional consensus embedded in the medical tradition itself.

As a supplement to these sources, research and clinical case studies provide additional data on an on-going basis that serve to justify particular procedures and therapeutic modalities. Other less direct sources include professional journals, topical seminars, peer review and utilization review reports, outcomes measurement studies, collegial communication, case consultations, professional reports, and the like. Through education, training, and professional experience, physicians internalize clinical practice standards and criteria derived from such sources, and develop methods of applying these objective factors to particular patients in the form of medically appropriate care.

Thomasma refers to these objective, technical factors as "medical indicators", which he defines as the scientific facts, statistical data, standards of medical care, and collegial consensus relevant to the patient's underlying condition that the physician combines and weighs along with the patient's preferences to form a sound clinical judgment.¹⁶ According to Thomasma, medical indicators evolve through a dynamic scientific and clinical process as a necessary component of the ethical justification for the practice of medicine. As a component of the medical tradition itself, the results of this process are often formally tested in the legal community and other public forums and serve to adjudicate questions of medical malpractice. In his view, relying on medical indicators enables the physician to recommend and provide appropriate medical care.

As a result, the physician may not arbitrarily set aside either the justificatory process itself or generally accepted determinations of appropriate medical care in favor of an idiosyncratic approach to particular patients. Even when searching for remedies of last-resort, as might happen in a case of unbearable suffering at the end of life, the physician still must recommend care that has the support of scientific and clinical data. Experimental medicine is no exception in this regard. Although the benefits of experimental medicine may be hypothetical and risks to the human research subject minimal, ethical procedures and guidelines limit an investigator's curiosity to ensure safety and professional accountability. Thus, patient care that lacks clinical and scientific support also lacks ethical justification and amounts to no more than a-shot-in-the-dark medicine.

¹⁶Thomasma, David C. (1986), "Philosophical Reflections on a Rational Treatment Plan." *The Journal of Medicine and Philosophy* 11: 157-165.

On the other hand, a plan of treatment that combines medical facts and patient preference is medicine-as-art circumscribed by medicine-as-science. When combined in a mutual fashion by patient and physician, these factors form the basic structure of what Thomasma refers to as a rational treatment plan. In other words, a rational treatment plan combines the relevant medical science with the patient's preferences to specify the proportionate means by which to promote the patient's welfare in an ethically and professionally sound manner.¹⁷ Proportionate care in this sense reflects two fundamentally different but interrelated perspectives.¹⁸

From the physician's perspective, proportionate care is a function of the physician's clinical judgment about the patient's quality of life in physiological terms. As determined from the patient's perspective, on the other hand, proportionate care is a function of the patient's personal judgment about her own quality of life in terms of its overall value to her, including her current physiological condition as one factor. In other words, a rational treatment plan depends on the physician's clinical judgment about the physiological benefits of intervention, in light of the patient's personal preferences about continued living in her present condition.¹⁹ In this light, "good for the patient" means that appropriate medical care is delivered in a proportionate manner that accords with the patient's preferences and consent.²⁰ Thomasma summarizes his view of a rational treatment plan in the following way:

¹⁷Thomasma (1986), p. 157.

¹⁸Cassell, Eric (1976), "Healing." Hospital Physician 12: 28-29.

¹⁹Thomasma (1986), p. 162.

²⁰Consider the emotional and legal turmoil that frequently arises in situations where physicians provide medical care that has no physiological benefit for the patient. For a discussion of futile care, see Rubin, S. B. (1998). <u>When Doctors Say No</u>. Bloomington and Indianapolis, Indiana University Press.

A rational treatment plan combines scientific standards, collegial consensus, preferential indications by the patient or guardian, and the burdens/benefits calculus, including a judgment of the proportion between the proposed intervention and the current condition of the patient...through which a consensus [between patient and physician] is reached about interventions to affect the course of a disease process.²¹

Thomasma admits that proportionality is a key but "tricky" term that involves a "benefits versus burdens" calculus in terms of the patient's values.²² For Pellegrino, the fundamental value at stake in any clinical encounter is the personhood of the patient. In this light, medically appropriate care is morally defensible medicine when it reflects more than a mutual agreement between patient and physician about what will be good for the patient. Morally defensible medicine is both technically right and morally good.²³

Technically right medicine conforms to the best available scientific and clinical information, as applied to a particular patient with specific facets and characteristics, such as gender, age, race, occupation, and who lives in a concrete socioeconomic and cultural situation and has certain personal aspirations. Morally good care, on the other hand, is technically right medicine that aims at healing the patient as multi-faceted person. For Pellegrino, healing in this sense is a process by which the patient as person becomes whole again in the fullest possible physiological and psychological sense.²⁴ What the sick person seeks from the physician in this regard is "restoration to his or her definition of wholeness. If full restoration is not possible, then amelioration of suffering, adaptation, or coping with chronic or fatal illness" become the goals of the physician as

²¹Thomasma (1986), p. 162.

²²Thomasma (1986), p. 160.

²³Pellegrino, Edmund D. (1983), p. 158.

²⁴Pellegrino, E. D., M.D. (1987), "Toward a Reconstruction of Medical Morality." *The Journal of Medical Humanities and Bioethics* 8(1), pp. 7-18.

healer.²⁵ The physician's obligation with respect to achieving these goals must begin with an agreement to offer technically correct medicine. Such medicine aims at healing in a manner consistent with how "the patient wishes to spend her life...even when the patient's choice flies in the face of what the physician or even a rational bystander might dictate. The patient is the one who must balance his vision of the good life with the realities illness forces upon him."²⁶ In Pellegrino's view, evaluating the worth of continued living belongs strictly to the patient.

In defining the goals of morally defensible medicine in terms of healing the whole person, Pellegrino gives moral prominence to personhood in the context of personal suffering. Although he offers no specific view of personhood beyond suffering-patient, the sketch that he offers coincides with the views of Eric Cassell, who states: "Doctors do not deal with suffering in the abstract--they treat persons who are afflicted by something that leads to the suffering."²⁷ Cassell describes personhood in terms of characteristics, such as personality, character, memory, relationships, culture, and so forth.²⁸ For him, personhood is not a static goal attained once and for all, but a dynamic, creative process of transformation that continually unfolds in and through the experience of daily living. Although such a process clearly involves factors not entirely within the range of individual control, there is a substantial element of personal responsibility in the sense that "people not only become persons; they make themselves into persons."²⁹

²⁵Pellegrino (1983), p. 163.

²⁶Pellegrino (1983), p. 165.

²⁷Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, p. ix.

²⁸Cassell (1991), <u>The Nature of Suffering and the Goals of Medicine</u>, pp. 37-43.

²⁹Bakan, D. (1996), "Origination, Self-Determination, and Psychology." *Journal of Humanistic Psychology* 36(1): 9-20.

This process of transformation, however, is never quite complete nor is it certain, since it depends on heredity, environment, and chance, as well as the will, imagination, and personal competence of the individual to confront and overcome the vicissitudes and challenges of living in the world. For the most part, the development and refinement of personhood is ordinary and unremarkable. It consists in the acquisition of habits and thought patterns about the self by living within a particular social and cultural milieu comprised of relationships, personal projects, interests, aspirations, and a myriad of choices made spontaneously as well as in reflective deliberation.³⁰ On this view, personhood does not develop as a series of parts, one of which is suffering, but is a seamless whole that continually evolves and, at times, stands in special need of healing.

B. Elaborating the concept of proportionality.

According to Pellegrino and Thomasma, healing the person in a clinical setting commences most concretely when the physician's professional judgment and the patient's preferences merge in a rational treatment plan that seeks the patient's good. In their view, a rational treatment plan partly depends on a principle of proportionality that enables physicians to better fulfill their professional obligations of beneficence in an ethically sound manner and in a way that demonstrates respect for patient autonomy. Because Pellegrino and Thomasma do not specify the parameters of such a principle, however, its application in any sort of care situation is not very clear.

Given that ambiguity, how can a principle of proportionality help resolve end-oflife care issues involving physician-assisted suicide? To illustrate the troubling aspects of this question, consider a terminally ill, competent patient whose personhood is so

³⁰Agich, George J. (1990), "Reassessing Autonomy in Long-term Care." Hastings Center Report (Nov/Dec): 12-17.

diminished by suffering (or by pain) that she requests physician-assisted suicide. Ordinarily, the physician's desire to relieve such unbearable suffering (or unbearable pain) is a laudable and traditional goal of medicine. Given the extent of the patient's suffering and her perception that the benefits of death outweigh any potential harm, the question arises as to whether assisting the patient's suicide would be an appropriate medical response. According to the reasoning of Pellegrino and Thomasma, the answer depends not only on whether the personhood of the patient has been seriously and irreversibly diminished by unbearable suffering, but also on whether physician-assisted suicide is a proportionate medical response. In other words, is physician-assisted suicide appropriate medical care? The answer requires a more precise explication of proportionality than Pellegrino and Thomasma provide.

III. The second stage: two versions of proportionality.

There are many occasions in clinical practice when the anticipated benefits of treatment for a particular patient must be weighed against the likely harms to determine the best course to follow. Although many persons, especially the attending physician, become involved in this process, a final determination of "proportionate benefits and burdens of treatment...[should be]...left to the individual patient or to those qualified to speak on behalf of the sick person."³¹ A determination of proportionate treatment depends on many factors, including "the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements

³¹Sacred Congregation for Faith (1980), *Declaration on Euthanasia*. Vatican City, p. 9.

with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources."³²

In some cases, this process of weighing benefits and burdens of treatment yields a dilemma in the sense that, whatever course is followed, the outcome will include unwanted side effects. Such cases are classic examples of double effect, where the good sought by patient and physician alike involves good as well as unavoidable and harmful side effects. The current justification usually centers on whether there is a proportionately grave reason for allowing the bad effects to occur. This sort of justification is consistent with a modern interpretation of proportionality as proposed by Gury and Knauer, but not necessarily with the classical view posited by Aquinas.

A. Classical proportionality and Thomas Aquinas.

1. Aquinas' version of proportionality.

Aquinas does not use the modern term "proportionate reason" in discussing the principle of double effect. Instead, he uses the phrase "proportioned to the end" in questioning whether an act that produces both good and evil consequences should be carried out.³³ Using self-defense as the example that illustrates a correct resolution of such conflicts, Aquinas holds that the morally right thing to do depends on the agent's intention, the purpose for which the act is carried out, and the surrounding circumstances, including the means. For Aquinas, the moral status of the means as an act depends on whether such means are morally acceptable in and of themselves and whether they are

³²Sacred Congregation for Faith (1980), p. 9.

³³Summa Theologica, II-II, Q. 64, a. 7 in corpus. As double effect reasoning developed, modern versions of this principle articulate this last criterion in terms of a proportionately grave reason for permitting or allowing the evil effect. Since this reformulation has a different connotation than Aquinas intended, it has contributed to a basic incompatibility between the modern and classical interpretations of proportionality. See Johnstone (1985) p. 225.

proportioned to the end. In this sense, the means chosen must not exceed what is necessary to accomplish the intended goal.

Aquinas offers the following criteria as a measure of the morally right thing to do with respect to acts that have double effects:

- 1. The end or effect sought must be good in itself or at least indifferent.
- 2. The good effect and not the evil effect must be intended.
- 3. The good effect must not be produced by means of the evil effect.
- 4. The act must be proportioned to the end.

In the example case of self-defense, Aquinas argues that preserving one's life satisfies the first criterion insofar as preserving one's life is a purpose good (or at least neutral) in itself.³⁴ He also reasons that, as long as this legitimate purpose maps back to the defender's intended purpose, the act satisfies the second criterion. In this way, Aquinas gives intention a pivotal psychological role, such that a good intention makes for a good act, while a bad intention makes for a bad act.³⁵ Intention alone, however, is not a sufficient moral justification. Analytically, the kind of act in question stands on its own merits, apart from the actor's intention. For example, killing an innocent person as the means to an end is morally impermissible, irrespective of the moral status of that purpose.³⁶

To provide for a separate analysis of the means, Aquinas offers the third criterion, which specifies that the chosen means must not be evil. Aquinas illustrates this qualification by noting that the use of force in self-defense is not an evil means in and of

³⁴Johnstone (1985), p. 228.

 ³⁵Janssens, L. (1982), "Saint Thomas Aquinas and the Question of Proportionality." *Louvain Studies* 9: 26-46.
 ³⁶Kenny, Anthony J. (1973), "The History of Intention in Ethics." <u>Anatomy of the Soul</u>. Oxford, England, Basil Blackwell: appendix.

itself, since repelling force with force is morally permissible. The reason behind such force, however, always must be to preserve life and never to kill the attacker.³⁷

Aquinas further qualifies the means with a proviso in the fourth criterion, which he explains in terms of moderation. According to this proviso, even when using means that are otherwise morally acceptable, such means must be proportioned to the end. For example, in the case of self-defense, the force used must remain equal to or less than the attacking force, which is an amount necessary to preserve life, but no more.³⁸ Together with the previous criterion, this last criterion limits the amount of force to a systematic, reasonable level that ideally matches the amount of force used by the attacker. In this theoretical sense, morally defensible force exists on a continuum that gradually may increase to an amount sufficient to kill the attacker. At that fatal point, causing the attacker's death is a foreseen but unintended consequence that stems from the attacker's use of a potentially lethal amount of force. Killing the attacker is morally permissible if and only if preserving life remains the intended goal throughout. With this explanation, Aquinas equates psychological attitude with moral intention, which must reflect moderation regarding the choice of means.

By contrast, using more force than is necessary in repelling an attack stems from a psychological shift, however subtle, in the defender's intended purpose, which renders such means morally impermissible.³⁹ In that case, the act of defense simply becomes an act designed to kill the attacker. Aquinas states this psychological qualification in the

³⁷Kaczor, C. (1998), "Double-Effect Reasoning From Jean Pierre Gury to Peter Knauer." *Theological Studies* 59(2): 297-316. Aquinas considers self-defense permissible, but not obligatory. It is permissible, because life is a basic but not an absolute good. If life were an absolute good, self-defense would be obligatory.

³⁸Kaczor (1998), p. 300.

³⁹Johnstone (1985), p. 228.

following way: "Therefore, if some one in defending his own life uses greater violence than is necessary, it will be unlawful. But if he repels the violence with moderation it will be a licit defense..."⁴⁰ In this sense, Aquinas explains "proportionate reason" as a relationship between an act and an intended purpose.

For a determination of whether an act remains proportioned to the end, Aquinas appeals to the requirements of charity, which centers on a person's spiritual and physical good. In his view, charity is more than mere kindness or sensitivity to the needs of others. Rather, it is a special kind of love that grows out of and expresses a friendship with God.⁴¹ By friendship, Aquinas means a mutual relationship wherein the partners sustain a benevolent regard toward each other for the other's sake and not for the benefactor's advantage. In this sense, benevolence entails an efficacious regard for the good of the other, the full realization of which leads to complete happiness and occurs only in the spiritual realm. For Aquinas, charity is the overarching principle of human acts such that individual acts are good to the extent that they harmonize with the good of the whole person in both a spiritual and physical sense.⁴² As a result, the choice of means in any sort of moral dilemma must accord with the principle of charity, which is a point that Gury also emphasizes in his explication of proportionate reason.

In sum, Aquinas interprets proportionality in the context of double effect reasoning, not as a new principle of human behavior, but as an application of such

⁴⁰Summa Theologica, II-II, Q. 64, a. 7 in corpus.

⁴¹Clark, M. T., Ed. (1972), <u>An Aquinas Reader: Selections from the Writings of Thomas Aquinas</u>. Garden City, New York, Image Books, p. 406.

⁴²Cessario, R., O.P. (2001), "Towards an Adequate Method for Catholic Bioethics." *The National Catholic Bioethics Quarterly* 1(1): 51-62.

principles.⁴³ For him, proportionality expresses a relationship between the chosen means and the intended purpose. On this view, proportionality helps answer the question of whether, in light of the present circumstances, the chosen means are within reasonable limits.⁴⁴ The answer itself is part of a more comprehensive process of deliberation and choice, which must be guided by the principle of charity.

Analytically, the moral status of a particular act, including those with double effects, depends on three specific features, namely, the kind of act involved, the surrounding circumstances, and the intended purpose.⁴⁵ Evaluating the moral status of an act in this general sense is an all-or-nothing proposition. An act is morally permissible if and only if each morally relevant feature complies with the demands of charity as revealed by reason, while a failure of any one feature in that regard renders that act morally impermissible. On this view, although acts of a certain kind are intrinsically wrong, such as taking what belongs to another person,⁴⁶ the moral status of a particular act also depends on the surrounding circumstances, including time, place, manner of acting, what was done, who did it, and by what means it was done.⁴⁷ Aquinas also claims that the means chosen must be proportioned to the end, or intended purpose. In this sense, the means must reflect a reasonable degree of moderation with respect to their anticipated effects.

⁴³Kaczor (1998), p. 298.

⁴⁴Summa Theologica, II-II, Q. 64, a. 7 in corpus.

⁴⁵Marshner, William H. (1995), "Aquinas on the Evaluation of Human Actions." *Thomist* 59(3), p. 357
⁴⁶Clark (1972), p. 345. Not all moral rules are absolute for Aquinas. Only those that represent primary principles. Secondary and tertiary principles, which derive from primary principles, can be altered after due reflection and in some circumstances. For a discussion on this point, see Black, Peter, C.Ss.R. (1999), "Do Circumstances Ever Justify Capital Punishment?" *Theological Studies* 60: 338-345.

⁴⁷Summa Theologica, I-II, Q. 7, a. 3, c, a. 4, c

In regard to those acts having double effects, although consequences matter insofar as expected outcomes contribute to the formation of intention and choice of means, achieving a net balance of values in the outcome is not the moral norm to apply in determining which course to follow. Rather, for Aquinas the moral norm of all human acts, including those with double effects, amounts to "what reasonableness requires of the choosing person in all the circumstances," as determined by the supreme moral principle, "love of neighbor as oneself."⁴⁸

2. Classical proportionality and the effects of assisted suicide.

Applying a classical interpretation of proportionate reason to the question at hand should begin by acknowledging that Aquinas did not hold a thesis regarding physicianassisted suicide. Had he held such a view, it most likely would have paralleled his rejection of suicide as contrary to human nature and our spiritual destiny. In this respect, he argues that suicide stems from a desire to be rid of a life whose intrinsic value has been overshadowed by hardship and misery, which gives death the appearance of a good.⁴⁹ Because life is a basic good that must be pursued within reason and death is the deprivation of that good, Aquinas rejects suicide as a disproportionate response to misery that violates the individual's obligation to preserve life, regardless of how diminished its value might appear to that person.⁵⁰ On this view, suicide is a disproportionate means of relief because it seeks the deprivation of good, which is contrary to reason.

⁴⁸Finnis (1998), op. cit., pp. 138-9.

 ⁴⁹Novak, David (1975), "Suicide and Human Nature in Aquinas." <u>Suicide and Morality</u>. New York, Scholars Studies Press, Inc., p. 50. Novak claims that it is not clear whether Aquinas perceived this as the only motivation for suicide. ⁵⁰Novak (1975), p. 48. There is no conflict between this conclusion and the permissibility of martyrdom, since fending off a lethal attack is not obligatory. Aquinas also would see no conflict with the removal of life support, when its continuation is unreasonable, since physical life is a basic good but not an absolute good.

Although sympathetic to the suicidal person who is in misery, Aquinas offers three specific reasons as to why an individual should reject suicide as immoral.⁵¹ First, on a human level, suicide goes against the self-preservation instinct, and, on a moral level, opposes the principle of charity. Second, suicide harms the common good, because the person who commits suicide thereby avoids a personal obligation to serve the community. Third, suicide violates one's personal friendship with God by usurping his authority over life and death. For these reasons, Aquinas rejects suicide as a disproportionate response to the misery and hardships of life.

Adapting Aquinas' line of reasoning about suicide to the question of physicianassisted suicide requires both a change in perspectives and a change in principle. Aquinas adopts the subjective viewpoint in arguing against suicide, because he views the individual's role as decisive in that act. Since the physician's role is uniquely vital to the outcome in physician-assisted suicide, it seems more appropriate to analyze the ethics of physician-assisted suicide from the physician's perspective, rather than from the patient's. The other change concerns the principle of charity, which Aquinas views as an overarching principle and guide for human affairs. In the practice of medicine, however, there is no overarching ethical principle. Physicians abide by several fundamental ethical principles and many secondary principles, any one of which might become primary in a given set of circumstances.

Nevertheless, the one principle that consistently guides physicians' behavior in relation to their patients is that of beneficence. Thomasma and Pellegrino explain

 $^{^{51}}$ Aquinas discusses these reasons in *Summa Theologica*, II-II, Q. 64, a. 5. This section deals with the question of homicide.

beneficence as the physician's chief requirement to promote the patient's health in a proportionate manner with technically right and morally good medicine. Given that view, the demands of beneficence map back to the demands of charity insofar as both principles serve a person's best interests. In a moral context, charity ideally promotes a person's good character, while in a medical context, beneficence ideally promotes a patient's good health. As a result, the following analysis of physician-assisted suicide as it relates to classical proportionality incorporates beneficence as the background principle and counterpart to a Thomistic principle of charity. By adopting Aquinas' argument against suicide as a framework for discussion, the conclusion reached is that the medical community should reject physician-assisted suicide for similar reasons.

Since a request for physician-assisted suicide often reflects the tragic aspects of life, a hypothetical case might highlight the more poignant difficulties surrounding that procedure. Consider the following situation:

Bill was paralyzed in a gymnastics accident approximately 30 years ago. A quadriplegic since then, he rarely leaves the hospital because of a constant need for 24-hour care and dependency on a respirator. Despite these complications, Bill's life has not been empty. Now in his early fifties, he has many friends and is known for his vitality, generosity, and sense of humor. He often raises money for charity, and computers offer him a window to the outside world. Even so, Bill has decided that 30 years of suffering is long enough. In his view, to live any longer would cause undeserved and undue emotional, physical, and financial burdens on his family. To avoid this, Bill wants to die a quick and painless death, despite objections from his family, friends, pastor, and the hospital staff. Over the last several weeks, he has persistently asked his physician for a lethal dose of medication that will bring a quick and painless end to his suffering.⁵²

Had Bill asked for assisted suicide as a way to relieve intolerable pain instead of

unbearable suffering, his physician might have responded by administering all the pain

⁵²Anonymous (1999). "Moreover: Let Death Be My Dominion." *The Economist* 353(8141): 89-92, adapted. This kind of situation raises another troubling question that John Hardwig addresses, namely, whether there is in some cases a duty to die. See Hardwig, John (1997), "Is There a Duty to Die?" *Hastings Center Report* (March-April): 34-42. For a discussion of Hardwig's thesis, see Chapter 4 herein.

medication that Bill wants and needs, even if hastening death is the end result.⁵³ Indeed, an intentional failure to relieve pain adequately in this case might constitute both a professional and a moral failure. Pain relief, however, is not what Bill has asked of his physician. Instead, his request is for release from thirty years of suffering that has become unbearable and is only going to get worse. With the financial and emotional burdens on his family associated with his slow, agonizing death, Bill perceives death as the best alternative, rather than as a harm. Despite the physician's compassionate response to his desperate plea for assisted suicide, such requests raise complex professional and moral issues for the physician.

On the one hand, the physician has a professional obligation to relieve suffering and pain with appropriate medical care that the patient finds acceptable and that causes the least harm. On the other hand, the physician also has a moral duty to preserve life, despite the fact that medical science currently has no cure for quadriplegia, a primary cause of Bill's suffering and partly the reason he requests assisted suicide. When the only kind of "care" that some patients find acceptable is assisted suicide, however, the professional and moral implications of the physician's involvement raise a serious concern as to whether a physician ought to accede to requests such as Bill's.

This issue can be structured in terms of classic double effect reasoning. Given relief of suffering as a traditional goal of medicine and the purpose of physician-assisted suicide, acceding to a patient's request in that regard seems to satisfy the first criterion that the end sought must be good in itself. Although the patient's death is one of the

⁵³For a comparison of palliative options of last resort, including terminal sedation, see Quill, T. E., et al. (1997). "Palliative Options of Last Resort." *JAMA* 278(23): 2099-2105.

effects of pursuing that goal, in a case like Bill's, death might be viewed as a regrettable and unavoidable side effect that does not harm the patient. In that case, acceding to a request for physician-assisted suicide also appears to satisfy the second criterion that the good effect and not the evil effect be the intended result.

The last two criteria of a classical model both address the choice of means. The third criterion specifies that the good effect must not be produced by means of the evil effect, while the fourth requires the use of proportionate means. Because the physician makes a direct contribution to the patient's suicide by introducing an original cause of death distinct from the underlying pathology, that contribution involves killing the patient. As a result, Paul Ramsey dismisses a question about the physician's involvement in that suicide rather tersely with the claim that healing in the medical profession is not meant "to relieve the human condition of the human condition, "⁵⁴ In his view, because suffering is an inextricable part of the human condition, physicians should not kill patients to relieve their suffering, however willing the patient may be.

Although Ramsey's objection has a certain intuitive appeal, a stronger claim is that physician-assisted suicide is morally impermissible because the physician's part in killing the patient as a way to relieve suffering is a disproportionate medical response that fundamentally opposes the physician's duty to heal. This objection attempts to strike a balance between beneficence and patient autonomy by relying on the dictum of Pellegrino and Thomasma. On their view, morally defensible medicine must consist in proportionate care that is both technically right and morally good.

⁵⁴Ramsey, Paul, as quoted in Campbell, Courtney S. (1990), "Religion and Moral Meaning in Bioethics." *Hastings Center Report* 20 suppl. (July/August): 4-10.

Based on a classical concept of proportionality, however, physician-assisted suicide is neither technically right nor morally good because it constitutes a disproportionate medical response to suffering for three reasons. One, it violates the healer's duty to care for all human life with medically appropriate care relevant to the patient's quality of life. Two, it harms the common good because it perpetuates an inherent potential for abuse. Three, it opposes the virtuous practice of medicine insofar as the physician relies on her own subjective evaluation of the patient's quality of life as valid clinical support for her decision to assist the patient's suicide. Although Aquinas' argument against suicide serves as a framework for the following explanation of these reasons, that explanation is not an argument against suicide, but an argument against the physician's participation in assisting a suicide.

a. The duty to heal.

With reference to Aquinas' framework, consider his first reason against suicide. He claims that suicide is a disproportionate response to pain and misery that violates the principle of charity, which requires due care for physical life, and opposes the instinct of self-preservation. In the medical realm, there is a corresponding ethical requirement for the physician that Pellegrino and Thomasma describe in terms of seeking the patient's good in a proportionate manner. Zaner interprets this requirement as beginning with the least irreversible method of care, which culminates at a point of optimum physiological and psychological health that within reason accords with patient preferences.⁵⁵ Although limited in many respects, this ideal stops short of causing the patient's death in the sense

⁵⁵Zaner (1990), p. 318. See also Beauchamp, T. L. and Childress, J. F. (1994), <u>Principles of Biomedical Ethics</u>. 4th ed. New York, Oxford University Press, p. 34, for a discussion of a similar "least onerous" kind of analysis with respect to balancing the requirements of competing ethical principles. On their view, the infringement of one principle on another should be the "least possible, commensurate with achieving the primary goal of the action."

of either directly or indirectly killing the patient. This is not to say that life must be preserved at all costs. Rather, it merely expresses the view that human life itself is a basic value that requires due care in all circumstances, which bars its deliberate destruction.

Kass makes this same point by arguing that the goals of medicine define the physician's role in such a way that the physician must act so as to benefit the wholeness of the patient. In his view, assisting the patient's suicide is morally wrong because it contradicts the physician's duty to heal.⁵⁶ In other words, killing the patient has nothing to do with the physician's commitment "to use scientific knowledge and clinical experience in making decisions and advising patients about the prevention, diagnosis, and treatment of disease and the maintenance of health."⁵⁷

Kass' point is consistent with a long-standing tradition that puts physician-assisted suicide outside the bounds of ethical medicine. In assisting a patient's suicide, the physician provides the means, even though the patient self-administers the lethal dose. In making that contribution, the physician decides against the patient's life, which unavoidably involves the physician in killing an innocent person.⁵⁸ All patients are innocent from the physician's perspective, and as Aquinas put it, there is "simply no justification for taking the life of an innocent person."⁵⁹ Although the state traditionally reserves a right to kill some members of society, as in war and capital punishment, the

⁵⁶Kass, L. (1991), "Why Doctors Must Not Kill." Commonweal 118 (August 9), p. 474.

⁵⁷Jonsen, A. R. (1988), "Beyond the Physicians' Reference--the Ethics of Active Euthanasia." *Western Journal of Medicine* 149 (August), p. 196

⁵⁸Rhonheimer, Martin (1994), "Intrinsically Evil Acts and the Moral Viewpoint: Clarifying a Central Teaching of *Veritas Splendor*." *Thomist* 58(1), p. 12.

⁵⁹Summa Theologica II, II, Q. 64, a. 6, responsio.

moral justification for doing so, albeit controversial, relies in part on the assumption that those killed are not innocent in some respect. Legally and morally, there are no exceptions to intentionally and deliberately killing innocent persons. For this reason alone, the physician who becomes directly or indirectly involved in killing a patient acts outside the ethical and legal bounds of medicine, despite a voluntary request in that regard by the patient and irrespective of the physician's motive.

By contrast, the physician as healer acknowledges and fulfills a professional commitment to "care" for the patient, even when that patient has an incurable, poor quality of life and death is imminent. When cure is no longer possible, the physician still must seek the patient's medical good, which always may be possible on some level. To that end, the physician continues caring for the patient by applying her technical skills and professional knowledge in a way that results in the greatest comfort and least amount of suffering and pain.⁶⁰ Although this duty to heal includes efforts to relieve suffering, the physician must not use her skills to destroy human life, "...either the last of it or the first of it. The good physician is not a mere technician; [but] is committed by the practice of medicine to certain goods and to certain standards."⁶¹ Such standards reflect a long-standing legal, medical, and moral tradition that excludes intentionally and deliberately killing innocent persons, which rules out the use of physician-assisted suicide.

Those who favor physician-assisted suicide might argue against this line of reasoning with the claim that innocence can be interpreted in two senses; as "free from

⁶⁰Cf. Preston, Thomas A., M.D. (1998), "The Rule of Double Effect." *NEJM* 338(19): 1389. Preston responds to Quill, Dresser, and Brock on their critique of the rule of double effect.

⁶¹Verhey, Allen (1984), "The Doctor's Oath--and a Christian Swearing it," in <u>Respect and Care in Medical Ethics</u>, ed. David Smith. New York: University Press of America.

blame" or as "not posing a threat". In the first sense--free from blame--an innocent individual is not guilty of having committed any crime or wrong-doing, and thus does not deserve punishment of any kind, especially the punishment of death. Those who favor physician-assisted suicide would agree that killing the patient clearly would be wrong in the sense that the patient does not deserve to die, given that the patient has not committed any crime or wrong-doing that warrants such punishment. In any case, determining criminal guilt and the appropriate punishment is a right that belongs only to the state.

On another interpretation, however, "innocent" can mean harmless in the sense of "not posing a threat". Aquinas relies on this latter sense of the term, for example, when he claims that the state's right to kill malefactors "is legitimate insofar as it is ordered to the well-being of the whole community."⁶² On this interpretation, a person who threatens a community lacks innocence by virtue of that threat. As authorized caretaker of the common good, then, the state has the right to judge that threat, and subsequently may protect society to the extent of executing the one who poses such a threat.⁶³

Lisa Sowle Cahill applies this line of reasoning about a community's right of selfprotection to the individual.⁶⁴ In her view, the individual person is a kind of community in the sense that "person" means a unified whole, constituted by physical and spiritual aspects, with an ultimate spiritual destiny that determines the priorities of life. To this view of a person, she factors in a "principle of totality" that allows the destruction of a part, as in amputating a gangrenous limb to save the person's whole life.

⁶²Summa Theologica, art. 2 and art. 3, responsio.

⁶³Summa Theologica, art. 2 and art. 3, responsio.

⁶⁴Cahill, Lisa Sowle (1987), "A "Natural Law" Reconsideration of Euthanasia." <u>On Moral Medicine</u>. Stephen E. Lammers and Allen Verhey. Grand Rapids, MI, Wm. B. Eerdmans Publishing: 445-453.

Cahill then applies the principle of totality to physical death, and claims that death is not necessarily the worst thing that can happen to a person. In her words: "Sometimes continued life does not constitute a good for a certain individual because it cannot offer him the conditions of meaningful personal existence. Sometimes the continued life of an individual is incompatible with the preservation of other values which also claim protection."⁶⁵ She concludes that, "Since the distinctive and controlling element of human nature is the personal self or spirit, then according to the principle of totality, the body which is a 'part' may in some cases be sacrificed for the good of the 'whole' body-soul entity."⁶⁶

Although Cahill uses this line of reasoning primarily to justify withholding and withdrawing medical care as an acceptable means of "sacrificing" the body for the good of the whole person, she goes a step further by defending the morality of suicide itself on the same grounds. In her view, when biological life is diminished by pain and suffering such that spiritual growth is no longer possible, the physical aspect of that person's life threatens the whole person, including the spiritual dimension. The body then becomes the "enemy" or that part which threatens the whole person, and can be eliminated by suicide without moral guilt. To support this conclusion, Cahill claims that a community's moral right to protect itself extends to the individual. In her view, the individual's right to self-protection includes suicide as a legitimate means to that end.

Those who disagree with Cahill on this score might suggest that she misconstrues some fundamental aspects of Aquinas' views on the common good and altogether ignores

^{65&}lt;sub>Cahill</sub> (1987), p. 447.

⁶⁶Cahill (1987), p. 452.

his rejection of suicide itself. Nevertheless, her analysis raises legitimate questions about physician-assisted suicide and active euthanasia as a matter of social policy. For instance, in light of Aquinas' claim that society has the right to protect itself from serious threat, consider the threat to society posed by those who consume vast amounts of limited healthcare resources. The continued existence of such persons might pose the kind of threat to the common good that Aquinas envisioned as justification for executing certain members of society.

On this view, perhaps the state may allow physicians, as agents of the state, to conduct optional physician-assisted suicide and voluntary active euthanasia on such patients as a way to protect the healthcare resources of the community. Would a social policy of this sort fall under a Thomistic general justification for killing persons who are not innocent in the sense that they pose a threat to society? How far would a social policy of this sort logically extend? Suppose those who threaten scarce healthcare resources do not opt for physician-assisted suicide or voluntary active euthanasia. Could the state then deem the life of such persons no longer worthy of legal protection, in much the same way as it declared the life of certain unborn humans unworthy of legal protection? Would such a determination clear legal ground for involuntary euthanasia to be carried out by physicians at their discretion? A lack of innocence in the sense of posing a threat to the community might constitute an involuntary waiver of the patient's right to life, as those who are guilty of capital crimes must relinquish such a right. Resolving such issues is a formidable task that takes time and reflection.

In the interim, the general unacceptability of physician-assisted suicide stands in sharp contrast to the general acceptability of omitting or removing treatment. Ordinarily,

allowing the patient to die by such means can be an acceptable and compassionate medical response to a patient's suffering, while killing that same patient by means of physician-assisted suicide or voluntary active euthanasia as an alleged way to relieve suffering is not. Proponents of physician-assisted suicide who take exception to this ordinary distinction claim that relief of suffering can be the overriding intended purpose in a case of physician-assisted suicide, just as it can be in a case of removing treatment. Because relief of suffering often serves to justify such removal, and since both practices involve the use of means that bring about the patient's death, such proponents argue that a distinction between killing and allowing to die carries no moral weight. In their view, allowing the practice of removing treatment while banning the practice of physicianassisted suicide is a contradiction that can be sustained only by ethical legerdemain.

Dan Brock argues this way, and illustrates his point with the situation of a competent patient, who has ALS and depends on a respirator.⁶⁷ This patient wants to die and repeatedly asks that the respirator be removed for that purpose. According to Brock, most would agree that physician compliance in this case would be an acceptable instance of allowing the patient to die. He then compares this scenario to another case in which a greedy son, impatient for his inheritance, secretly removes his mother's respirator, after which she dies. In his view, most would classify removal in this latter case as an unacceptable killing.

Brock argues against this sort of distinction, and claims that both acts of removal are simply a means of killing that can be justified by a legitimate purpose as defined by

⁶⁷Brock, Dan (1992), "Voluntary Active Euthanasia." *Hastings Center Report* 22 (March/April), pp. 13-14. Brock is not so much concerned with a distinction between physician-assisted suicide and omitting or removing treatment as he is with a distinction between killing and allowing the patient to die by any means.

intention alone. In his view, killing and allowing to die are means of equal moral status that bring about the patient's death. For him, the crucial question concerns the intention of the actors. In the first case, for example, because the physician intends to relieve the woman's suffering by removing the respirator, which is done at her persistent and voluntary request, the removal is a justified killing. In the second case, however, the son acts with a selfish motive and without his mother's consent. Hence, the removal of her respirator is an unjustified killing.

Brock concludes that, because both killing and allowing to die can be conducted with and without consent and for good as well as for bad reasons, the moral distinction between these two methods ought to be rejected. He reasons that such a distinction reflects the faulty premise that, for the most part, allowing to die is justifiable, while killing is not. In his view, given a morally acceptable purpose as defined by intention, the remaining crucial question is whether the patient consents to the killing.⁶⁸ For Brock, intention makes all the difference.

Those who disagree with Brock might suggest that, in gathering intention, purpose, and means into a single psychological package for moral assessment, he omits some valid analytical differences. One analytical difference affects the logic of his argument. Although he correctly observes that a particular case of removing treatment can be equivalent to killing the patient and thus morally wrong, it does not follow that the general acceptability of removing treatment likewise extends to killing the patient, either by direct or indirect means. The moral unacceptability of physician-assisted suicide as well as active euthanasia is due, not to the physician's intention, but primarily to the fact

⁶⁸Brock (1992), p. 13.

that these practices always involve unacceptable means, namely, killing an innocent person, while removing life-sustaining treatment ordinarily does not. In the latter case, "life-sustaining" is a term that refers to treatment that temporarily suspends the course of an otherwise fatal pathology, and does not refer to treatment that sustains life indefinitely, much less save it. To remove such treatment for good reason is to stop interfering with the progress of that pathology, after which it resumes its progress to an inevitable end, death. In such cases, the cause of death is the underlying pathology, whereas in cases of physician-assisted suicide, the physician introduces an original cause of death apart from that pathology, which culminates in an otherwise preventable death.

This additional cause introduced by the physician is the aspect that Brock fails to account for in his argument. Omitting the phrase "killing an innocent person" from the definition of physician-assisted suicide and inserting an acceptable motive in its place does not render that practice morally acceptable merely because the physician acts from that motive. Brock's contention that the difference between physician-assisted suicide and removing treatment carries no moral weight is a radical break with a long-standing medical, legal, and moral tradition that recognizes a clear moral distinction between "killing an innocent person" and "fatal pathology". Killing an innocent person is clearly a moral wrong, while dying from a fatal disease is one of the unfortunate consequences of human existence. For this reason, Brock needs a stronger defense than the one allowed by his treatment of physician-assisted suicide as a unified psychological process that turns on intention and proximate cause.

Brock also does not consider a valid difference in the weight that patient authorization carries in relation to providing medical care as compared to removing such

care. In a case of allowing to die by removing or stopping treatment, for instance, the right to self-determination alone can support a competent patient's decision to withdraw treatment, which in turn authorizes the physician to stop or omit that care. Although the end result might be the patient's death, the authority and responsibility for the decision to withdraw treatment belongs entirely to the patient. In stopping such treatment, the physician merely acquiesces in the patient's request.

On the other hand, the physician who agrees to assist the patient's suicide does not merely acquiesce in the patient's request. In such cases, the physician decides to contribute an original cause of death apart from the patient's underlying pathology. All else being equal, authorization for the physician's decision to make that contribution would depend not only on the patient's voluntary and informed consent, but on the classification of physician-assisted suicide as appropriate medical care. Such a classification has technical and ethical aspects distinct from those that apply to the patient's consent. Aside from the ethical considerations, to qualify as appropriate medical care from a technical standpoint, the physician's contribution in physician-assisted suicide requires the support of the relevant scientific and clinical data that shows death as a potentially beneficial way to relieve suffering.

To date, however, the necessary data showing physician-assisted suicide as a valid form of medical care that relieves patient suffering are missing. In the absence of such cognitive data, the physician's contribution to a patient's suicide as a way to relieve suffering lacks technical warrant. An investigation that might yield such data ought to begin with the premise that the suffering itself is a cognitive experience related to the person's subjective evaluation of her own life, as compared to an experience of pain,

which is the person's subjective evaluation of her own body. Although suffering and pain are often interrelated and occur simultaneously, they are distinct phenomena. If analysis is to yield appropriate support for physician-assisted suicide as a valid form of medical care, the relevant cognitive factors that give rise to patient suffering must be included and evaluated in the same way that physiological factors have a part in an analysis of pain.

As a result, the physician who agrees to assist a patient's suicide merely provides a service that does not qualify as appropriate medical care. In addition, the physician's assistance exposes the patient to unknown risks that the patient's voluntary consent alone cannot justify in the way that it justifies the removal of treatment. In the case of removal, the patient alone assumes such risks, while in the case of physician-assisted suicide, the physician must assume responsibility for that exposure. Because the physician acts in a professional role, the implication is that physician-assisted suicide qualifies as appropriate medical care. The physician's professional and ethical error is that she does so without medical warrant.

This difference in the role of patient authorization can be viewed from another angle as well. In a case of removing treatment, the physician has an obligation to honor a valid request in that regard, despite the causal outcome. In other words, "From both a legal and moral point of view...[physicians must]...recognize and act upon a valid refusal, irrespective of the causal outcome."⁶⁹ Sometimes, the causal outcome is the patient's foreseeable and intentional death. Although the physician might not agree with the patient's choice, respect for autonomy bars the physician from acting on such disapproval

⁶⁹Beauchamp, T. L. (1999), "The Medical Ethics of Physician Assisted Suicide." *Journal of Medical Ethics* 25: 437-439.

by forcing treatment on a competent patient who requests that such treatment be discontinued.⁷⁰ A right to self-determination protects the patient's person and body from being invaded against her will. Harsh as it may seem, the trump value of a competent patient's autonomous choice when it comes to refusing treatment includes the freedom to surrender a reasonable chance of recovery. In such cases, convincing the patient to do otherwise then depends on the physician's skill of persuasion. In a case of physician-assisted suicide, however, physicians have no professional obligation to honor such requests, despite the voluntary nature of such a request and despite the assumption that doing so will relieve the patient's suffering.⁷¹ The medical profession itself makes it clear that the physician's duty to relieve suffering does not extend as far as eliminating the sufferer by killing the patient, either directly or indirectly.⁷² Yet, Brock's claim that there is no moral distinction between killing and allowing to die has exactly this implication with respect to a physician's professional obligation.

Consistent with Brock's view, physicians might have a professional duty to provide physician-assisted suicide or active euthanasia, which parallels their duty to remove or omit treatment. Given that respect for patient autonomy grounds such an obligation and no real moral distinction between killing and allowing to die, it seems that physicians must comply with a patient's voluntary request for either physician-assisted suicide or active euthanasia. On what grounds would a physician refuse? Thus, Brock's claim that a legitimate, intended purpose and consent alone together underwrite physician behavior

⁷⁰Kamm, Frances M. (1998), "Physician-Assisted Suicide, Euthanasia, and Intending Death." <u>Physician Assisted Suicide</u>. Margaret P. Battin, Rosamond Rhodes and Anita Silvers. New York and London, Routledge, p. 40.
 ⁷¹Miller, Franklin G., Ph.D. and Meier, Diane E., M.D. (1998), "Voluntary Death: A Comparison of Terminal

Dehydration and Physician Assisted Suicide." Annals of Internal Medicine 128(7): 559.

⁷²Council on Ethical and Judicial Affairs (1996), "Physician Assisted Suicide," Report Number E 2.211. Chicago. American Medical Association.

in both killing and allowing to die may extend beyond the level of professional option for physicians. His claim may extend to the level of duty that is virtually impossible for physicians who oppose the practice on moral grounds to avoid. If Brock would support such an extension, which seems likely, he needs a stronger defense of his original claim.

b. The common good.

According to Aquinas' framework, his second reason for rejecting suicide is the harm it causes the common good. For him, "common good" is an ideal system of institutions and social conditions designed to enhance the availability and just distribution of public goods and services.⁷³ Included among such considerations are the talents, skills, and personal existence of each member, although the common good is not an attribute of individuals. Neither is it the "collective good" of society as a whole. Rather, it is the welfare of persons in communion with each other that flourishes in direct proportion to the flourishing of society, which in turn depends on the contribution that each member must make in that regard.⁷⁴ In this sense, "There is no such thing as a happy society without happy citizens."⁷⁵ Despite his emphasis on a personal obligation to promote the public welfare, Aquinas did not view the common good itself as the highest good, since human destiny transcends civil society. Nevertheless, he viewed suicide as a social harm because the person who commits suicide abandons a personal obligation to contribute to the common good.

 ⁷³Coleman, John A., S.J. (2001), "American Catholicism, Catholic Charities U.S.A., and Welfare Reform." *Journal of Policy History* 13(1): 74-77. See also Coleman (1995), "A Common Good Primer," *Dialog* 34 (Fall), pp. 249-54.
 ⁷⁴Coleman (2001), p. 77.

⁷⁵Novak (1975), p. 66.

In contrast to such a claim, a contemporary justification for physician-assisted suicide includes the idea that, at some point, it is reasonable for a person to decide that the ability to make social and familial contributions is diminished and outweighed by the cost of personal suffering. When it so happens that such a person also views her continued physical existence as having little value, or as being a drain on social and familial resources, or as involving intolerable suffering, the sufferer then might view physician-assisted suicide as the best method of relief.⁷⁶ In these circumstances, the assumptions might be that suicide itself is not morally wrong, and that the physician is the one better able to provide a painless and quick end to life. When asked to assist a patient under these conditions, some physicians might concur with the patient that continued life has little value and conclude likewise that hastening death by suicide is the better course.

Others take such reasoning a step further and consider suicide the last magnanimous social contribution to be made, or perhaps required, since doing so rids both society and family of a burden.⁷⁷ Sidney Hook, for example, wrote extensively on the ethics of suicide, and aptly expressed this sort of view in the following way:

Far from being a crime against society, suicide may actually further the welfare of society. The logic of utilitarian ethics inevitably leads to this position, to the surprise of a number of its adherents. The greatest good or happiness of the greatest number may sometimes be attained by personal sacrifice, as the annals of heroism and martyrdom will attest...it is not altogether inconceivable that sometimes refusal to commit suicide would constitute a crime against society.⁷⁸

⁷⁶Brock makes such a case for competent adult patients. See Brock, Dan W. (1999), "A Critique of Three Objections to Physician-Assisted Suicide." *Ethics* 109: 519-547.

⁷⁷Marzen, T. J., et al. (1985), "Suicide: A Constitutional Right?" *Duquesne Law Review* 24(1): 1-101. For a discussion of the family role in healthcare decisions, see Hardwig, John (1990), "What About the Family?" *Hastings Center Report* March/April: 5-10; and Hardwig (1997), "Is There a Duty to Die?"

⁷⁸Hook, Sidney (1927), "The Ethics of Suicide." *International Journal of Ethics* 37. Cf. Hardwig (1997). "Is There a Duty to Die?"

Such utilitarian reasoning would not have been all that foreign to Aquinas, who considered and rejected the idea that the interests of society have this sort of priority over human life. He argued that a person's specific moral duty to society is limited by a greater duty to God. According to Aquinas:

Man is not ordained to the body politic according to all that he is and has; and so it does not follow that every act of his acquires merit or demerit in relation to the body politic. But all that man is, and does, and has, must be referred to God; and therefore every act of man, whether good or bad, acquires merit or demerit in the sight of God...⁷⁹

By contrast, a modern resolution of a conflict between personal duties and those owed the state looks more to the secular law than to divine law. An underlying premise of the modern approach concerns the way in which the law and morality connect at certain vital points to promote the common good.⁸⁰ At a fundamental connection point, social policy sanctioned by the law receives a *de facto* moral acceptability by virtue of that connection.⁸¹ From a psychological standpoint alone, then, the fundamental connection between law and morality tends to generate fidelity from those to whom the law applies.

Two such points of connection concern the content of law and its administration.

The content of the law gives formal expression to those basic moral values and principles

⁷⁹Summa Theologica, I-II, Q. 93, a. 3.

⁸⁰Hart, H.L.A. (1991), "Positivism and the Separation of Law and Morals." <u>Philosophy of Law</u>. Joel Feinberg and Hyman Gross, eds. Belmont, California, Wadsworth Publishing Company, p. 100.

⁸¹Some theorists deny any such connection between law and morality. Nineteenth-century English writer John Austin, for instance, places human law entirely outside of the moral order. Like Hume before him, Austin held the view that laws should be distinguished from the prevailing societal rules of morality. On Austin's view, laws function merely as commands of the supreme political authority. The only motive for obeying such laws is habit or fear of reprisal. See Austin, John (1832). <u>The Province of Jurisprudence Determined</u>. New York, Noonday Press (1954), p. 184. Cf. Holmes, Oliver Wendell, Jr. (1897), "The Path of the Law." *Harvard Law Review* 10, p. 458.

vital to the common good, such as "vetoing murder, violence, and theft."⁸² A genuine legal system will incorporate such values and principles to insure peace and security for the community. Likewise, the administration of such rules must comply with the demands of justice, which requires treating like cases alike.⁸³ Without such fairness in application, the law becomes a set of meaningless taboos. Equal application of rules that provide for the protection of persons and property by guaranteeing a "degree of mutual forbearance and respect for the interests of others" is fundamental to any genuine legal system.⁸⁴

Given the current lack of medical warrant for physician-assisted suicide, prudence requires that society err on the side of caution by maintaining a legal prohibition of that practice. The absence of relevant scientific and clinical data showing its effectiveness justifies limiting the physician's role in this way. Another way of stating this prohibition is to say that it derives largely from the idea that physician-assisted suicide violates a professional duty to heal and indirectly involves the physician in causing a patient's intentional death. Because there is no medical and legal support for doing so, however, vulnerable patients are at serious risk of abuse. To avoid that possibility, society has demonstrated its prudence through state law (except Oregon) and professional codes of ethics that expressly prohibit physician-assisted suicide.

The American Medical Association's Council on Ethics and Judicial Affairs policy statement regarding physician-assisted suicide is an example of the many ways in which society expresses this concern about abuse. According to that policy:

⁸²Hart (1991), p. 100.

⁸³Hart (1991), p. 100.

⁸⁴Golding, Martin P. (1975), <u>Philosophy of Law</u>. Englewood Cliffs, NJ, Prentice-Hall, p. 34.

Allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.⁸⁵

Although not all physicians belong to the AMA, this statement influences the practice of medicine in part because it is consistent with the laws of most states⁸⁶ and with recent U.S. Supreme Court opinion that rejects a constitutional "right to die".⁸⁷

Some proponents argue, however, that the systemic failure of medicine to provide adequate pain relief at the end of life and to protect against unwanted intrusions of lifeprolonging medical technology are reason enough to legalize physician-assisted suicide as a sorely needed counter to badly practiced medicine. Such advocates claim that protecting patients is just a matter of factoring in the right amount of stringency, and a worry about abuse in physician-assisted suicide, such as that expressed by the American Medical Association, is much ado about nothing.⁸⁸

Nevertheless, there is evidence to suggest that not even very stringent safeguards provide a reasonable degree of protection against abuse. The U.S. criminal justice system and the Dutch experience with euthanasia are two venues that provide such evidence. Regarding the first, the U.S. criminal justice system fails to provide fair protection of many African-American men charged with capital crimes. This failure occurs despite the use of very stringent safeguards designed to protect the interests of the accused throughout the legal course of determining innocence or guilt. Such safeguards include

⁸⁵Council on Ethical and Judicial Affairs (1996), Report Number E 2.211

⁸⁶Myers, Richard S. (2001), "Physician-assisted Suicide: A Current Legal Perspective." *The National Catholic Bioethics Quarterly* 1(3): 45-361.

⁸⁷*Washington v. Glucksberg,* 79 F.3d 790 (9th Cir. 1996), cert. granted, 117 S. Ct. 37 (1996); *Vacco v. Quill*, 80 F.3d 716 (2nd Cir. 1996), cert. granted, 117 S. Ct. 36 (1996).

 ⁸⁸Bok, Sissela (1998), "Euthanasia." <u>Euthanasia and Physician Assisted Suicide: For and Against</u>. Gerald Dworkin,
 R.G. Frey and Sissela Bok. New York, Cambridge University Press, p.134.

an adversarial system of representation wherein a panel of jurors, selected at random, consider the facts presented by opposing sides. This system itself unfolds in an open public forum ideally in the presence of an impartial judge who guides the process throughout. The judicial process also contains numerous procedural safeguards and subsequent reviews at many levels, the records of which are available for public scrutiny. Indeed, the U.S. Supreme Court's ruling in *Furman v. Georgia* imposed this degree of protection for the accused in capital punishment cases to ensure fairness and to prevent the state from killing innocent persons.⁸⁹

Despite the presence of these very stringent safeguards, imposition of the death penalty is riddled with disparity between whites and blacks, rich and poor, from locale to locale, as much now as it has been throughout its use in this country.⁹⁰ The consistent end result is a disproportionate number of blacks on death row.⁹¹ As of 1999, for example, blacks comprised only 13% of the U.S. population but 43% of those on death row and one third of those executed in that same year.⁹²

The suggestion that the disproportionate number of blacks on death row or executed is due simply to the disproportionate number of blacks committing crimes that carry the death penalty is not convincing. Consider the wide discretionary power of prosecutors either to seek the death penalty or to plea bargain as they see fit. Prosecutorial discretion and economic disparity has contributed to the unfair imposition

⁸⁹Furman v. Georgia, 408 U.S. 238 (1972).

⁹⁰United Nations (1998), "Death Penalty in the United States." New York, Appendix 8.
⁹¹Michigan State University (2000), "Death Penalty Information," Available WWW:

http://deathpenaltyinfo.msu.edu/c/about/arguments/arguments4a.htm.

⁹²*Policy Almanac* (2001), "History of the Death Penalty," Available WWW: http://policyalmanac.org/crime/death_penalty.shtml.

of the death penalty on African-American males, despite very stringent procedural safeguards in the criminal justice system.⁹³

Since capital punishment is a morally debatable though legalized form of intentionally killing certain members of society, while physician-assisted suicide is a form of intentionally, albeit indirectly, killing certain patients, this failure of the criminal justice system has at least two important implications for the practice of physician-assisted suicide. First, science thus far is unable to ensure fairness with respect to the practice of physician-assisted suicide as it has with respect to the operation of the criminal justice system. Specifically, the science of DNA has promoted fairness in the criminal justice system by producing irrefutable evidence to support the release of innocent persons from death row, and more recently, by helping the accused secure acquittals.⁹⁴

Physician-assisted suicide, on the other hand, lacks the scientific and clinical evidence supporting its use as a way to relieve suffering. Moreover, the clinical evidence produced by near-death experiences suggests that death does not relieve suffering for some patients. Second, procedural justice is not a panacea. If the publicly centered procedural safeguards surrounding the imposition of the death penalty can fail for vulnerable members of society, then there is reason to suppose that the privately centered patient-physician safeguards in physician-assisted suicide likewise can fail to protect

⁹³Policy Almanac (2001), Appendix 12.

⁹⁴ Approximately three years ago, Governor Ryan of Illinois placed a moratorium on the death penalty pending the results of a study of that system. Those results, made public by Governor Ryan in January 2003, revealed egregious errors that routinely fail to protect innocent persons from being convicted of crimes they did not commit, and in some cases, of being unfairly sentenced to death for those crimes. These and other blatant inequities led Governor Ryan to exonerate and release 4 death row inmates, and commute to life the death sentences of all remaining inmates on death row in that state.

vulnerable patients against abuse.⁹⁵ Given the likelihood of that possibility, legalizing physician-assisted suicide is a premature and unacceptable step that harms the public interests.

The specific nature of such harm concerns the inequitable distribution of the benefits and risks associated with legalized physician-assisted suicide. Those who are likely to reap the alleged benefits are the "relatively educated, well-off, politically vocal people...[who] tend to have good health insurance, intact, supportive families, and social skills and know-how to get what they want from an increasingly bureaucratized health care system."⁹⁶ In other words, "Advocates are likely to reap the benefits while avoiding most of the harms. Conversely, the harms of legalization are likely to fall on vulnerable members of our population."⁹⁷

Since vulnerability increases as the availability of personal resources decreases, those who are most vulnerable include the poor, the elderly and the very young, the financially distraught, the homeless, those without a personal support system, the marginalized, the burdensome, the incurable, and very often the terminally ill.⁹⁸ Legalizing physician-assisted suicide poses a special risk for these patients because their need is great and their resources limited, which can unduly influence their decisions for physician-assisted suicide. Given the irreversible consequences of physician-assisted

 $^{^{95}}$ In the context of physician-assisted suicide, the vulnerable also may include women. For example, one study of the practice of physician-assisted suicide in the U.S. shows that 60% of those who obtained such assistance were women. See Emanuel, E. J., et al. (1998), "The Practice of Euthanasia and Physician Assisted Suicide in the United States." *JAMA* 280: 507-513. Given the uneven diagnosis and treatment by physicians of women, it seems reasonable to include women among the vulnerable in the case of physician assisted suicide.

⁹⁶Emanuel, Ezekiel J. (1999), "What Is the Great Benefit of Legalizing Euthanasia or Physician Assisted Suicide?" *Ethics* 109(3), p. 641.

⁹⁷Emanuel (1999), p. 641.

⁹⁸Emanuel (1999), p. 641.

suicide, a reliable method of protecting vulnerable patients from abuse is needed, but not very likely. The troubling question is, "Who will be around to notice when the elderly, poor, crippled, weak, powerless, retarded, depressed, uneducated, demented, or gullible are mercifully released from the lives their doctors, nurses, and next of kin deem no longer worth living?"⁹⁹

Additional evidence that safeguards are ineffective in preventing abuse comes from the Dutch experience with euthanasia and physician-assisted suicide. Although controversial, such data is useful in that the core requirements of commonly recommended guidelines for the U.S., such as those proposed by Brock, and those of the 1986 Dutch "Guidelines on Euthanasia" (codified in 1994) share common ground.¹⁰⁰ According to both sets of guidelines, the decisive motivation for death-dealing action must be that of unbearable suffering; the request must be made by the patient as a voluntary, informed, and enduring choice; and the attending physician must have consulted with another physician who concurs with the prognosis. In addition, both sets of guidelines refer to this kind of death-dealing action as a "last resort" strategy, which means either that no other methods of relief are available, or that the patient has evaluated those alternatives as unacceptable.¹⁰¹ Lastly, both guidelines have strict reporting requirements and regulatory oversight.

⁹⁹Kass, Leon and Lund, Nelson (1996), "Courting Death: Assisted Suicide, Doctors, and the Law." *Commentary* 102 (6), p. 25.

¹⁰⁰See Canady, Charles T. (1998), "Physician-Assisted Suicide and Euthanasia in the Netherlands: A Report to the House Judiciary Subcommittee on the Constitution." *Issues in Law and Medicine* 14(1): 301-324. Cf. Brock (1999), p. 540.

¹⁰¹Jochemsen, Henk, Ph.D. (2001), "Update: The Legalization of Euthanasia in The Netherlands." *Ethics and Medicine* 17(1): 7-12. See Appendix 21.

Cultural differences notwithstanding, these similarities, along with the presumption that physicians in the Netherlands profess a similar commitment to their patients as do physicians in the U.S., the Dutch experience provides important evidence regarding possible outcomes for a similar public policy in this country. One source of such evidence is the extensive survey of euthanasia twice commissioned by the Dutch government in 1990 and again in 1995, both of which were supported by the Royal Dutch Medical Association and conducted with immunity from prosecution for the physician-respondents.¹⁰² These surveys provide data on those "medical decisions concerning the end of life" that involved "the prescription, supply or administration of drugs with the explicit intention of shortening life, including euthanasia at the patient's request, assisted suicide, and life termination without explicit and persistent request."¹⁰³

The results of these two surveys indicate that safeguards in the Dutch system have major flaws in three particular areas: reporting, physician consultation, and the incidence of non-voluntary euthanasia. With respect to the reporting requirement, although reported cases of euthanasia and physician-assisted suicide showed an increase between 1990 and 1995 as compared to the total that should have been reported, approximately 60% of such cases still go unreported each year.¹⁰⁴ The primary reason given by physicians for not reporting is their reluctance to become involved in legal procedures.¹⁰⁵ Physicians avoid regulatory oversight primarily by falsifying death certificates with a

¹⁰²Jochemsen (2001), p. 8.

¹⁰³Cohen-Almagor, Raphael, D.Phil. (2001), "An Outsider's View of Dutch Euthanasia Policy and Practice." *Issues in Law and Medicine* 17(November 1), p. 37.

¹⁰⁴Cuperus-Bosma, Jacqueline M., et al. (1999), "Assessment of physician assisted death by members of the public prosecution in the Netherlands." *Journal of Medical Ethics* 25: 8-15: 18% in 1990 to 41% in 1995.
¹⁰⁵Cuperus-Bosma, et al., (1999), p. 9.

notation indicating a natural cause of death.¹⁰⁶ Since the watchful eye of mandatory reporting to public authorities is a basic method of preventing abuse, such deception and failure to report on the part of physicians suggests that safeguards do not protect against abuse.

The consultation requirement is equally ineffective in preventing abuse. Although physicians consulted a colleague in virtually all reported cases of euthanasia, they did so in only 11% of the unreported cases. In addition, 20% of the unreported cases were conducted without an explicit request from the patient.¹⁰⁷ In addition to a frequent lack of consultation, the quality of the consultation that does occur is less than optimal. For example, although genuine consultation in a case of euthanasia should be "...with a colleague who is an expert in the field and who is able to verify that there are no available alternatives for treatment," accessibility and familiarity dominate the consult process.¹⁰⁸ For example, the attending physician usually selects a consult from among the members of his or her own specialty, rather than a physician-expert in matters related to euthanasia. Once selected, the consultant does not always make a personal visit with the patient, which renders professional assessment in such cases less than reliable. The consult also agrees with the prognosis more often after having been consulted by the attending physician in previous assisted-death cases.¹⁰⁹ Such results indicate a substantial breakdown in safeguards, and perhaps a significant level of abuse in the Dutch system.

¹⁰⁶Wright, Walther (2000), "Historical Analogies, Slippery Slopes, and the Question of Euthanasia." *The Journal of Law, Medicine, and Ethics* 28(2), p. 183.

¹⁰⁷Wright (2000), p. 183. The fact that 20% of unreported cases are not supported by a patient's request suggests a higher level of abuse in physician-assisted suicide than Brock acknowledges.

¹⁰⁸Cohen-Almagor (2001), op. cit., p. 47.

¹⁰⁹Onwuteaka-Philipsen, Bregje D., et al, (1999), "Consultants in Cases of Intended Euthanasia or Assisted Suicide in the Netherlands." *Medical Journal of Australia* 170: 360-363.

Lastly, some of the controversy surrounding the evidence from the Netherlands concerns the reported cases of non-voluntary euthanasia. Dutch investigators cited a decrease in the number of such cases, despite safeguards aimed at preventing the non-consensual termination of patients. Physicians justified their actions primarily with the claim that, in their opinion, the patient's condition was unbearable.¹¹⁰ Some commentators argue, however, that investigators erroneously excluded the number of cases in which physicians gave pain medication with the intent to end the patient's life without patient consent. These commentators claim that including these cases in the count would reveal an increase, rather than a decrease, "in the number of patients killed without having requested it."¹¹¹ Although non-consensual termination is contrary to the law's original intent, such cases often receive medical and judicial approval after the fact.¹¹²

In sum, the Dutch experience with euthanasia and physician-assisted suicide provides at least four lessons regarding a similar social policy in this country:¹¹³

1. Despite the presence of substantial safeguards, physician-assisted suicide functions as an unconstrained private practice largely determined by physicians, which jeopardizes the lives of all patients, not just those who are more vulnerable.

2. The financial and emotional burdens that often accompany dying, coupled with a suggestion by a family member or attending physician that the patient consider assisted-

¹¹⁰Johchemsen (2001), op. cit., p. 8.

¹¹¹Wright (2000), p. 183

¹¹²Canady (1998), p. 301. Cf. Jochemsen, Henk (1998), "Dutch Court Decisions on Nonvoluntary Euthanasia Critically Reviewed." *Issues in Law and Medicine* 13(4): 447-455.

¹¹³Adapted from Jochemsen (2001), pp.11-12.

death as an option, can exert undue pressure on patients to agree to physician-assisted suicide, which imposes a need on such patients to justify their non-agreement.

3. The justification for physician-assisted suicide based on unbearable suffering will widen to include loss of dignity as additional justification for assisted-death. In that case, the existential criteria, if at all discernible, that ultimately must guide physicians in resolving such requests will become even more ambiguous and difficult to apply.¹¹⁴

4. Lastly, euthanasia in the Netherlands has evolved from the legally tolerated practice of physician-assisted death for terminally ill, competent patients who suffer unbearably to the current practice of judicial and medical sanctioning of non-consensual termination of some patients.¹¹⁵ This development suggests that initiating a restricted practice of physician-assisted suicide in the U.S. along the lines that Brock recommends likewise will lead to a broader social acceptance and increased practice of assisted death that ultimately includes non-voluntary, and perhaps involuntary, euthanasia.

c. The virtuous practice of medicine.

Lastly, the third reason that Aquinas offers against suicide is the claim that those who commit suicide assume an authority over life that belongs to God.¹¹⁶ For Aquinas, human life is a gift from God that expresses God's love and goodness such that human existence itself establishes a relationship with God that Aquinas characterizes as a friendship. On this view, life is no ordinary gift between friends that the recipient may refuse or return, even in the face of overwhelming misery. Rather, life is a personal journey with intrinsic value and a spiritual purpose and responsibility originated in the

¹¹⁴Emanuel, Ezekiel J. (1999), p. 630.

¹¹⁵Canady (1998), p. 301.

¹¹⁶Summa Theologiae, II-II, Q. 64, a. 7 in corpus.

physical realm at God's discretion and authority. On a human level, the instinct for selfpreservation demonstrates the intrinsic value of life, while reason itself imposes an obligation of due care towards life as a basic good to be pursued, which precludes the act of suicide. On a spiritual level, Aquinas contends that suicide opposes our ultimate spiritual purpose and friendship with God, a friendship and destiny that require a resolute practice of virtue. Thus, by nature and by virtue, we must reject suicide as a disproportionate response to the miseries of human life.

Aquinas' emphasis on a virtuous regard for life by the individual parallels a traditional view of the physician's role as one that also requires a virtuous regard for the patient's life and health. In a classic sense, virtue is an acquired habit of mind and firm disposition to act with reasonable moderation in the circumstances at hand.¹¹⁷ By implication, the virtuous practice of medicine involves a kind of friendship between patient and physician that entails a benevolent regard for the patient as a person in special need of appropriate medical care.

Physicians determine appropriate medical care in particular cases using a combination of objective factors, including their education, training, clinical experience, and professional instinct, balanced against the relevant scientific and clinical data, personal knowledge of their patients, and what a particular patient thinks is best in the circumstances at hand.¹¹⁸ Thomasma refers to these factors as the medical indicators, which the physician relies on to evaluate a patient's condition and to determine which

¹¹⁷Aristotle, *Nicomachean Ethics*, McKeon, R., Ed. (1941), <u>The Basic Works of Aristotle</u>. New York, Random House, 1094a; 1095a15.

¹¹⁸Tanenbaum, S. J., Ph.D. (1993), "What Physicians Know." NEJM 329(17):1269.

care is appropriate for that particular patient.¹¹⁹ A clinical judgment of this sort generally reflects the clinical protocols suggested by professional standards and practice guidelines relative to the patient's condition.

Such standards are accepted and followed by those who practice within particular areas of medicine because they encapsulate the considered professional opinion about the effectiveness of a specific treatment modality.¹²⁰ The supporting evidence for such treatment includes the scientific and clinical data that suggests a benefit in terms of cure, amelioration, or comfort, as appropriate, with respect to a particular disease or ailment.¹²¹ In other words, aware that patients look to the medical profession with trust and hope for relief of their suffering and pain, physicians agree to provide such relief by rendering appropriate medical care that reflects proven professional opinion.

Although "appropriate medical care" refers to a level of care that is proportionate to the patient's physiological condition, it also must include the patient's preferences, which entails a balance between patient autonomy and physician integrity.¹²² Responsibility for achieving such a balance falls primarily to the physician, who

¹¹⁹For a discussion of these standards, see Thomasma (1986), pp. 157-165.

¹²⁰Although practice standards and guidelines are not without controversy, their popularity continues to increase. The AMA's 1993 Clinical Practice Guidelines Directory listed approximately 700 guidelines, whereas its 1999 Directory listed approximately 2000. In addition to physicians, various groups of medical professionals subscribe to and follow formal and informal practice guidelines, known by a variety of names. By whatever name known, practice guidelines tend to fulfill one of the requirements of evidence based medicine by focusing on utilization of patient services under specific conditions, especially when evaluating alternative treatment modalities and when professional knowledge needs guidance or is uncertain. Overall, designers of practice guidelines intend to promote high quality, appropriate, cost effective health care with reasonably objective criteria. See Hsu, J., M.D., M.B.A. (1998). "Assessing the Appropriateness of Medical Care." *NEJM* 339(20): 1241-1245; Council on Ethical and Judicial Affairs (1996), "Code of Medical Ethics," Principle I, American Medical Association, Chicago, xiv; Field, M. J. and Lohr, K. N. (1992). <u>Guidelines for Clinical Practice: From Development to Use</u>. Washington, DC, National Academy Press, p. 2; Hirshfeld, E.B., JD (1991), "Should Practice Parameters Be the Standard of Care in Malpractice Litigation?" *JAMA* (November 27), p. 2886; Leape, L. L., M.D. (1990), "Practice Guidelines and Standards: An Overview." *Quality Review Bulletin* (February), pp. 42-44; AMA (1999). "Clinical Practice Guidelines Directory."

¹²¹Institute of Medicine (1990), "Clinical Practice Guidelines: Directions for a New Program," p. 38.
¹²²Pellegrino (1983), p. 168.

accomplishes that task by integrating a patient's experience and interpretation of his or her own illness with the prevailing scientific and clinical evidence relevant to that patient's condition. This integration then forms the basis of a recommended plan of treatment. The goal of this process ideally centers on cure, amelioration, adaptation, or enhanced coping for the patient, tempered by the patient's health status and preferences regarding treatment.¹²³ In this way, professional integrity, along with the principles of beneficence and respect for patient autonomy, set the ethical bounds of clinical practice.

Beauchamp and Childress describe this process of integration and planned medical response in terms of basic ethical principles that guide the practice of Western medicine.¹²⁴ In their view, beneficence is the primary ethical principle that guides the practitioner as she earnestly seeks the patient's best interests with medically appropriate care, while respect for autonomy, nonmaleficence, and justice limit the pursuit of that goal.¹²⁵ Because the precise terms of beneficence can be difficult to specify in clinical practice, however, its application in particular cases is subject to interpretation by both physician and patient, limited by the physician's professional and social duties as well as the patient's medical need and personal autonomy.¹²⁶

Although this interpretive process often involves conflict, the ideal end result is a medical response that addresses the patient's specific medical condition in light of her preferences.¹²⁷ In that sense, the most effective plan of response evolves when

¹²³Zaner (1990), p. 306.

¹²⁴Beauchamp and Childress (1994). See also Clouser, K. Danner and Gert, Bernard (1990), "A Critique of Principlism." *The Journal of Medicine and Philosophy* 15: 219-236.

¹²⁵Beauchamp and Childress (1994), p. 273.

¹²⁶Beauchamp and Childress (1994), p. 273.

¹²⁷Beauchamp and Childress (1994), pp. 261; 270.

beneficence and patient autonomy neither compete with each other nor function independently. In an ideal situation, both principles work in conjunction to guide the formation of a mutually acceptable treatment plan that promotes the patient's best interests.¹²⁸ In less than ideal situations, the effort may require a compromise or reconciliation of a conflict between these two principles.

The model of clinical medicine that Beauchamp and Childress describe acknowledges an indispensable role for both patient and physician in the treatment process that is both informed and limited by their respective areas of expertise. By training and experience, the physician's realm of expertise and decision-making authority relates to the scientific and clinical data that support the recommended medical treatment. On the other hand, the "expertise" of patients concerns those "personal normative values that guide their lives and therefore inform their responses to the available medical" options as presented for their consideration.¹²⁹ This distinction in types of expertise both defines and limits the decision-making authority of patient and physician alike. Although patient and physician resolve some aspects of the treatment process on a mutual basis, some decisions relevant to that process belong to the patient, while still others belong to the physician.

As a practical matter, such limits are easily breached. Veatch emphasizes that possibility by observing a common tendency among scientists in policy-making situations to breach the limits of their expertise, which he characterizes as the generalization of

¹²⁸Beauchamp and Childress (1994), pp. 272; 277.

¹²⁹Rubin (1998), pp. 76-77.

expertise.¹³⁰ As Veatch describes it: "Generalization of expertise arises when, consciously or unconsciously, it is assumed that an individual with scientific expertise in a particular area also has expertise in the value judgments necessary to make policy recommendations simply because he has scientific expertise."¹³¹ In his view, such an assumption is unwarranted because it confuses the fact "that expertise in scientific facts of a case also leads to expertise in judgments [of] policy making regarding that case."¹³²

Veatch claims that the role-specific nature of decisions with respect to policymaking belies a common assumption that those with scientific expertise to judge "the way things are" also have expertise to judge "the way things should be." Veatch argues that this assumption confuses a distinction between the technical and evaluative components of decision-making. In his view, whether those with expertise in the technical component also have expertise in the evaluative component is debatable. He concludes that, as long as that point goes unsettled, a generalization of expertise is an unwarranted assumption that can be avoided by adopting a decision model that assigns a separate role to these two components.

Although Veatch's primary concern is with the limits of scientific expertise in the context of policy making, his use of clinical cases in the development of his decision-making model suggests that he views the tendency to generalize expertise as common in the clinical setting as well, especially among physicians.¹³³ As a result, his recommended

¹³⁰Veatch, Robert M. (1973), "The Generalization of Expertise: Scientific Expertise and Value Judgments." *Hastings Center Studies* 1: 29-40.

¹³¹Veatch (1973), p. 29.

¹³²Veatch (1973), p. 31.

¹³³ Veatch, Robert M. (1991), <u>The Patient-Physician Relation: The Patient as Partner, Part 2</u>, Bloomington: Indiana University Press. In the concluding chapter, he makes this point explicit.

decision-making model ought to apply in the clinical setting as well. On this model, the technical component of a treatment decision belongs to the physician, whose technical expertise clearly includes the authority and responsibility to frame a range of medical options for the patient's consideration. On the other hand, the evaluative component belongs to the patient, who alone has authority and responsibility to determine the personal worth of pursuing those options. In short, the technical component of a treatment decision involves matters of scientific and clinical fact and properly belongs to the physician, while the evaluative component involves matters of personal values and preferences and strictly belongs to the patient.

These two different judgments--the physician's clinical judgment and the patient's personal judgment--merge in a plan that both patient and physician agree to follow. Although some patients reject the physician's clinical recommendations for various reasons, consent to treatment usually follows the patient's own determination that the benefits of receiving the recommended care outweigh the associated burdens.¹³⁴ Such consent then enables the practitioner to render the care deemed medically appropriate and reflected in the mutually agreed upon treatment plan.

Veatch's decision model, as applied in the clinical setting, underscores the requirement that physicians must remain neutral with respect to those decisions that belong to the patient. This requirement of neutrality is consistent with the concept of medically appropriate care, even though such care reflects the endorsement of one goal or

¹³⁴Commission (1983), p. 88; Lynn, J., M.D. and Childress, J.F., Ph.D. (1986), "Must Patients Always Be Given Food and Water," in <u>By No Extraordinary Means</u>. Lynn, J., M.D., Bloomington and Indianapolis, Indiana University Press, p. 54.

another.¹³⁵ As Pellegrino claims, the physician's goal is to provide patient care that is both technically right and morally good. Technically right medicine, in his view, conforms to the best available scientific and clinical data gleaned from a variety of sources as adjusted to the particularities of illness for each patient. Morally good medicine, on the other hand, seeks to heal the whole person in a proportionate manner, subject to the best interests of the particular patient. Pellegrino reiterates a required neutrality on the physician's part in relation to those decisions that belong to the patient, which he explains in terms of the objective aspects of medicine that depend on the scientific and clinical data provided by groups of patients as applied to particular patients.

Sulmasy describes the application of such medical data as a science of probability and the art of managing uncertainty.¹³⁶ On this view, the application of scientific and clinical data by the physician in a particular treatment plan is twofold. One is to eliminate or minimize as much as possible the uncertainty in treating a patient's specific medical condition in light of that patient's preferences. The other aim is to maintain a reasonable degree of physician-neutrality with respect to those decisions that belong to the patient. To avoid imposing her own personal values on the patient's decisions, the physician adopts a nonjudgmental attitude toward those decisions that strictly belong to the patient, especially in end-of-life care situations.¹³⁷

From this ideally neutral perspective, physicians summarize their clinical analyses and diagnoses relative to a patient's medical condition as a physiological "quality of life"

¹³⁵Sharpe, Virginia A. (1997), "The Politics, Economics, and Ethics of 'Appropriateness'." *Kennedy Institute of Ethics Journal* 7.4, p. 337.

¹³⁶Sulmasy, Daniel P., O.F.M., M.D. (1997), The Healer's Calling. New York, Paulist Press, p. 31.

¹³⁷Orentlicher, David (1992), "The Illusion of Patient Choice in End-of-Life Decisions." JAMA 267(15), p. 2101.

judgment, which forms the basis of their recommendations to the patient. Such recommendations reflect the physician's combination of relevant medical facts with the patient's expressed interests and values. The physician's professional aim is to benefit the patient's physiological quality of life, while the patient's consent to treatment ideally reflects a similar expectation. The treatment process itself ordinarily begins with the least burdensome course relative to the projected outcome, and unfolds as a contingent blend of burdens and benefits that continuously varies with the medical facts and the patient's preferences. Although the physician's clinical judgment about the patient's physiological quality of life is clearly within the professional purview, the patient alone has the authority and right to determine the worth of living that life.¹³⁸

In this context, a patient's request for assisted suicide seriously challenges the ethical integrity of this treatment decision process. The nature of that challenge is such that an affirmative response by the physician, even when motivated by compassion for the patient, violates the virtuous practice of medicine. The violation occurs in part because the ordinary blend of medical facts and patient preferences that contributes to a determination of appropriate medical care in ordinary cases is lacking in the case of physician-assisted suicide. The blend is lacking because the data indicating death as an effective way to relieve intractable and unbearable suffering, as opposed to physical pain, are missing. Suffering is an existential problem associated with the person, in contrast to physical pain, which is a physiological problem associated with the body.¹³⁹ Since there are no objective existential criteria beyond a patient's report by which to clinically

¹³⁸Angell, Marcia (1988), "Euthanasia." NEJM 319(20): 1348-1350.

¹³⁹Thomasma and Graber (1990), pp. 192-3. Also see Chapter 2 herein.

evaluate the patient's suffering, physician-assisted suicide lacks a technical foundation. Hence, there is no basis for the allegation that physician-assisted suicide is appropriate medical care.

As a result of this technical deficiency, the physician who agrees to assist a patient's suicide must look for other ways to justify their agreement. This attempt begins with the physician's clinical judgment about the patient's poor quality of life, as indicated by the current medical condition and prognosis. Such physicians then combine their clinical judgment with the patient's evaluation of her own life, which theoretically serves as the technical ground for their agreement. In other words, motivated by a patient's request for physician-assisted suicide, physicians who agree to provide such assistance compare their clinical judgments with the patient's view that, due to illness and unbearable suffering, continued living has no value. When the comparison is favorable, such physicians accept the request as valid and agree to provide the assistance.

A less obvious factor in this process is the physician's own subjective evaluation that the patient's life has no value worth preserving or protecting. Without this personal judgment on the part of the physician, agreeing to assist the suicide of a patient whose life the physician views as worth preserving would be either irrational or nothing more than a technical response to the patient's request. Assuming that neither is the case, physicians justify their agreement by necessarily inserting their own evaluation of the patient's life as an additional factor. Physicians are led to take this step because the relevant scientific and clinical data indicating that physician-assisted suicide is appropriate medical care are missing. In taking that step, however, physicians deviate from the established medical, legal, and ethical protocol in regard to rendering

appropriate medical care, which exceeds the limits of their professional expertise and by virtue of which they abandon the virtuous practice of medicine.

The ethical implications of the physician's error go beyond the particular case. In agreeing to assist a patient's suicide, the physician not only implies that suicide itself has a certain medical legitimacy, such agreement elevates the physician's own anecdotal views about the value of continued living for a particular patient to the level of medical principle for all other patients similarly situated. Yet, there is no reason to suppose that a physician's idiosyncratic approach to suffering and death in a particular case, should be the ethical basis of a medical policy that allows killing a person who no longer wants to live. Veatch put the matter well when he argued against the assumption "that expertise in scientific facts of a case also leads to expertise in judgments [of] policy making regarding that case."¹⁴⁰ At bottom, the physician's substitution of her personal views for missing medical facts in attempting to justify her participation in physician-assisted suicide reflects a subjective, selective attitude about whose life is worth living, which is an ungrounded show of expertise regarding patient suffering and perhaps the value of innocent life.

In the past, when physicians have acted on such a misguided principle, individuals and society have endured seriously harmful consequences.¹⁴¹ Despite such consequences, there is evidence that some physicians view their expertise and professional authority as including a right to determine the value of individual human

¹⁴⁰Veatch (1973), p. 31.

¹⁴¹For a discussion of the medical experimentation conducted by Nazi physicians, see Ivy, A. C. (1947), "Nazi War Crimes of a Medical Nature." *Federation Bulletin* 33; for a discussion of the medical experimentation done on African-American men without their knowledge or consent, see Mariner, Wendy K. (1997). "Public Confidence in Public Health." *Public Health Reports* 112(1): 33-37.

life. For an example of such presumption, consider the results of one study in light of the current prohibition on allocating organs based on social criteria. That study indicates that physicians continually show a bias toward lifestyle by routinely not placing recovering alcoholics on the transplant waiting list for livers.¹⁴² According to this study, only 10% of liver transplants went to recovering alcoholics, even though alcoholism is the leading cause of liver failure in the U.S.¹⁴³

Such disparity is even more difficult to explain in light of yet another study that shows the survival rate for alcoholics who received liver transplants within a 25-month period did not differ from that of patients who received liver transplants as treatment for liver disease due to other causes.¹⁴⁴ As a further comparison of these two groups of liver recipients, other studies indicate low alcohol consumption recidivism rates among recovering alcoholics, comparable alcohol consumption rates, and similar psychological complications after transplant.¹⁴⁵ Such evidence suggests that the current disparity in liver allocations between these two groups of patients results from a classic "blame the patient" attitude by some physicians, which unfairly devalues the lives of such patients.¹⁴⁶

¹⁴²Thomas, D. J. (1993), "Organ Transplantation in People with Unhealthy Lifestyles." *AACN* 4(4), pp. 665-668. This may depend on what Thomas means by "recovering". Most centers require some period of proven sobriety, ranging from 6 months to 2 to 3 years.

¹⁴³Van Thiel, David H. (1996), "Liver Transplantation for Alcoholics with Terminal Liver Disease." *Alcohol Health and Research World* 20(4): 261-265.

¹⁴⁴Kumar, S., et al. (1990), "Orthotopic Liver Transplantation for Alcoholic Liver Disease." *Herpatology* 11(2): 159-164.

¹⁴⁵Hewes, Robert L. and Toriello, Paul J. (1998), "Societal Attitudes and Alcohol Dependency: The Impact on Liver Transplantation." *Journal of Rehabilitation* 64(2): 19-23.

¹⁴⁶For a defense of the view that alcoholics should not receive liver transplants, see Moss, Alvin H., M.D. and Siegler, Mark, M.D. (1991). "Should Alcoholics Compete Equally for Liver Transplantation?" *JAMA* 265(10): 1295-1298. For a refutation of this claim, see Caplan, Arthur L. (1994), "Ethics of Casting the First Stone: Personal Responsibility, Rationing, and Transplants." *Alcoholism Clinical and Experimental Research* 18: 219-221.

The fact that physician-assisted suicide requires a similar misplaced evaluation of a patient's life by the physician does not deter some physicians from claiming a legitimate role for themselves in assisting a patient's suicide, which reinforces their patients' expectations in that regard. Consider a *New England Journal of Medicine* article that reported on physicians' attitudes about assisted suicide.¹⁴⁷ According to that report, when asked whether they ought to assist in the suicide of hopelessly ill patients, a group of physicians responded affirmatively by an overwhelming majority of 10 to 2. Other studies indicate that psychiatrists display a similar attitude about assisting a patient's suicide.¹⁴⁸

A counter claim, however, is that physician-assisted suicide is unlike a case of allowing to die, primarily because it puts the physician's agency and judgment center stage. The physician must exercise her unique agency status in deciding to provide (but not to administer) the means to an otherwise preventable death.¹⁴⁹ The patient's act of administering the lethal dose is a proximate cause of death that has no bearing on the moral status of the physician's decision to provide that assistance. Although a patient's request for physician-assisted suicide sets the stage for the physician's agreement, the physician does not merely acquiesce in that request, but makes a separate decision to contribute an original cause of death. That decision can and must be evaluated on its own scientific and ethical merits, apart from the patient's decision. Since physician-assisted suicide fails to meet generally accepted ethical and clinical standards of medical practice,

 ¹⁴⁷Wanzer, S. H. (1989), "The Physician's Responsibility Toward Hopelessly III Patients: A Second Look." *NEJM* 320: 844-849.

¹⁴⁸Ganzini, L., et al. (1996), "Attitudes of Oregon Psychiatrists Toward Physician Assisted Suicide." *American Journal of Psychiatry* 153: 1469-1475.

¹⁴⁹American Medical Association (1997), Opinion 2.21. Although death is inevitable, death in "this" way for "this" patient is not.

it constitutes a professional impediment for the physician that may not be outweighed by a substituted subjective evaluation of the patient's life that has been combined with respect for patient autonomy. To put it another way, securing medical and ethical warrant for assisted suicide is a requirement that the physician may not neglect out of compassion for the patient's suffering.

In response to this claim, proponents of physician-assisted suicide might argue that introducing a different proximate cause of death in the form of assisted suicide should not void a right to assume the risks of a death ultimately caused by a fatal pathological condition. According to such proponents, a lack of technical warrant for physician-assisted suicide that gives rise to the necessity of physicians relying on their own subjective views about death, human suffering, and the worth of continued living for particular patients has no moral bearing on an individual right to choose physicianassisted suicide. Such proponents also might claim that the most effective way of accomplishing this goal is to legalize physician-assisted suicide for competent adult patients only.

3. Brock's objection to the legal ban.

Brock adopts this line of reasoning in advocating the legalization of physicianassisted suicide for competent adult patients who are terminally ill and who choose this method as their preferred mode of dying. In taking this approach, Brock goes against a long-standing medical, legal, and moral tradition that bans the practice of physicianassisted suicide. Nevertheless, his overall aim is to accommodate the moral diversity surrounding this issue by appealing to a fundamental respect for patient autonomy and a right to self-determination.

Brock explains his position in a recent critique of what he characterizes as a fairly common objection to legalizing physician-assisted suicide.¹⁵⁰ The objection that Brock opposes is that physician-assisted suicide should not be legalized because it carries a greater potential for abuse than foregoing life support and other forms of end-of-life care. He provides a three-step analysis that addresses the empirical aspects of this objection.

In the first step, Brock defines abuse as "decisions which conflict with what patients do or would want."¹⁵¹ He then relies on this broad definition in restricting physician-assisted suicide to competent adult patients, in hopes of reducing the level abuse in the case of physician-assisted suicide to a level below that of incompetent patients, whose abuse is due to faulty surrogate decision-making. His second step is to legalize physician-assisted suicide with substantial procedural safeguards aimed at reducing abuse in physician-assisted suicide to a level below that in other kinds of end-of-life care, including pain medication that may hasten death, terminal sedation, "underground" physician-assisted suicide, and especially foregoing life support.¹⁵² In his view, these other practices are, for the most part, legally permissible and also result in the patient's death, but lack the safeguards that he recommends for physician-assisted suicide. The third step is an attempt to allay the fear that legalizing physician-assisted suicide is a slippery-slope strategy that ultimately will lead to involuntary euthanasia.¹⁵³ To address this fear, Brock claims that the same strong public support of autonomy and a right to

¹⁵⁰Brock (1999), pp. 519-547.

¹⁵¹Brock (1999), p. 539.

¹⁵²Brock (1999), p. 540

¹⁵³ Rachels, James (1988), "Euthanasia." <u>Bio-Ethics</u>. Rem B. Edwards and Glenn C. Graber, Harcourt Brace Jovanovich, p. 426. Rachels distinguishes between voluntary, nonvoluntary, and involuntary euthanasia. In his view, voluntary means the patient requests it; nonvoluntary means the patient is unable to make such a request; involuntary means the patient makes an explicit request not to be killed. For a richer typology, see Thomasma and Graber 1990), Chapter 3.

self-determination that support permitting competent adults to choose physician-assisted suicide will act as a formidable barrier to killing patients against their wishes. According to Brock, involuntary euthanasia is just too alien to our cultural mindset to worry about.

4. A rejoinder to Brock's position.

Despite Brock's trust in safeguards, his argument is an empirical claim that does not coincide with the evidence provided by our own criminal justice system and the Dutch experience with euthanasia, as discussed above. In addition, his claim raises both procedural and substantive issues. Procedurally, Brock relies on a broad definition of abuse as the basis for restricting physician-assisted suicide to competent adult patients. Since the definition that he relies on obscures an ordinary distinction between errors in judgment and outright abuse, which is a distinction necessary for settling issues of culpability, his definition calls for more precise language. Contrary to his original claim, however, such a refinement eliminates the empirical basis for excluding incompetent patients from participating in physician-assisted suicide.

In addition, defining abuse more precisely leaves unresolved a substantive issue that Brock's argument raises. Due to his concern for protecting vulnerable persons against abuse (however defined), Brock relies on safeguards as an essential ingredient in the legalization of physician-assisted suicide. Yet, there is strong evidence to suggest that even the most stringent safeguards do not protect some vulnerable persons from abuse. Since vulnerability is a characteristic common to all humans and may be exaggerated at any time, especially during terminal illness, physician-assisted suicide is a social practice that ultimately undermines autonomy for everyone, which puts all of society at risk.

Since abuse in physician-assisted suicide is more likely than Brock recognizes, legalizing that practice is an unsound strategy that perpetuates harm to the common good.

As a result, Brock's reliance on respect for patient autonomy and a right to selfdetermination as the primary means for limiting unwanted extensions of physicianassisted suicide is unwarranted. Contrary to his thesis, physician-assisted suicide inherently serves to undermine patient autonomy in at least two ways. First, it requires that a personal decision to commit suicide must pass medical scrutiny, which exceeds the physician's professional expertise and authority. Second, acceding to such a request changes the locus of responsibility for the decision to commit suicide from the patient to the physician. As a result, Brock's assertion that physician-assisted suicide for competent adult patients will not evolve into a social policy that includes involuntary euthanasia is unsupported.

To explain this objection, Brock's first step is to restrict physician-assisted suicide to competent adults, which has a certain appeal to it, but only because he defines abuse itself very broadly. As it now stands, Brock's definition includes not only deliberate and intentionally faulty decision-making, but also any judgment that conflicts with what a patient would do or want. In this sense, his definition does not distinguish between outright abuse and errors in judgment.

Yet, an ordinary understanding of abuse includes the notion of a deliberate, intentional, or reckless disregard for a patient's preferences. Thus, an ordinary understanding distinguishes abuse itself from errors in judgment, a distinction necessary for deciding issues of culpability. Abuse is clearly a culpable matter, while unavoidable errors in judgment, although regrettable, often eliminate culpability altogether.

Since culpability is a vital component of accountability in cases involving a patient's intentional death, as in physician-assisted suicide, preserving the distinction between "abuse" and "errors in judgment" is necessary. Given the seriousness of the outcome for the patient and the related issue of culpability, a definition of abuse requires more precise language than Brock offers. A more precise definition of abuse would include the notion of a deliberate, intentional, or reckless disregard for what patients would do or want.

Using more precise language to define abuse, however, eliminates the empirical basis for restricting physician-assisted suicide to competent adults. Brock originally based his restriction on the allegation that surrogate decision-making is frequently "abusive" because it frequently conflicts with the incompetent patient's preferences. With a more precise definition of abuse, this becomes an unsupported claim. When surrogate decision-making reflects an "unavoidable faulty prediction" about the incompetent patient's preferences, which might occur frequently, rather than a deliberate, intentional, or reckless disregard of those preferences, the frequency of which is unknown, such a decision is an error in judgment rather than outright abuse. Brock offers no empirical evidence to support the claim that surrogate decision-making represents a deliberate, intentional, or reckless disregard of what incompetent patients would do or want. Hence, there is no longer reason to accept his assertion that end-of-life care involving surrogate decision-making is more abusive than physician-assisted suicide would be, even if restricted to competent adult patients.

In any case, incorporating a more precise definition of abuse into Brock's argument would not address the substance of that argument, which he articulates most clearly in the

second proviso. In that proviso, Brock claims that safeguards will provide a reasonable degree of protection against abuse (however defined) in physician-assisted suicide. This proviso amounts to an empirical claim that does not square with the evidence. Consider the current and unambiguous ethical and legal prohibition of physician-assisted suicide, based in part on the theory that it puts patients at serious risk of abuse from their physicians and is fundamentally opposed to the physician's duty to heal. Despite that prohibition, however, studies show that 12% of physicians, when asked, have acceded to their patient's request for assisted suicide.¹⁵⁴ Other studies suggest a more extensive "underground" practice of physician-assisted suicide. For example, according to a *New England Journal of Medicine* report on physicians' attitudes about assisted suicide, when asked whether they ought to assist in the suicide of hopelessly ill patients, physicians replied in the affirmative by an overwhelming majority.¹⁵⁵ Still other studies indicate that psychiatrists view assisted suicide with a similar attitude.¹⁵⁶

In light of such data, Brock's claim that legalizing physician-assisted suicide with substantial safeguards will provide a reasonable degree of protection against abuse through the force of law is not persuasive. Given that some physicians do not follow the current legal ban on physician-assisted suicide, there is reason to suppose that physicians would place themselves above the law once again, should they see fit, and not follow other safeguards that allow that practice within certain parameters. The dominant role of physicians in healthcare decisions means that the effectiveness of safeguards depends on

¹⁵⁴Back, A.L., et al. (1996), "Physician-assisted Suicide and Euthanasia in Washington State." *JAMA* 275: 919-925; see also Lee, M.A., et al. (1996), "Legalizing Assisted Suicide: Views of Physicians in Oregon." *NEJM* 334: 310-315.
¹⁵⁵Wanzer (1989).

¹⁵⁶Ganzini (1996).

their voluntary compliance. According to the above data, however, if physicians were to find the safeguards regarding the practice of physician-assisted suicide unacceptable, it seems that their compliance is not very likely.¹⁵⁷

The prospect of criminal prosecution for failing to follow specific safeguards is not likely to encourage physician compliance either. Although some physicians ignore the current legal ban on physician-assisted suicide, no physician has ever been successfully prosecuted for participating in an "underground" practice of physicianassisted suicide.¹⁵⁸ Hence, there is reason to suppose that prosecution would not likely follow on the heels of non-compliance with respect to legalized physician-assisted suicide guidelines. At issue is the effectiveness of safeguards to protect patients from abuse. The troubling question is, which physicians won't comply with those safeguards and under what conditions? At worst, will allowing physician-assisted suicide eventually lead to involuntary euthanasia?

Brock attempts to allay such fears with the claim that legalizing physicianassisted suicide on a restricted basis will not lead to involuntary euthanasia. In taking this third and final step in his three-part compromise, he cites strong public support for autonomy and an individual right to self-determination as a formidable bulwark against involuntary euthanasia. Contrary to this assurance, however, is the suggestion that the

¹⁵⁷ Whether the "unlawful" practice of physician-assisted suicide constitutes an acceptable form of civil disobedience is a separate issue to be resolved at another time and place. Although a theoretical foundation for that practice can be found in ancient Greek philosophy, Thoreau provides a modern interpretation in his classic essay, "Civil Disobedience." In his essay, "Love, Law, and Civil Disobedience," Martin Luther King Jr. combines both classical and modern interpretations in specifying some of the defining characteristics of civil disobedience. See Washington, J.M., ed. (1991), <u>Testament of Hope: The Essential Writings and Speeches of Martin Luther King, Jr.</u> San Francisco, Harper Collins. For another justification of that practice, see Rawls, John (1971), <u>A Theory of Justice</u>. Cambridge, Harvard University Press, Chapter 6. Other contributors to the current discourse on civil disobedience can be found in Bedeau, Hugo Adam, ed. (1969), <u>Civil Disobedience: Theory and Practice</u>. Indianapolis, Pegasus.

¹⁵⁸Quill, et al. (1997). Kevorkian was convicted of homicide in the form of active euthanasia, and was not charged with breaking the law as it applies to physician-assisted suicide.

practice of physician-assisted suicide inherently serves to undermine patient autonomy in at least two ways. First, it requires that a personal decision to commit suicide must pass medical scrutiny, which exceeds the physician's expertise. Second, acceding to such a request changes the locus of responsibility for that decision from the patient to the physician.

Regarding the first way, the patient who requests assisted suicide from a physician transfers a personal decision about suicide to the clinical setting. In that setting, the patient's decision must pass medical scrutiny before it can be carried out. Medical scrutiny takes precedence in this situation because the physician must judge not only the patient's competence, as expected, but also the extent and intensity of the patient's suffering to determine whether death is the appropriate remedy. Yet, there are no medically relevant criteria or clinical practice guidelines by which to judge the existential quality of the patient's suffering or the worth of continued living.¹⁵⁹ Suffering is an existential problem associated with the person, in contrast to physical pain, which is a physiological problem associated with the body.¹⁶⁰

Regarding the second way in which physician-assisted suicide undermines patient autonomy, consider the roughly 30,000 suicides each year in the United States carried out without help from others.¹⁶¹ Consider also that physicians do not possess unique knowledge about how to succeed at suicide. Pharmacists and nurses, for example, also have that kind of knowledge. In addition, the Hemlock Society publishes information

¹⁵⁹Farsides, Bobbie and Dunlop, Robert J. (2001), "Is there such a thing as a life not worth living?" *British Medical Journal* 322(16): 1481-1483.

¹⁶⁰Thomasma and Graber (1990), pp. 192-3.

¹⁶¹Lester, David (1996), "Psychological Issues in Euthanasia, Suicide, and Assisted Suicide." *Journal of Social Issues* 52(2), p. 59.

regarding methods that lead to a successful suicide. There are organizations based in other countries that publish similar information. Hence, there is no technical reason for the physician's participation in physician-assisted suicide.¹⁶² As a result, the patient's request for such assistance and the physician's agreement must be explained in terms other than autonomy and self-determination.

One likely explanation is that a patient's request for physician-assisted suicide reflects a desire to change the locus of control and responsibility from the patient to the physician. In other words, "those who commit suicide on their own may have an internal locus of control; [while] those who want others to assist them may want to avoid responsibility for their own death."¹⁶³ Indeed, some studies show that people are "more willing to accept responsibility for good deeds than for bad deeds, for successes rather than failures, and for joint outcomes than for outcomes produced by oneself."¹⁶⁴ Given the social and moral stigma attached to suicide, "some potential suicides may see the participation of others, especially physicians, as making them less morally at fault themselves."¹⁶⁵ The psychological factors that cause such a desire might render the patient's request understandable, but those factors also serve to undermine autonomy and self-determination, which invalidates the physician's agreement to assist the patient's suicide predicated on that basis.

¹⁶² There may be a public policy reason, however, since only physicians can prescribe drugs. Nevertheless, such a reason seems arbitrary, as any competent pharmacist, nurse, or other designated persons with proper training could just as effectively initiate drug prescriptions for the purpose of assisting a suicide.

¹⁶³Lester (1996), p. 59.

¹⁶⁴Lester (1996), p. 59.

¹⁶⁵Lester (1996), p. 59.

For these reasons, Brock has not shown that legalizing physician-assisted suicide on a restricted basis with substantial safeguards renders it less abusive than other forms of end-of-life care, including foregoing life support. Because legalizing physician-assisted suicide perpetuates its inherent potential for abuse, it poses a serious risk for all of society, especially the more vulnerable members. Thus, the ethical and legal ban should continue.

B. Modern proportionality times two: Gury and Knauer.

Like the classical interpretation of proportionality as developed by Aquinas, modern interpretations of that concept also have roots in double effect reasoning, but yield a very different meaning. While the classical meaning concerns the use of reasonable means in a given set of circumstances, modern interpretations of proportionate reason, which are based on the works of Jean Pierre Gury and Peter Knauer, focus on outcomes. Gury's original interpretation stresses a predominance of good in the immediate outcome, while Knauer's later interpretation of that concept entails a maximizing of values or minimizing disvalues in the long run and on the whole.¹⁶⁶

According to Gury, "It is permitted to posit a good or indifferent cause, from which a twofold effect follows, one good, but the other bad, if there is...a proportionately grave reason, the end of the agent is honest, and the good effect follows from that cause, not from a mediating bad one."¹⁶⁷ With a focus on positing causes, Gury places less emphasis on forming the right intention and insists on a proportionately grave reason for

¹⁶⁶Gury, J. P., S. J. (1869), <u>Compendium theologiae moralis</u>. Rome and Turin; see also Knauer, P. (1979), "The Hermeneutical Function of the Principle of Double Effect," in <u>Readings in Moral Theology</u>. C. E. Curran and R. A. McCormick. New York, Paulist Press: 1-39.

¹⁶⁷Boyle, J. M., Jr. (1980), "Toward Understanding the Principle of Double Effect." *Ethics* 90(July): 527-538.

causing an evil effect, unless a particular virtue requires one to refrain from actuating that cause. Later theorists interpret Gury's requirement in terms of weighing or balancing various goods against evils or harms, which is an important shift in meaning and emphasis for the later development of proportionalism as a distinct moral theory.¹⁶⁸ Although Gury reformulates Aquinas' double effect reasoning in terms of positing causes and proportionate reason, he adopts the classical prohibition of evil means, relying on the Pauline principle that it is unlawful to do evil that good may come of it.¹⁶⁹

Knauer provides yet another shift in the meaning and scope of proportionate reason. Although he follows Gury by focusing on a net balance of good in the outcome as justification for allowing evil to occur, Knauer adds the requirement that such effects must be measured in the long run and on the whole, which is to measure an act in its fullest sense.¹⁷⁰ In Knauer's view, an act that does not produce a net balance of good in its fullest sense is counterproductive and, as he says, ultimately self-contradictory. Because such acts oppose their own end, as excessive whaling ultimately depletes the supply of whales, they are morally impermissible. Knauer claims that such acts are at bottom exploitative, and in his view, exploitation is intrinsically evil.¹⁷¹

Knauer further modifies Gury's line of reasoning with the claim that every act has evil consequences insofar as choosing a value unavoidably precludes choosing another value, and value foregone is a premoral evil in the sense of deprivation.¹⁷² In other

¹⁶⁸Kaczor (1998), pp. 300-01.

^{169&}lt;sub>Romans</sub> 3:8

¹⁷⁰Knauer, P. (1988), "A Good End Does Not Justify an Evil Means--Even in a Teleological Ethics," in <u>Personalist</u> <u>Morals</u>. J. A. Selling. Leuven, Leuven University Press: pp. 71-85.

¹⁷¹Knauer (1988), p. 79

¹⁷²Kaczor (1998), p. 303.

words, the pursuit of good always extracts a certain price, if only in terms of fatigue, which is "opportunity costs" in the jargon of an economist. Justification for causing such deprivation depends on whether there is a commensurate reason as specified by the sum total of an act in its fullest sense. For this reason, Knauer considers this sort of calculus the fundamental principle of all morality. As he puts it, "Today, the principle of double effect is most briefly formulated as follows: One may permit the evil effect of this act only if this is not intended in itself but is indirect and justified by a commensurate reason."¹⁷³

On Knauer's account, "commensurate reason" amounts to maximizing values or minimizing disvalues in the long run and on the whole, which is a thesis that McCormick summarizes with the following criteria:

- 1. There is a value at stake at least equal to the value sacrificed.
- 2. There is no less harmful way of protecting the value here and now.
- 3. The manner of its protection here and now will not undermine that value in the long run.¹⁷⁴

These criteria suggest that Knauer's interpretation of proportionate reason is a matter of weighing different values against each other or against harms.¹⁷⁵ As proponents of utilitarianism have long known, establishing a predominance of good in any sense, either in the immediate outcome or in the long run and on the whole, can prove difficult in

¹⁷³Knauer (1979), pp. 1-39.

¹⁷⁴McCormick, Richard A., S.J. (1981), "Notes on Moral Theology." *Theological Studies* 42. There is no reason to suppose that McCormick intended "value" in a singular sense.

¹⁷⁵See Grisez, Germain (1970), "Towards a Consistent Natural Law Ethics of Killing." *American Journal of Jurisprudence* 15: 64-96. Grisez discusses the incommensurability of basic goods. For a list of such goods, see Finnis, John (1980), <u>Natural Law and Natural Rights</u>. Oxford, Clarendon Press. Cf. Frankena, William (1963), <u>Ethics</u>. Englewood Cliffs, New Jersey, Prentice-Hall, Chapter 5.

practice.¹⁷⁶ Since tragic choices are inevitable in the real world, such criticisms perhaps highlight the difficulty rather than the impossibility of doing so.

Knauer also reintroduces the familiar "intention" language found in the Thomistic version of double effect reasoning, which compensates for Gury's neglect in this regard, but distinguishes between psychological and moral intention. For Knauer, psychological intention pertains to the practical aspects of an act, while moral intention corresponds to the presence or absence of commensurate reason.¹⁷⁷ An agent might psychologically intend an evil cause or means, as long as there is a commensurate reason for doing so. For example, a surgeon who amputates a gangrenous limb psychologically understands and accepts that the patient will no longer have use of the limb, but morally intends to preserve that patient's life. In such cases, preserving life is a commensurate reason that justifies the premoral harm of amputation. For Knauer, the moral question is whether an act having bad effects is permitted. In his view, the answer depends entirely on whether there is commensurate reason for allowing that harm.¹⁷⁸

A primary difference between these three versions concerns the way in which each handles proportionate reason. Classical proportionality concerns the relationship between the means and the end, and as an aspect of double effect reasoning does not entail that the good outweigh the bad. Indeed, although there must be a substantial reason for allowing bad effects, such effects can outweigh the good.¹⁷⁹ To put it another way, Thomistic proportionalism functions on the premise that an act of a certain kind is

¹⁷⁶Johnstone (1985), p. 234.

¹⁷⁷Kaczor (1998), p. 303.

¹⁷⁸Knauer (1979), p. 20.

¹⁷⁹Kaczor (1998), p. 311.

always right (or wrong), while the Gury-Knauer versions focus on the consequences that one should bring about, namely, a predominance of good in the outcome.¹⁸⁰ In this respect, Gury looks to the immediate outcome, while Knauer requires a choice of the greater good by evaluating consequences in the long run and on the whole. For Knauer, maximizing the good is the only fundamental moral principle.

1. Gury and the immediate effects of assisted suicide.

These differences notwithstanding, physician-assisted suicide fares no better under a modern interpretation of proportionality than on a classical interpretation of that principle. Consider first Gury's account of proportionality as a predominance of good in the immediate outcome, excluding the use of evil means.¹⁸¹ Whether physician-assisted suicide has the desired effect must be judged from two different perspectives. From the patient's perspective, the desired effect must be that death brings an immediate relief of suffering, which must outweigh both the burdens of continued existence and the negative effects, if any, of causing death. Since possibly only the patient knows whether a physician-caused death has the necessary desired effect, the physician is unable to verify the relevant effects of causing the patient's death. Thus, the patient's perspective has no bearing on whether physician-assisted suicide is a proportionate medical response.

From the physician's perspective, physician-assisted suicide clearly fails to meet Gury's requirement regarding the immediate net effects of an act. The immediate effects of death are only partially known by the physician and chiefly concern the neurophysiological status of the patient's corpse. The remaining effects concern the

¹⁸⁰Broad, C. D. (1930), <u>Five Types of Ethical Theory</u>. London, Routledge and Kegan Paul, pp. 206-07.
¹⁸¹Boyle (1980), p. 528.

patient's suffering and are unknown by the physician. Hence, the physician is unable to evaluate physician-assisted suicide in a technical sense. Since physician-assisted suicide has no technical basis, it cannot qualify as a proportionate medical response. As a result, according to Gury's account of proportionality, the physician's agreement to assist the patient's suicide as a way to relieve the patient's suffering is technically and thus morally unfounded.

Physician-assisted suicide also fails to meet Gury's criterion that the end cannot justify the means. Since physician-assisted suicide involves the physician in killing the patient, who is innocent in any morally relevant sense, the physician's agreement to assist the patient's suicide involves the physician in means traditionally viewed as morally unacceptable. As a result, the burden of proof rests with those who would take exception to the widely held view that killing innocent persons is morally unacceptable social policy, especially when carried out by private citizens, such as physicians.

Proponents of physician-assisted suicide might counter with the suggestion that physician-assisted suicide can be viewed as a form of experimental medicine or research involving human subjects.¹⁸² In the case of medical experimentation, risks to the human subjects are frequently unforeseen but accepted by the participant, while all benefits might accrue to others who do not participate in the experiment.¹⁸³ The proponents of physician-assisted suicide might claim that the same condition applies in a case of physician-assisted suicide. The patient who requests physician-assisted suicide could

¹⁸²Still others suggest that, if done for altruistic reasons, physician-assisted suicide might constitute a form of martyrdom. See Thomasma, D.C. (1998), "Assisted Death and Martyrdom." *Christian Bioethics* 4(2): 122-142. Chapter 4 offers an analysis of Thomasma's claim.

¹⁸³Department of Health and Human Services (1991), CFR, Title 45, Part 46, "Protection of Human Subjects." Washington: GPO.

voluntarily accept the risks of that procedure, unforeseen or not, and can do so despite the fact that others are the primary recipients of the associated benefits. As a case in point, terminally ill patients might request physician-assisted suicide, based on the belief that their loved ones will be relieved of the financial and emotional burdens associated with their prolonged terminal illness.¹⁸⁴

Those who oppose this sort of altruistic reasoning, based on the suggestion that physician-assisted suicide is analogous to experimental medicine, might claim that this comparison fails for the following two reasons. First, the ethics of research involving human subjects is such that current law does not release investigators from liability for negligence, despite the participant's voluntary assumption of risks.¹⁸⁵ In the case of physician-assisted suicide, however, such a proviso may have little force because a question of negligence is not likely to arise. Since family members are the most likely source of charges of neglect, such a charge is not likely to arise in the case of physician-assisted suicide that centers primarily on relieving their suffering, and secondarily on relieving the patient's suffering. When the family members so burdened consent to the patient's choice for physician-assisted suicide so as to bring them relief, and they indeed experience such relief after the patient's death, they are not likely to bring charges of neglect against the physician who helped bring about their relief. Such a charge also seems less likely when patients seek physician-assisted suicide to help their families.

The second point concerns the fact that researchers not only expect medical experimentation to yield benefits, which partly justifies the experiment itself, they also

¹⁸⁴Hardwig, John (1997), "Is There a Duty to Die?" See Chapter 4 for an analysis of Hardwig's claim.
¹⁸⁵Department of Health and Human Services (1991).

expect to measure those benefits, if not in conjunction with the current experiment, then at a subsequent point when sufficient evidence from additional experimentation accumulates. In the case of physician-assisted suicide, however, since evidence concerning the medical benefits of death in terms of relief for patient suffering does not accumulate on this side of death, so to speak, such benefits remain a matter of personal conjecture, or theological and philosophical speculation rather than clinical fact. Because scientific measurement of how well physician-assisted suicide relieves patient suffering is thus far not possible, the underlying rationale for experimental medicine itself, namely, a measurable enhancement of human life, is absent. Proponents of physician-assisted suicide substitute that missing rationale with a view of suffering as a contingent, uncharacteristic feature of human life to be eliminated at all costs, including the elimination of the sufferer in a painless manner.¹⁸⁶ Such a claim seems as extreme as the view that the sufferer's life should be preserved at all costs, especially when doing so allows healthcare providers and caregivers opportunity to indulge their concern for the one who suffers. Given the difference in the underlying rationale for physician-assisted suicide as compared to experimental medicine, supporters of physician-assisted suicide will have to look elsewhere for ethical support.

2. Knauer and the long-term effects of assisted suicide.

Physician-assisted suicide fares no better under Knauer's theory of proportionality. Knauer modifies Gury's requirement that there must be a "predominance"

¹⁸⁶Hannay, A. (1980), "Propositions Toward a Humanist Consensus in Ethics." <u>Humanist Ethics</u>. M. B. Storer, ed. Buffalo, Prometheus Books, p. 186-7. Hannay does not make a claim about eliminating the sufferer by means of physician-assisted suicide. Instead, he claims that eliminating the sufferer so as to eliminate suffering is a glorification of the human species that fails to appreciate the primary source of moral competence, namely, knowledge of human and other suffering. In his view, given the universality of suffering, such a notion in principle could justify eliminating the entire human race as a moral act.

of good in the immediate outcome" by adding the notion that a commensurate reason must be measured in the long run and on the whole, which is to measure an act in its fullest sense. Knauer's insistence on this measure derives from his claim that every act seeks a value that unavoidably involves the foregoing of some other value. While economists refer to such trade-offs as opportunity costs, Knauer maintains that this sacrifice in values constitutes a premoral evil to the extent that double effect reasoning governs every act.¹⁸⁷ For this reason, Knauer rules out all acts that ultimately produce a net gain in evil, because such acts are counterproductive and self-contradictory in the long run and on the whole. By the same token, he also insists on the less onerous method of pursuit. By placing double effect reasoning at the heart of moral analysis, Knauer provides the foundation for the moral theory now known as proportionalism.¹⁸⁸

On Knauer's account, physician-assisted suicide fails as a proportionate medical response for two reasons. First, the practice itself undermines individual autonomy and self-determination in the long run due to its potential for abuse, and on the whole, because it yields an injustice for those with fewer resources. Second, there is a less onerous method of relief available, namely, acceptance.

Regarding the first reason, Knauer claims that the net effect of pursuing certain values must be measured in the long run and on the whole. According to these criteria, the realization of certain values ultimately must not undermine or nullify those or other equally important values. In the case of physician-assisted suicide, as shown earlier in the objection to Brock's argument, the likely failure of safeguards to protect the

¹⁸⁷Kaczor (1998), p. 303.

¹⁸⁸Kaczor, p. 302.

autonomy and right to self-determination of vulnerable persons ultimately applies to all others as well. Because terminal illness often intensifies one's vulnerability, the potential for abuse in the practice of physician-assisted suicide exists for all persons. Hence, allowing that practice undermines autonomy and self-determination in the long run.

On the whole, aside from a question of abuse, the practice of physician-assisted suicide raises an issue of justice for those with fewer resources.¹⁸⁹ To explain, like Brock, some proponents of physician-assisted suicide argue that one way to prevent an injustice stemming from a premature choice is to establish that practice as an option of last resort.¹⁹⁰ Such a requirement usually means that the patient is terminally ill,¹⁹¹ and that certain prior steps have been taken, including "adequate screening for depression, full exploration of alternatives," and that "appropriate medical and social supports" have been exhausted.¹⁹² On this view, it would be an injustice for some persons to choose physician-assisted suicide and thereby forfeit a portion of their lives that they otherwise would have chosen to live out had other available care existed. A last-resort strategy seeks to avoid such a possibility by ensuring that a patient's choice is free from physician bias regarding when and for whom the option is appropriate.¹⁹³ It also helps ensure that a patient's choice is free from erroneous assumptions about prognosis and the effects of

¹⁸⁹ Coleman, Carl H. (2002), "The 'Disparate Impact' Argument Reconsidered: Making Room for Justice in the Assisted Suicide Debate." *Journal of Law, Medicine and Ethics* 30, p. 19.

¹⁹⁰ See Brock (1999), *supra* note 77.

¹⁹¹ See Gunderson, Martin and Mayo, David J. (2000), "Restricting Physician-assisted Death to the Terminally III", *Hastings Center Report* (November-December), pp. 17-23.

¹⁹² Coleman (2002), p. 19. Coleman argues that the principle of justice requires comparable responses by physicians to patients' requests for assisted suicide, "including adequate screening for depression, full exploration of alternatives, and appropriate medical and social supports."

¹⁹³ New York State Task Force (1994), "When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context." New York. New York State Task Force on Life and the Law, p. 125. According to the Task Force, acknowledging physician bias "does not reflect the view that physicians are more prejudiced or influenced...than the rest of society—only that they are not exempt from the prejudices manifest in other areas of our collective life."

treatment.¹⁹⁴ In theory, the end result is that a patient's choice of physician-assisted suicide more likely reflects a "voluntary, informed, and settled decision to die."¹⁹⁵

In practice, however, such a policy cannot be applied fairly. All competent adults who would choose physician-assisted suicide simply do not have an equal amount of resources to purchase the medical care available or to establish and maintain the kind of relationship with a physician that ought to precede and support a voluntary and informed choice for assisted suicide.¹⁹⁶ For those with adequate resources, "last resort" truly means "after all that can be done technologically has been done," while for those with fewer resources, it means "after all that can be afforded has been bought." Those falling into this category include the poor, the underinsured, the uninsured, and many of the elderly. Their lack of resources, which puts them into this category, is largely due to socioeconomic factors not entirely within their control. Yet, society is unwilling to mitigate the effects of such a disparity by ensuring the same level of healthcare for all persons.

As a result, physician-assisted suicide may become an option of last resort for the disadvantaged sooner than for the privileged who can afford the available healthcare to alleviate their medical condition. On the flip side, physicians, who are under various pressures from third-party payers and others, may too readily accept such requests because their disadvantaged patients do not have the resources to explore alternatives or to undergo the appropriate psychological evaluation that might suggest another

¹⁹⁴ Arras, John D. (1997), "Physician-assisted Suicide: A Tragic View", *Journal of Contemporary Health Law and Policy* 13, pp. 373; 380.

¹⁹⁵ Coleman (2002), p. 18.

¹⁹⁶ Such consequences for vulnerable members of society in part prompted the New York State Task Force on Life and the Law, which studied the question of deliberately hastening death, to reject a right to physician-assisted suicide, although it supported a right to refuse life-sustaining treatment. See New York State Task Force, pp. 125;130-31.

approach.¹⁹⁷ Such consequences cause serious doubt about a genuine exercise of autonomy and self-determination, to the extent that allowing physician-assisted suicide constitutes an injustice for those competent adults with fewer resources.¹⁹⁸

The autonomy of patients who request assisted suicide may be compromised by psychological factors as well, which ultimately raises a question of competency. Although a request for assisted suicide is not necessarily irrational, the request can be motivated by factors other than desire for death. Factors such as "grief, depression, anxiety, organic mental disorders, and family and personality issues have all been implicated in patients' decision to hasten death," whether through the cessation of life-sustaining treatment or through physician-assisted suicide.¹⁹⁹ There is evidence, however, showing a direct link between requests for physician-assisted suicide and clinical depression.²⁰⁰ For example, a recent study shows that "Desire for hastened death among terminally ill cancer patients is not uncommon. Depression and hopelessness are the strongest predictors of desire for hastened death in this population and provide independent and unique contributions."²⁰¹

Based on such evidence, the New York Task Force claimed that, "The majority of individuals who kill themselves suffer from depression that is treatable with appropriate

¹⁹⁷ Coleman (2002), p. 19.

¹⁹⁸ The fact that similar inequities exist in some cases of withdrawing and withholding treatment is insufficient reason to establish another social policy that is likewise flawed, especially when such a policy constitutes a radical departure from the traditional practice of medicine, structure of the patient/physician relationship, and morally acceptable alternative means of caring for patients who are terminally ill.

¹⁹⁹ Rosenblatt, Laurie and Block, Susan D. (2001), "Depression, decision making, and the cessation of life-sustaining treatment," *Western Journal of Medicine* 175, p. 320.

²⁰⁰ DiLoreto, Stacy (2000), "The complexities of assisted suicide," Patient Care (November 30), p. 70

²⁰¹ Breithart, William, M.D., et al (2000), "Depression, Hopelessness, and Desire for Hastened Death in Terminally III Patients with Cancer," *JAMA* 284(22), p. 2907.

clinical care.²⁰² Yet, "too often, clinicians fail to detect treatable depression or other psychiatric illness, assuming that the depression is expected or beyond treatment.²⁰³ This professional failure can be explained in part by the fact that "most doctors are not adequately trained to diagnose depression especially in complex cases such as patients who are terminally ill.²⁰⁴ Such consequences led the American Medical Association to state that a physician's initial response to a request for assisted-suicide, regardless of the physician's willingness to comply, must be to explore the meaning behind the request.²⁰⁵

Part of that exploration must include evaluating the patient's competency. Indeed, evaluating the competency of patients who request physician-assisted suicide is often proposed as an important safeguard against abuse.²⁰⁶ Such evaluations not only help determine "whether the request is competent and voluntary or the result of distorted judgment from a mental disorder such as depression."²⁰⁷ Assessing the competency of patients who request assisted suicide is an indispensable preliminary step to interventions aimed at treating depression, hopelessness, and the inadequacies of social support systems, which are "important aspects of adequate palliative care, particularly as it relates to desire for hastened death."²⁰⁸

²⁰² New York State Task Force (1994), p. 126.

²⁰³ New York State Task Force (1994), p. 126.

²⁰⁴ New York State Task Force (1994), p. 127.

²⁰⁵ Council on Ethical and Judicial Affairs (1994), "Code of Medical Ethics," Report 59, American Medical Association, Chicago.

²⁰⁶ For a discussion of the major mental health issues related to hastened death, including physician-assisted suicide, see Holdwick, Daniel J., Jr. (2000), "A Primer on Rational Suicide and Other Forms of Hastened Death," *The Counseling Psychologist* 28(4), pp. 511-539.

²⁰⁷ See Quill, T.E., Cassel, C.K., and Meier D.E. (1992), "Care of the hopelessly ill: proposed clinical criteria for physician-assisted suicide," *NEJM* 327, pp. 1380-1384.

²⁰⁸ Breithart, et al (2000), p. 2907.

Although evaluating a patient's desire for death might ensure that "only competent patients have access to assisted suicide," the guidelines and standards to aid in such evaluations have not been developed by mental health experts, especially psychiatrists, who are usually identified as the best qualified to protect the autonomy of such patients.²⁰⁹ The absence of standardized measures in this area might explain why a majority of psychiatrists in one survey reported a lack of professional confidence "to determine in the context of a single consultation if a mental disorder or depression impaired the judgment of a patient requesting assisted suicide."²¹⁰ Such results also might reflect the fact that psychiatrists ordinarily do not work with seriously ill and dying patients in hospitals, nursing homes, or hospice settings.²¹¹

On the other hand, a group of forensic psychiatrists, who frequently evaluate competency of individuals in the judicial process, reported in another survey that the evaluation process they recommended to assess the competency of patients requesting assisted suicide might be burdensome for terminally ill patients.²¹² Without some form of standardized measures, however, there is no benchmark against which to assess the validity of particular evaluations of patients who request assisted suicide. In that case, the claim that physician-assisted suicide in the long run and on the whole promotes autonomy and self-determination is unsubstantiated.²¹³

²⁰⁹ Ganzini, Linda, M.D., et al, (2000), "Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists", *American Journal of Psychiatry* 157(4), p. 595.

²¹⁰ Ganzini (2000), p. 595; See also Sullivan, Mark D., et al, (1998), "Should Psychiatrists Serve as Gatekeepers for Physician-assisted Suicide?" *Hastings Center Report* (July-August), p. 343.

²¹¹ Sullivan (1998), p. 344.

²¹² Ganzini (2000), p. 595.

²¹³ For one measuring device, see Breitbart W., Rosenfeld, B.D., and Passik, S.D. (1996), "Interest in Physicianassisted Suicide Among Ambulatory HIV-infected Patients," *American Journal of Psychiatry* 153:238-42. The authors developed a self-report true/false questionnaire to assess medically ill patients' desire for hastened death. For

Turning now to the second reason that Knauer's interpretation of proportionality fails to support physician-assisted suicide, he claims that there must be no less harmful way of securing the value sought. In the case of physician-assisted suicide, however, where the value sought is relief of suffering, a less onerous method of securing that value is through acceptance. Although difficult--if not impossible--for some patients to achieve, acceptance is more likely when treating the patient as a whole person, rather than simply as a patient who is terminally ill. This conclusion relies on a view of acceptance that Kubler-Ross and others advocate in their treatment of the terminally ill.

In the clinical setting, acceptance should not be left solely to the patient. It can be promoted by the physician and other caregivers who can inspire the patient with hope for the "good that is yet to be...even when there is no remedy for the sickness."²¹⁴ The caregiver, especially the attending physician, fosters a sense of hope "by a spoken or unspoken promise that this man or woman who puts such trust in [the physician] will not be abandoned to die alone; that the meaning of the life soon to end will be perpetuated within our memories and our actions; and that insofar as this can be managed, no suffering will disturb the tranquility of the final days."²¹⁵ Although this last step is not always possible, to be sure, "The methods of palliative care, or comfort care, have in the past few decades reached a level of effectiveness such that suffering thought at first to be

preliminary results of using this questionnaire, see Rosenfeld, Barry, Ph.D., et al (1999), "Measuring Desire for Death Among Patients With HIV/AIDS: The Schedule of Attitudes Toward Hastened Death," *American Journal of Psychiatry* 156:94-100.

²¹⁴ Nuland, Sherwin B. (2002), "The Principle of Hope," *The Human Life Review* (Summer), p. 46. See also Foley, Kathleen and Hendin, Herbert, eds. (2002), <u>The Case Against Assisted Suicide: For the Right to End-of-Life Care</u>, Johns Hopkins University Press.

²¹⁵ Nuland (2002), p. 46.

intractable can almost always be relieved."²¹⁶ The genuinely compassionate caregiver will undertake the effort.

IV. The heart-wrenching cases and assisted suicide.

After every available treatment has been carried out, however, suppose some terminally ill patients cannot achieve acceptance, their pain management is no longer effective, and their suffering remains unbearable. Although perhaps rare, these are the "hard cases" that raise a question of whether such patients have a right to die by some active means that hastens death. This question compels a reexamination of the absolute rule against both physician-assisted suicide and voluntary active euthanasia. Many proponents would argue that, in banning both options, society forces such patients to live in "irremediably distressing and degrading conditions."²¹⁷

Proponents want to avoid such an outcome by allowing physician-assisted suicide and voluntary active euthanasia in "hard cases" where nothing else medically can be done to alleviate the patient's suffering. Likewise, some opponents of legalizing either practice still make room for such cases in their opposition. For example, John Arras opposes the legalization of both physician-assisted suicide and voluntary active euthanasia, but would permit the covert practice of both in exceptional, rare cases. Arras refers to such cases as tragic, and claims that "compassionate physicians…like Dr. Timothy Quill, will ultimately be willing, albeit in fear and trembling, to 'take small risks for people [they] really know and care about" and accede to requests for assisted

²¹⁶ Nuland (2002), p. 46.

²¹⁷ Lindsay, R.A. (2002), "Should We Impose Quotas? Evaluating the 'Disparate Impact' Argument Against Legalization of Assisted Suicide," *Journal of Law, Medicine & Ethics* 30 (1), p. 10.

suicide.²¹⁸ Arras' willingness to accommodate hard cases relies on the assumption that "...whatever choice we make, whether we opt for a reaffirmation of the current legal restraints or for a policy of legitimation and regulation, there are bound to be victims."²¹⁹ Although a covert policy would not be subject to regulation aimed at preventing abuse, Arras claims that the force of law and the threat of licensure revocation would "serve, for the majority of physicians, as powerful disincentives to abuse the system."²²⁰

Ezekiel Emanuel is another opponent of legalization that holds a similar view about permitting physician-assisted suicide on a covert, rare-case basis. Emanuel argues that society ought to continue the legal ban on physician-assisted suicide, but claims that "in exceptional cases [such] interventions are appropriate, as acts of desperation when all other elements of treatment—all medications, surgical procedures, psychotherapy, spiritual care, and so on—have been tried."²²¹ In his attempt to modify an absolute ban on physician-assisted suicide, however, Emanuel does not consider the current lack of psychiatric guidelines or standards by which to evaluate a request for assisted suicide.²²²

Howard Brody also opposes legalization of physician-assisted suicide, but would permit that practice in cases where all medical interventions have failed to achieve a good death and the patient makes a voluntary request for such assistance. Brody, however, advocates a *post facto* approach similar to the course once followed by the Dutch. He proposes that, when the physician who carries out the patient's request has been charged

²¹⁸ Arras (1997), p. 389; see also Quill, Timothy (1991), "Death and Dignity: A Case of Individual Decision-making", *New England Journal of Medicine* (691), p. 694.

²¹⁹ Arras (1997), p. 387.

²²⁰ Arras (1997) p. 388.

²²¹ Emanuel, E. (1997), "Whose Right to Die?" *Atlantic Monthly*, March, p. 79. He does, however, consider the situation where patients do not have the necessary resources to opt for other methods of treatment. See *supra*, Emanuel (1999). "What Is the Great Benefit of Legalizing Euthanasia or Physician Assisted Suicide?"
²²² Ganzini (2000), p. 595.

with criminal homicide or assisting in a suicide, the physician be allowed to invoke a legal defense that he refers to as a "compassionate response to a medical failure."²²³ In explicating the nature of that defense, Brody describes an elaborate and open review process by which the morality (and legality) of providing assisted suicide can be determined on the merits of each case.²²⁴ With this strategy, Brody wants the legal ban on assisted suicide continued, while allowing that practice as an option for patients no longer willing to endure their condition in the face of medical futility.

While these and similar proposals appear to offer a compromise position between extremes, they are problematic in at least three ways. First, as discussed above, such approaches fail to account for the complex nature of suicide itself, "particularly among patients confronting a terminal illness, which makes interpreting and responding appropriately to requests for assisted suicide far more difficult than is often assumed."²²⁵ According to some specialists in end-of-life care, thoughts of suicide are common among the terminally ill. Rather than reflecting a genuine desire to die, however, such requests are generally symptoms of undiagnosed clinical depression, unexplored fears of dying or of becoming a burden, or improperly managed physical pain.²²⁶

Without exploring and treating the underlying issues that cast doubt on the voluntary nature of such requests, the danger of a social policy that allows physician-assisted suicide and voluntary active euthanasia, even in rare cases, is that a patient's

²²³ Brody, Howard (1992), "Assisted Death – A Compassionate Response to a Medical Failure," *NEJM* (327), p.1384.

²²⁴ Brody (1992), p. 1387.

²²⁵ Coleman (2002), p. 19.

²²⁶ Muskin, P. R. (1998), "The Request to Die: Role for a Psychodynamic Perspective on Physician-Assisted Suicide." *JAMA* 279, pp. 323-28. See also Foot, Phillipa (1977), "Euthanasia", *Philosophy and Public Affairs* 85.

request may be accepted at face value. Legitimizing either practice would encourage acceptance on that level.²²⁷ After all, once physician-assisted suicide and voluntary active euthanasia become acceptable medical practice, physicians would have less incentive to explore the reasons behind a request for such assistance, especially when the attending physician has already formed a judgment that such a choice is appropriate. The consequences of that possibility, however remote, are unacceptable, especially when there are less drastic ways of addressing the patient's needs.²²⁸ Without further research and clinical training preparing physicians to confront and respond in a professionally competent manner to the underlying issues that give rise to such requests, allowing either practice even in rare cases is an inadequate and premature medical response.

Second, advocates of the "hard case" rule presume and highlight the rarity of such cases as reason to allow physician-assisted suicide and voluntary active euthanasia, but reality would suggest otherwise. For, it is difficult to control the expansion of a social policy that allows exceptions to an absolute ban on either practice. Other "hard cases" are "bound to emerge on the other side of the line and with it the pressure to extend the outer boundaries of the exceptions to embrace these new 'hard' cases."²²⁹ Although such expansion may not be unlimited, setting out the criteria that identifies a genuine "hard case" could be an endlessly flexible and downright illusive undertaking. Consequently, the irreversible and radical consequences for the patient render the "hard case" scenario an inappropriate basis of a social policy that allows either practice.

²²⁷ Keenan, James F. (1998), "The Case for Physician-Assisted Suicide?," *America* (November), p. 17.
²²⁸ Coleman (2002), p. 19.

²²⁹ Kamisar, Yale (1998), "Physician-Assisted Suicide: The Problems Presented by the Compelling, Heartwrenching Case." *Journal of Criminal Law and Criminology* 88(3), p. 1145.

Third, because rare and exceptional cases by their nature are not representative, the class of persons who qualify under the exception must be carefully identified. This entails the adoption of criteria and guidelines to carve out the exceptions and the establishment of safeguards to protect against abuse. That very process would transform physician-assisted suicide and voluntary active euthanasia into social policy, subject to the same considerations discussed above. Those considerations yield the conclusion that "hard cases" cannot transform either physician-assisted suicide or voluntary active euthanasia into acceptable medical practice.

V. Conclusion.

The claim that physician-assisted suicide is a disproportionate and unacceptable medical response to patient suffering might seem counterintuitive. Given the nature of suffering as an unrelenting and oppressive tension between hope and despair, the psychology of its relief seems obvious. On this view of suffering, "if you are hopeful that some end can be achieved, then you normally ought also to be afraid when its accomplishment is threatened, relieved when the threat does not materialize, angry at those who intentionally obstruct progress toward it, and satisfied when you finally achieve it (or disappointed when you fail)."²³⁰ On this approach, the principle of beneficence, or acting in the patient's best interests, might be construed as doing what the patient wants, given her autonomy and a preemptive right to self-determination.

Although the traditional interpretation of beneficence has meant acting in the patient's best interests, historically, that principle has given preemptive status more to the

²³⁰Helm, B. (2000). "Emotional Reason: How to Deliberate About Value." *American Philosophical Quarterly* 37(1): 1-22.

physician's wishes than to the patient's. In addition, there have been different views about how the physician ought to promote the patient's best interests. Beneficence as strong physician paternalism perhaps began in 1803 with Thomas Percival's *Medical Ethics*, augmented in 1847 by the American Medical Association's first Code of Medical Ethics, both of which deemed the patient's best interests as equivalent to her medical interests.²³¹ On this view, because the physician had the training and skill to determine the patient's medical interests and the knowledge to secure those interests, the physician expected the patient to defer all medical judgments to him (rarely to "her" in those days). Combined with the physician's legitimate authority to decide about medical facts, this expectation quite naturally gave rise to a view of beneficence in terms of paternalism. Paternalistic physicians believe they know what is best for the patient better than the patient.²³² On this model, physician authority ranks above patient autonomy in the clinical setting.

A shift away from the physician's authority as preemptive in the clinical setting toward the dominance of patient autonomy began with changes in payment mechanisms for healthcare services in the early 1940's. At that time, employers and employee unions began acting as third party payors for healthcare services, which increased demand for those services.²³³ This demand increased steadily through the 1960's, and rose sharply in 1965 with the federal enactment of the Medicare and Medicaid healthcare payment plans for the elderly and indigent. As a result, patients began to view themselves as consumers

²³¹McCullough, L. B. (1985), "Virtues, Etiquette, and Anglo-American Medical Ethics in the Eighteenth and Nineteenth Centuries." <u>Virtue and Medicine</u>. E. Shelp. Boston, D. Reidel Publishing.

²³²Pellegrino and Thomasma (1993), p. 57.

²³³Marsh, F. H. and Yarborough, M. (1990), <u>Medicine and Money</u>. New York, Greenwood Press, p. 13.

of healthcare services, and consumers have a voice in which services they want and when.

The trend toward a consumer-based healthcare market continues unabated, which has produced a corresponding refinement in the public's expectations about the scope and quality of healthcare services.²³⁴ Not surprisingly, physicians have responded to that trend by recognizing patients as consumers in need of satisfaction.²³⁵ One result has been to supplant the physician's preemptive authority with the patient's autonomy, which carries the weight of a more sophisticated view of healthcare and financial ability to pay.

The patient's preemptive right to make treatment decisions has been reinforced with several landmark legal cases that have affirmed the patient's rights over the physician's authority. Consider the 1972 ruling in *Canterbury v. Spence* that affirmed the patient's right to an informed consent before receipt of care, and the 1976 ruling in *In re Quinlan* that affirmed the patient's right to refuse life-sustaining technology. The rulings in these two cases clearly show that patients or their surrogates legally can and should make autonomous healthcare decisions, even over the objections of their physicians.²³⁶ This emphasis by the judiciary on patients' rights has further eroded the physician's traditional unilateral decision-making authority, correctly so, but also has contributed to the replacement of beneficence with autonomy as the fundamental value.

The transformation from physician authority to patient autonomy as the predominant ethical principle in the clinical setting has produced a gratifying public

²³⁴Marsh and Yarborough (1990), p. 13.

²³⁵Weithman, P. J. (1999), "Of Assisted Suicide and 'The Philosopher's Brief'." *Ethics* 109(3): 548-578.
²³⁶Pellegrino, E. D., M.D. and Thomasma, D. C., PhD. (1988). For the Patient's Good. New York, Oxford University Press.

confidence in the view that it is permissible to forego life-sustaining technologies under a variety of conditions, although death will be the result. Now, public opinion is shifting even further to the view that requesting aid from physicians in dying is no longer a request for mercy killing, but merely a request for aid in hastening an entirely natural process.²³⁷

One objection to this conclusion is the claim that the pendulum of public opinion has shifted too far. Rather, patient autonomy and beneficence must remain in balance with one another so as not to endanger vulnerable members of society, such as those with AIDS, Alzheimer's disease, spinal cord injuries, severe deformity, and those who are a financial burden on family and society. Given that vulnerability, a request for physicianassisted suicide calls for an alternative response by the caregiver.

The view that patient autonomy alone can justify causing the patient's death presents a view of the patient as "body to be disposed of at the patient's will." Such a view treats the patient as the means to an end, which objectifies the body as a mere instrument. To comply with the moral imperative to treat persons as more than mere ends, the physician must view all patients, including the terminally ill, in a more holistic way---as situated persons with spiritual and intellectual as well as physical needs, all of which vitally influence and determine the patient's suffering. Paying attention to all of these aspects of the patient's life rather than to just the physical better enables the physician to treat the whole person and to relieve the patient's suffering without causing her death.

²³⁷Beauchamp, Tom L. (1999), "The Medical Ethics of Physician Assisted Suicide." *Journal of Medical Ethics* 25: 437-439.

Such an attitude requires the physician to sustain a compassionate presence with that patient. Ideally, the physician fulfills this commitment best by refusing to leave her patient alone and isolated in her illness, and by not confirming the patient's fears about death with a promise of death that relies on the patient's fears and feelings of despair to work its relief. This physician also insists that those who can and should provide comfort and care to the patient, regardless of professional standing, should do so as an integral part of the healing process, as the patient so desires. This physician relieves all unnecessary pain of any kind or intensity when relief is available, even if such relief hastens an unintended death and provided that the patient's continued life in a reasonable manner so as to avoid postponing an inevitable death against her patient's will. By sustaining a compassionate presence in this way, the physician relieves the patient's suffering by satisfying the clinical needs of her patient, as those needs relate to illness and death.

In sum, the morally defensible alternative response to a request for physicianassisted suicide is to treat patients as whole persons and to help the suffering patient find peace through acceptance. Assisting the patient in this way can be part of an essential palliative care plan, which should aim for a level of acceptance comparable to that attained by those who go through divorce, or death of a loved one, or other such personal tragedies. Hospice care programs often use this approach effectively, which depends on viewing the patient holistically.

As a result, the argument against physician-assisted suicide from the physician's perspective is not an argument against the right of patients to evaluate their own lives, nor

is it an attempt to refute the reasons patients might give in support of their choice of suicide. Such evaluations are subjective in nature and may be valid from the patient's perspective. In addition, the reasons supporting such conclusions are too numerous and too complex to consider. Although a decision to kill oneself is a *prima facie* denial that life is worth living, such a judgment is reserved to the individual whose life is in question and depends on a personal rather than a medical context.²³⁸ Hence, there is no quibble here over the view that suicide can be a rational decision, at least in the theoretical sense that one might support such a decision with reasons that other rational persons might affirm as valid.²³⁹

Second, this objection to physician-assisted suicide does not assume any value or purpose to suffering. For the religious minded, suffering can have redemptive or retributive value.²⁴⁰ Such interpretations may have relevance to the debate about causing the patient's death, and may help patients determine the meaning of their own suffering. Despite the personal value that suffering may have for some patients, the argument against physician-assisted suicide presented here relies on the view that suffering is a disvalue to be avoided, prevented, or resolved whenever possible, though not at all costs. Just as physicians have no obligation to preserve life at all costs, they likewise have no obligation to relieve suffering at all costs.

Lastly, the argument in this chapter is not against a right to die. Securing such a right can be a matter of legal stipulation, as the voters in Oregon and some other

²³⁸ Taylor (1989), especially Part I. Cf. Thomasma and Graber (1990), p. 19.

²³⁹For a discussion of the rationality of suicide, see Mayo, D. J. (1986). "The Concept of a Rational Suicide." *The Journal of Medicine and Philosophy* 11: 143-155.

²⁴⁰For a discussion of the value of suffering in a Christian context, see John Paul II (1984), "On the Christian Meaning of Suffering." Vatican City, and Proudfoot, Merrill (1964), <u>Suffering: A Christian Understanding</u>. Philadelphia, The Westminster Press.

countries have done. In the U.S., the petitioners in *Washington v. Glucksberg* and in *Vacco v. Quill* sought affirmation of a constitutional right to die from the U.S. Supreme Court. Their petition sought an exemption for physicians from criminal liability in causing a patient's death on condition that the patient was terminally ill, death was imminent, and the patient voluntarily requested such assistance from the physician. Although the justices did not find a constitutional right to die in either case, their ruling explicitly encouraged physicians to aid the dying process with more aggressive palliative care measures, even at the risk of hastening the patient's death but without causing that death.²⁴¹ The Court's emphasis on medically appropriate alternative methods of assisting the patient's death does not bar other states from enacting measures similar to Oregon's law that permits physician-assisted suicide. Thus, future efforts to provide for a right to die and a concomitant right to assisted suicide might very well succeed. Rather than argue against such a right, however, the claim defended in this chapter is that physician-assisted suicide is not morally defensible medicine.

²⁴¹For a discussion of the legal right to life, see Feinberg, Joel (1977), "Voluntary Euthanasia and the Inalienable Right to Life." *Philosophy and Public Affairs* 7(2): 93-123.

Chapter 4

Holistic Medicine

God, grant me serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference.

I. Introduction.

As the analysis in Chapter 3 shows, Thomasma and Pellegrino argue that a combination of several factors determines an appropriate clinical response to a patient's medical condition. In their view, choosing the appropriate medical care and providing that care in a proportionate manner are chief among those factors. The appropriateness of the care chosen depends on the physician's professional judgment, based on the relevant clinical and scientific data, and the patient's preferential judgment, based on various personal factors. Such appropriateness also depends on the outcome of a "benefits versus burdens" analysis related to the patient's condition and proposed treatment. This calculus should be guided by the principle of proportionality, which aims at maintaining a desired balance between the benefits and burdens of treatment. To maintain that balance in an ethical manner, however, the analysis must be conducted together by patient and physician. Such mutuality helps ensure that the principles of beneficence and respect for patient autonomy work in conjunction, rather than compete with one another. Ideally, these are the major factors that continuously shape and redefine the care plan as needed throughout the course of treatment.

To the extent that a patient's suffering lends itself to this medical protocol, the nature of suffering adds yet another dimension to the specific care plan eventually developed. According to the analysis provided in Chapter 2, suffering is a state of

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emotion that is a distinct experience from physical pain, although the two experiences may be and often are related. Suffering itself, however, is a psychological phenomenon with many specific causes, including pain, loss of function, disability, chronic illness, and so on. More generally, suffering is the feeling of distress that arises in connection with a disruption in the way important personal matters are perceived to be at the moment as compared to how it is perceived that such matters ought to be. Sufferers often describe this kind of experience in spiritual terms as grief over an actual or anticipated loss of self. Depending on the circumstances, this feeling of personal disintegration can give rise to an unrelenting and oppressive tension between hope and despair, the intensity of which varies with the magnitude of the loss and the sufferer's disposition.

From the individual's perspective, Viktor Frankl claimed that a crucial step in resolving all suffering depends on the meaning and value that each gives to our own experience in that regard. From the caregiver's perspective, on the other hand, Eric Cassell claims that there are two primary ways to relieve suffering in the clinical setting. One is to guide patients to assign meaning to their medical condition, which often resolves the suffering associated with that condition. The other is a spiritual focus that assists patients in developing a sense of transcendence, which is most effective in restoring a sense of wholeness after injury to an individual's self or personhood.

To that end, he offers three specific goals of patient care that seeks to reduce or minimize suffering.¹ The first goal is to define all diagnostic or therapeutic plans in terms of the sick person, rather than in terms of a disease. The second goal is to

¹Cassell, Eric J. (1991), <u>The Nature of Suffering and the Goals of Medicine</u>. New York and Oxford, Oxford University Press, p. 241.

maximize the patient's function and not necessarily thepatient's length of life. The third goal is to minimize the family's suffering as well as the patient's suffering, although Cassell does not offer a discussion of how to resolve a conflict in this regard between patient and specific family members.

The fundamental notion behind Cassell's approach is that caregivers must focus on fostering the best interests of the sick person rather than on merely treating a disease. In his view, sick persons usually know better than others what their best interests are, what aspects of function matter most to them, and when they are suffering. With this approach, Cassell acknowledges the clinical need to include the patient's knowledge as a vital element in relief of suffering. Doing so, however, requires working more closely with patients and their families than is customary in traditional medical practice. Cassell's approach minimizes this limitation by focusing on a patient's suffering as a psychological condition that involves the whole person, rather than as a physiological condition that involves primarily the patient's body. In this sense, Cassell offers a holistic approach to patient care.

Holism is a concept used by many disciplines to indicate an integrative and comprehensive understanding of whole systems with constituent linkages and continuities among related parts.² The life sciences, for example, often employ the term "vitalism" in referring to a holistic theory of living organisms.³ As applied in the healthcare context, holism is a particular patient care strategy wherein the caregiver

² Lawrence, C. and Weisz, G., eds. (1998), "Medical Holism: The Context," in <u>Greater Than The Parts: Holism in</u> <u>Biomedicine 1920-1950</u>. NY, Oxford University Press, p. 2.

³ Lawrence and Weisz (1998), p. 6.

focuses on the patient as a whole person, and not only as a person with a diseased body.⁴ In this sense, medical holism can refer to a wide range of care techniques, from the unconventional to the more orthodox methods that complement traditional medical practice.

Medical holism stands in sharp contrast to Cartesian dualism, which had farreaching effects on traditional Western medical practice.⁵ Descartes discarded notions of the harmony and unity of the human organism and substituted a conception of the body and mind as separate and distinct.⁶ Alster observes that some writers maintain that Cartesian dualism "wrecked havoc" on what was a holistic medical orientation at the time.⁷ Alster offers Capra's view as an example:

The greatest change in the history of Western medicine came with the Cartesian revolution. Before Descartes, most healers had addressed themselves to the interplay of body and soul, and had treated their patients within the context of their social and spiritual environment. As their world views changed over the ages, so did their views of illness and their methods of treatment, but their approaches were usually concerned with the whole patient. Descartes' philosophy changes this situation profoundly. His strict division between mind and body led physicians to concentrate on the body machine and

⁴ For an early discussion of what role medical holism was to play in healthcare, see Robinson, G. C. (1939). <u>The</u> <u>Patient as a Person: A Study of the Social Aspects of Illness.</u> New York, The Commonwealth Fund. Although medical holism has roots deep in antiquity, Robinson was one of the first advocates in the modern era of medicine. For another early advocate, cf. Peabody, F. W. (1925). "A Study of 500 Admissions to the Fourth Medical Service, Boston City Hospital." *Boston Medical and Surgical Journal* 193:630. See also Williams, T. F. (1950). "Cabot, Peabody, and the Care of the Patient." *Bulletin of the History of Medicine* 24: 462-481. For a discussion of the practice of herbal medicine, see Tobyn, Graeme (1997), "The English Physician: Herbal Medicine and Therapeutics", in his <u>Culpeper's</u> <u>Medicine: A Practice of Western Holistic Medicine</u>, Rockport, MA. Element Books, Inc., pp. 176-226.

⁵ Alster, Kristine Beyerman (1989). <u>The Holistic Health Movement.</u> The University of Alabama Press. Tuscaloosa and London., p. 11.

⁶ Alster (1989), p. 11.

⁷ Alster (1989), p. 11.

to neglect psychological, social, and environmental aspects of illness.⁸ Drawing on Hippocrates and Galen, through Galileo and Baron, Alster points out, however, that holistic and dualistic theories have always competed for dominance in the practice of Western medicine.⁹

Outside the bounds of conventional medicine, medical holism is often viewed as a radical alternative method of patient care that emphasizes preventive and therapeutic self-healing strategies. These unconventional strategies aim at enhancing one's own biological mechanisms with natural rather than artificial means.¹⁰ Naturopathy is one example of a self-directed healthcare regimen that heavily relies on "natural foods, light, warmth, massage, fresh air, regular exercise, and the avoidance of drugs" to cultivate and nurture the body's own healing powers.¹¹

Within the bounds of conventional medicine, on the other hand, holistic medicine can refer to techniques that complement and augment traditional medical practice. In this sense, medical holism functions on the premise that an adequate healthcare system responds to patients as persons who are ill and fully recognizes the need to integrate the many parts of their lives. Doing so promotes health, while ignoring that need can lead to sickness.¹² In sum:

Holistic health...is a state of integration of the physical body and of the mental and emotional soul-self, in harmony with the spiritual self....The concept refers to the fact that the whole of a person is greater than the mere sum of his parts, and that there is

⁸ Alster (1989), p. 11.

⁹ Alster (1989), p. 13.

¹⁰ Eskinazi, Daniel P. (1998), "Factors That Shape Alternative Medicine." JAMA 280(18), p. 1622.

¹¹ Glanze, Walter D., et al., eds. (1992). <u>The Mosby Medical Encyclopedia</u>. NY, Penguin Group. Herbal medicine, which has roots in both the East and West, might also extend outside the bounds of conventional medicine.

¹² Alster (1989), pp. 48-49. See also Gordon, J. S. (1996), "Alternative Medicine and the Family Physician." *American Family Physician* 54(7), pp. 2205-10.

an approach to the whole person who is ill, instead of merely to his parts or to his illness as if they were separate from the whole of him.¹³

Despite the appeal of this strategy, some physicians may find it difficult to situate the patient as a "person" in the way that medical holism requires. Such difficulty in part stems from the fact that each patient has a unique genetic makeup and personal history, which extensively shapes a person's current lifestyle, and might have led to the present medical condition. For example, alcoholism and sexually transmitted diseases are ailments directly related to lifestyle, although other factors are involved as well. The nature of these ailments demonstrates the extent to which lifestyle alone, however, can influence a patient's health status, which raises a question about how much treating physicians must learn about their individual patients to meet the expectations of medical holism. Such principles seem to require physicians to learn a great deal in this respect, or at least to communicate more effectively with their patients, before attempting to formulate a sound treatment plan.¹⁴ Given the financial and time constraints on most any clinical practice, however, such a task might prove unrealistic, if not impossible. As a result, perhaps in some cases or at some point the primary responsibility for patient care must shift to others.¹⁵

Another difficulty in treating the patient in a holistic sense concerns various other factors in the patient's life, including the patient's economic, social or employment

¹³ Svihus, R. H. (1979), "On Healing the Whole Person: A Perspective." *The Western Journal of Medicine* 131 (6): pp. 480-481.

¹⁴ Bar, Bonnie, RN, M.S. (1998). "The Effect of Holism on the Health Care System." *Hospital Materiel Management Quarterly* 20(1), p. 73. See also Principle Number 3 of the American Holistic Medical Association's Principles of Holistic Medical Practice (Albuquerque, NM), which states that "Holistic Physicians expend as much effort in establishing what kind of patient has a disease as they do in establishing what kind of disease a patient has."

¹⁵ Hardwig raises a similar question. For instance, he suggests that requiring physicians to spend more time with terminally ill patients on their spiritual concerns may be asking too much of physicians. In his view, physicians are already overburdened by other constraints. See Hardwig, John (2000), "Spiritual Issues at the End of Life: A Call for Discussion," *Hastings Center Report* 30(2), p. 30.

circumstances. These factors often play a significant role both in whether a clinical encounter takes place at all, and in the kinds of healthcare decisions made.¹⁶ The physician's or caregiver's awareness of these factors, however, often has no consequence in terms of prevention and cannot alter therapeutic outcomes. Imagine a typical coal miner with severe breathing problems after years of working in the mines. This miner also has a family to support, no other job skills or realistic employment alternative, and no means to look for work in another locale. Although some temporary medical relief might be available for this kind of patient, ultimately, such a person needs an altogether different work environment to realize any lasting health benefits. Telling him to quit his job to save his health and life seems pointless and insensitive, without simultaneously providing him with other social and economic remedies as well.

The reality of such difficulties suggests that medical holism will ultimately fail as an effective clinical approach to patient care, because, in the face of inevitable suffering and death, it cannot deliver on its promise of "wholeness" as a reward for human striving.¹⁷ Since health is not a static commodity, something to be attained once and for all time, medical holism is not a reliable patient care strategy. Health is an ideal maintained more or less through a dynamic process of living and caring that has a lot of loose ends and many uncontrollable variables.

¹⁶ Rosenberg, C. E. (1998). "Holism in Twentieth-Century Medicine." <u>Greater Than The Parts: Holism in Biomedicine</u>, 1920-1950. C. Lawrence and G. <u>Weisz</u>. NY, Oxford University Press, p. 339.

¹⁷ Marty, M. E. (1994). "The Tradition of the Church in Health and Healing." *International Review of Mission* 83(329): 227-243.

II. Modified medical holism.

The philosophy of William James provides a possible way to address such a criticism. James modified simple holism with a concept of "someness" to better understand the whole. In his view, "someness" indicates that only some of the parts of an integrated whole connect with each other, while other parts do not connect at all.¹⁸ Although James was articulating his world view with this concept, "someness" has relevance to resolving the apparently unrealistic claims of medical holism. A patient's life too has both connected and unconnected parts, which limits the attainability of wholeness and a corresponding health status. The limitations imposed by reality suggest that a modified version of medical holism that incorporates the notion of "someness" might offer a less ambitious but effective approach to patient care, especially at the end of life.

The limited connections in a patient's life yield a partial set of meanings useful for interpreting and coping with disease and suffering. As a result, modified medical holism means that neither physicians nor other caregivers can be expected to heal everything or be all things to all patients.¹⁹ Rather, modified medical holism addresses only the patient's medically relevant suffering, especially at the end of life. Within limits, it also may complement traditional medicine in acknowledging the efficacy of nontraditional preventive and therapeutic measures, such as spiritual exercises, various meditation techniques, and massage or touch therapy to name a few. Relying on such

¹⁸ James, W. (1977). <u>A Pluralistic Universe.</u> Cambridge, MA, Harvard University Press, pp. 40-41.

¹⁹ Kopelman, L. and Moskop, J. (1981). "The Holistic Health Movement: A Survey and Critique." *Journal of Medicine and Philosophy* 6(2), p. 226. See also Tillich, P. (1961). "The Meaning of Health." *Perspectives in Biology and Medicine* 5(1), p. 92.

unconventional measures when the occasion arises recognizes other dimensions of a patient's life—mental, spiritual, and emotional—in addition to the patient's physical needs. On this approach, the practitioner views the patient as a whole person with many needs, rather than merely as a patient with physical needs only.

Although some needs of the patient will go unmet, viewing patients in a holistic manner makes it possible to meet their needs more fully, which, in turn, makes it possible to relieve their suffering more effectively, irrespective of whether that suffering takes the form of grief or spiritual distress. From a clinical standpoint, the practitioner who follows this strategy must sustain a continuing compassionate presence with the one who suffers, especially at the end of life when suffering can be very intense and difficult to resolve. To sustain a compassionate presence, the caregiver must not only be physically present at the appropriate times, she also must make herself available to the patient and her family according to their need for personal contact. This entails a commitment to being with patients, "…at times in silence, to be a nonjudgmental force in their lives, and to allow them the time and space…to heal."²⁰

Giving deliberate attention to the physical, mental, emotion, and spiritual needs of a patient does not necessarily require a physician or nurse, although such professionals may orchestrate that attention as the need arises. Other professional healthcare providers, beloved family members, special friends, members of the clergy, or pastoral counselors can and should be involved more directly in the healing process. This kind of involvement by others seems especially crucial at the end of life, when the primary focus of patient care is relief of suffering.

²⁰ Slater, Victoria E., RN, Ph.D., et al. (1999). "Journey to Holism." Journal of Holistic Nursing 17(4), p. 373.

Resolving the grief and spiritual distress of dying patients depends on various techniques and many other persons besides the physician and nurse. As a result, modified medical holism means that at times others will share responsibility for the patient's care. If the medical profession were to embrace the claims of medical holism in this sense, a very different kind of academic and clinical training for physicians and other healthcare providers would become necessary to change the current orientation toward patients and the physician's responsibility in that regard.

A. Community.

The holistic approach to patient care, especially at the end of life, is centered in community, caring, compassion and comfort for the patient as a whole person, with a special emphasis on the patient's spiritual concerns. The aim is to inspire the patient to view herself yet as a person of value to be loved and cared for even in her end-of-life suffering. In some cases, this very caring may lead to her healing in an emotional or spiritual sense. In the words of Portier-Young:

Healing is a process which begins and ends with the formation of community; it is only through human relations that the greater illness of isolation finds a cure. The one who suffers alone finally breaks beneath the weight of her grief and chooses death over life. Those who see themselves in the midst of a caring and nurturing community that grieves with them, cares for them, and helps carry their burdens, choose life and rejoice in its blessings.²¹

Although it is clear that Portier-Young's description will not fit all patients, for some, the experience of personal healing may allow the expression of caring and compassion for others even as those patients embrace the end of their own lives.

²¹ Portier-Young, Anathea (2001), "Alleviation of Suffering in the Book of Tobit: Comedy, Community, and Happy Endings." *The Catholic Biblical Quarterly* 63, pp. 48-49.

If healing is a process that begins and ends with community, then the notion of who is community is important. Defining community can be a difficult task. Loewy explains community in this way:

...community originates in the family and in the nurture experienced by infants as they develop their sense of self and begin to stretch their fledgling autonomy in the embrace of ...beneficent communities. Such communities relate to and with other similar communities, and inevitably mingle. When I speak of community, I do not have a static entity in mind but rather see community as a fluid association and relationship. Starting with the family and the extended family and progressing outward, communities extend and interlock until they encompass the world.²²

Because communities are dynamic and not static, "defining communities and delineating the exact relationships between community and the individuals or smaller communities which compose it is...an evolutionary process."²³ Loewy argues that communities are more than mere associations of people, but rather a true community sees itself as a good.²⁴ He distinguishes mere associations and true communities in this way:

In a mere association, individuals who have used the association as a means toward attaining a private good will stand ready to abandon the association once the goal is attained....Members of a true community share values and goals which become communal values and goals rather than remaining merely private interests which at a given time happen to coincide...A community then is seen as an evolving entity, underwritten by a social contract conceived in the necessary nurture and beneficence shown toward the infant whose differentiation of self from nonself occurred in that setting and whose fledgling autonomy, therefore, began in the context of beneficence. A community is constituted not only to prevent mutual harm but, where possible, to ameliorate suffering. Solidarity in such a community is seen as cemented by the realization that all are concerned in each other's welfare and will, to the extent possible, focus their resources on furthering this shared value. The relationship of the individuals to community is one of mutual necessity: Individuals need community to express, to enunciate, and to enable their personal flowering and communities need individuals to continue their own communal existence and growth.²⁵

 ²²Loewy, Erich H. (1991), <u>Suffering and the Beneficent Community: Beyond Libertarianism.</u> SUNY Press, p. 77.
 ²³Loewy (1991), p. 79.

²⁴Loewy (1991), p. 79.

²⁵Loewy (1991), pp. 79-80.

For Loewy, community is the group of persons who care for each other and also for others outside the group who, by virtue of their being cared for, then become part of the community.

Loewy's focus on a "network of caring" as the defining characteristic of "community" with the family as its initial cornerstone parallels the definition of family described in a recent report commissioned by the Institute of Medicine. Although this report focuses on family as the primary setting for chronic disease management, the authors define family as a "group of intimates with strong emotional bonds (identification, attachment, loyalty, reciprocity, and solidarity) and with a history and a future as a group."²⁶ This definition includes the primary and secondary forms that families often take in contemporary society. Primary family configurations include not only the traditional group of biologically related individuals, but also those who reside in the same household, as well as those related by function, that is, the "group involved in dealing with the everyday affairs of the patient and the family."²⁷ Secondary family configurations include those temporary intimate relationships that develop during a crisis or bereavement episode, and those relationships of longer duration that depend on shared cultural and religious beliefs.²⁸ In any case, family relationships share three basic characteristics: "they persist over time, they are emotionally intense, and they involve

²⁶Weihs, Karen M.D., Fisher, Larry Ph.D., and Baird, Macaran, M.D. (2002), "Families, Health and Behavior: A Section of the Commissioned Report by the Committee on Health and Behavior: Research, Practice and Policy, Division of Neuroscience and Behavioral Health and Division of Health Promotion and Disease Prevention, Institute of Medicine, National Academy of Sciences." *Families, Systems and Health* 20(1), p. 8.

²⁷Medalie, Mack H., M.D., and Cole-Kelly, Kathy, M.S., M.S.W. (2002), "The Clinical Importance of Defining Family," *American Family Physician* 65(7), p. 1277.

²⁸Medalie and Cole-Kelly (2002), p. 1278.

high levels of intimacy in day-to-day life.²⁹ In this sense, a family is not constrained by the number, configuration, sex, sexual preference, age, or ethnicity of its various members.³⁰ Such conceptual flexibility at times can raise an important question as to who is family, who is community.

The question of who is community is similar to the one posed in the New Testament: who is my neighbor? In that parable, the answer is twofold. Your neighbor is the one you encounter who needs care, and a neighbor is one who cares for those she encounters in need of care. "To have the courage to see your neighbor's suffering and to assume responsibility to alleviate it without just walking by are the responses in which all care originates."³¹ Kierkegaard qualifies this "other-regarding" theme by describing "neighbor" as the one nearest, but not in a preferential sense. For him, neighbor is a concept that means a reduplication of self, or "what philosophers would call the 'other', the touchstone for testing what is selfish in self-love."³² In this context, Kierkegaard's phrase "reduplication of self" implies the familiar admonition to "love thy neighbor as thyself," for only by renouncing selfishness is one able to love the other, to be neighbor, to care for the other authentically.

²⁹Weihs, et al. (2002), p. 9.

³⁰Holder, B., et al. (1998), "Engagement of African American families in research on chronic illness: A multisystem recruitment approach." *Family Process* 37(2), p. 131.

³¹ Eriksson, Katie (1997), "Caring, Spirituality and Suffering," in Roach, M. Simone, C.S.M., ed., <u>The Convergence of Caring and Spirituality</u>. Paulist Press, p. 68.

³² Kierkegaard, Soren (1946), "Works of Love" in <u>A Kierkegaard Anthology</u>, Robert Bretall, ed., The Modern Library, New York, p. 288.

B. Caring.

In the health care context, caring in a holistic sense means to look upon the patient as a suffering human being, not simply as a person who is ill.³³ Katie Eriksson describes this kind of caring in this way:

Caring is...the essence of humanity and the basic constitutive phenomenon of human existence. True caring is not a form of behavior, nor a feeling or a state. It is an ontology, a way of living...Caring is a deep human and professional communion. The idea of caring is to alleviate suffering in a spirit of caritas, that is, faith, hope and love. It is compassion upon which true caring is based. The human person was born to live in communion with others. Communion is the basis for all humanity (citations omitted). One logical consequence of this premise is that all forms of caring are variations on human communion...communion means 'the act of sharing', 'an intimate relationship with deep understanding'...Caring communion, true caring, occurs when the one caring in a spirit of caritas alleviates the suffering of the patient.³⁴

On this view, "Caring communion provides a culture that is characterized by warmth, presence, rest, respect, frankness and tolerance. Fundamental entities are...eye contact, listening, and language...The meaning of caring communion can be summarized as the ability to do good for another person."³⁵

The caring theory described by Eriksson is expressed as the "Gerasim Model" by Susan L. Taylor.³⁶ Gerasim was Ilyich's servant who cared for Ilyich simply and gently in his final months. The Gerasim Model of caregiving has as its goal the care and nurture of the individual patient, as opposed to the cure of the patient. The model is based on the relationship between the patient and the caregiver, a crucial element of which is the caregiver's acceptance of the patient and the illness. This acceptance derives from honest

³³ Eriksson (1997), p. 73.

³⁴ Eriksson (1997), p. 79.

³⁵ Eriksson (1997), p. 80.

³⁶ Taylor, Susan L. (1997), "The Gerasim model of caregiving: Reflections on Tolstoy's novella, 'The Death of Ivan Ilyich'." *Death Studies*, pp. 299-304.

communication and yields patient-directed comfort measures that combine with a consistent, gentle and simple approach to caregiving.

The central theme of Tolstoy's novella is "our need to be loved even when we are unlovely and unlovable."³⁷ Gerasim, the servant, represents that unconditional loving and compassion, including the acceptance of the distasteful aspects of care, and communicates his acceptance of the illness and the person. Even as Ilyich comments on his feeling of separation and distance from those in good health, Gerasim's simple and gentle approach crosses this barrier. As a result, Ilyich is able to transcend his suffering and find a place where, for a moment, his suffering is forgotten. In contemporary parlance, Tolstoy describes a therapeutic milieu or clinical setting where a patient is able to complete her journey. In this setting, the patient can break free from fear to face her death and herself.³⁸

C. Compassion.

Compassion is another component of the modified holistic approach to patient care. Compassion "is the root of all our other-regarding concerns…Compassion is an affective attitude … that is, by nature, altruistic….It represents one's consideration for the welfare of others."³⁹ Friedland describes compassion more fully in this way:

Compassion is traditionally regarded as a mental state in which one takes the suffering of another as her or his own. This is not to say that one actually feels the pain itself. To feel compassion is to have a sympathetic concern for the condition of another, while engaging in some degree of empathy. Compassion...combines these two activities so that one person is able to gain a deeper insight into the inner life of another. It is an

³⁷ Greenwood, E.B. (1975), <u>Tolstoy: The Comprehensive Vision</u>. New York. St. Martins Press, p. 122.

³⁸ Taylor (1997), p. 299. As noted *supra*, Hardwig suggests that accepting a duty to die allows the patient to face and overcome her fear of death. Taylor suggests that a patient can face her fear of death as a result of unconditional love and compassion from another, and thus, by implication, the patient need not embrace the view that she has a duty to die in order to face her death.

³⁹ Friedland, Julian (1999), "Compassion as a means to freedom." *The Humanist* (Jul/August), pp. 35-39.

emotive feeling that looks into the totality of another's condition because it is motivated by a wholehearted concern for that person's welfare.⁴⁰

Cultivating a sense of compassion allows the caregiver to respond to the patient as the patient needs and to see the value in providing comfort to the patient.⁴¹

D. Comfort.

Katharine Kolcaba posits a comfort model of patient care based on the involvement of a compassionate caregiver.⁴² On this model, comfort has two dimensions.⁴³ The first dimension consists of three states--relief, ease and transcendence. Relief is defined as the experience of having had a specific need met; ease is defined as a state of calm or contentment; transcendence is defined as a state of enhanced ordinary powers.⁴⁴ Comfort facilitates gains in physical or psychological performance and is essential for a peaceful death, because a dying person requires psychic strength for acceptance and release. The second dimension of comfort refers to the particular contexts in which comfort occurs, which are four. The first context is physical and pertains to bodily sensations. The second context is psychospiritual, pertaining to the internal awareness of self, including self-esteem, the meaning in and to one's life, and one's relationship to a higher order or being. The third context is social, which includes the patient's interpersonal, family, cultural, financial and informational relationships,

⁴⁰ Friedland (1999), p. 35.

⁴¹ The way a patient perceives her needs may be her way of describing and communicating her suffering. Thus, listening to the patient's needs with compassion can give the caregiver clues as to how to ameliorate the patient's suffering. See Fagerstrom, Lisbeth RN, MNSc, et al. (1998), "The patient's perceived caring needs as a message of suffering." *Journal of Advanced Nursing* 28 (5), pp. 978-987.

⁴² Kolcaba, Katharine Y., MSN (1994), "A Theory of holistic comfort for nursing." *Journal of Advanced Nursing* 19: 1178-1184.

⁴³ Kolcaba (1994), p. 1179.

⁴⁴ Kolcaba (1994), p. 1179.

while the fourth context is environmental. On this model, providing comfort to patients requires the caregiver to acknowledge an "inter-related mind-body-person-world...[so as to promote] solidarity and connection rather than distance and control."⁴⁵ The caregiver who provides comfort must perceive the patient's needs from this perspective, which is an ability that depends on the caregiver's "attentiveness, noticing and presencing."⁴⁶

Ideally, an increase in comfort itself reduces negative tensions and increases positive ones. Positive tensions lead to constructive health-seeking behaviors on the part of the patient, including the dying patient. Enhancing comfort promotes the health of the whole person, even in the face of death.⁴⁷ Comfort also includes effective pain management, but is not limited to drug therapy. Comfort can be enhanced in many ways and by many different caregivers, including chaplains, who must take time to be present with the patient and to provide unconditional love.

E. Spiritual care.

In the course of providing unconditional love, caring, compassion and comfort for the patient, the holistic caregiver seeks to understand the spiritual needs of the patient as well, especially the dying patient. Spiritual needs extend beyond the religious dimension. Spirituality is an integral part of every individual's character and personality irrespective of the person's religious beliefs, and can ultimately affect the individual's response to illness and dying.⁴⁸ In its broadest sense, the spiritual dimension of the human person encompasses the inherent need to find satisfactory answers to the ultimate questions

⁴⁵ Benner, Patricia (1997), "A Dialogue Between Virtue Ethics and Care Ethics." *Theoretical Medicine* 18, p. 55.
⁴⁶ Benner (1997), p. 55.

⁴⁷ Kolcaba (1994), p. 1181.

⁴⁸ Oldnall, Andrew, BSc {Hons} RGN DPSN (1996), "A critical analysis of nursing: meeting the spiritual needs of patients." *Journal of Advanced Nursing* 23, pp. 138-144.

concerning the meaning of life, illness, and death.⁴⁹ The individual's deepest relationships with others, with self, and with God (or other influential focus) are at the core of the individual's spirituality.⁵⁰

The search for meaning in life has long been viewed as a central spiritual concern. As discussed in Chapter 2, Frankl claimed that a search for meaning is a search for understanding the world about us and is a significant, universal human motive. In this respect, Frankl shares the concern of existential phenomenologists, such as Heidegger, who focus on the meaning of life, virtue, morality, freedom, and death, and who recognize and understand that the search for meaning depends on certain assumptions. ⁵¹ As Carol Smucker points out in her study of spiritual distress, one such assumption is that people are a total indissoluble unity engaged in an interrelationship with the world.⁵² A person's existence has meaning through her experience of the world, and this personworld relationship can be known through analysis of the language or dialogue used to describe that experience.

From this perspective, certain experiences often lead to spiritual distress, characterized by a feeling of disharmony, of being disconnected and without meaning.⁵³ The types of experiences that most frequently cause spiritual distress include altered transcendent relationships, values or beliefs, loneliness, fear of the unknown, guilt and

⁴⁹ Oldnall (1996), p. 138.

⁵⁰ Oldnall (1996), pp. 138-139.

⁵¹ Gelven, Michael (1989), <u>A Commentary on Heidegger's *Being and Time*</u>, Northern Illinois University Press, Dekalb, Illinois, p. 16.

⁵² Smucker, Carol PhD, RN (1996), "A Phenomenological Description of the Experience of Spiritual Distress." *Nursing Diagnosis* 7(2), April-June, p. 82.

⁵³ Smucker (1996), p. 82.

regret, anger toward God, and loss of hope.⁵⁴ This loss of human contact, meaning, and hope can be especially poignant at the end of life. For the dying patient, meaning may be declining because the future is waning, which may signal spiritual distress or crisis.

The holistic caregiver is attentive to the patient's experience of such phenomena, and understands the need to respond to the patient's spiritual needs, distress or crisis. According to Smucker, the holistic caregiver responds to the patient's spiritual distress with the knowledge that healing is more than the simple correction of bodily ailments. ⁵⁵ In cases where physical cure is impossible, patients often need spiritual comfort, which the caregiver offers with sensitivity and respect for the patient's cultural and spiritual beliefs. Offering spiritual care in this manner requires an open dialogue with the patient, which establishes trust with the patient and encourages the patient to make her own suggestions about how the caregiver can assist. Through this same process, the caregiver obtains permission from the patient to respond from her own spiritual perspective to help the patient who is in spiritual distress.

For the caregiver, providing spiritual comfort as an aspect of medical holism relies on an integrative understanding of health care.⁵⁶ Integrative healthcare focuses on the individual's health and its decline in the context of the patient's life. In this respect, integrative healthcare is an "ethics of the everyday" because it stresses "those basic interactions that can profoundly shape and influence who we are and how we experience

⁵⁴ O'Brien, M. (1982), "The Need for Spiritual Integrity", in <u>Human Needs and the Nursing Process</u>, H. Yura and M. Walsh, eds., Norwalk, CT, Appleton-Century-Crofts.

⁵⁵ Smucker (1996), p. 90.

⁵⁶ Guinn, David E., J.D., Ph.D. (2001), "Ethics and Integrative Medicine: Moving Beyond the Biomedical Model." *Alternative Therapies* 7(6), p. 72.

ourselves in the world....⁷⁵⁷ Frequently, the source of at least some of the dying patient's suffering is her removal from the "everyday." Such isolation can interfere with, if not hinder, her final spiritual growth. When the caregiver regards the dying patient in light of who she is and has been in the world, such regard can stem the isolation that often clouds the dying process. For this reason, the mere presence of the caregiver can be a vital form of spiritual care.⁵⁸

Since spirituality concerns the wholeness of life, health and well-being, it often involves self-transcendence.⁵⁹ According to one definition, self-transcendence is "a characteristic of developmental maturity whereby there is an expansion of selfboundaries and an orientation toward broadened life perspectives and purposes."⁶⁰ In this sense, "spirituality" concerns "the ways we transcend ourselves that are not based on reason alone."⁶¹ Dunne describes self-transcendence in a spiritual sense as the search for ultimate meaning, for the "beyond" toward which we have been drawn throughout our lives:

...people facing death are concerned less with what they can account for and more with their hopes, their companionships, and all the happy, baffling decisions they made that opened up to them a richer and deeper life.⁶²

⁵⁷ Guinn (2001), p. 72.

⁵⁸ Oldnall (1996), p. 42. Given that holism recognizes the spiritual facet of the human being, Oldnall calls for better education for caregivers who want to respond in a holistic fashion, in particular nurses, in the area of caring for the patient's spiritual needs. Oldnall cautions that spiritual needs should not be confused with psychological needs, and thus nurses and other caregivers need more guidance about the total make-up of the human being. Oldnall observes that often, by their mere presence, nurses are offering spiritual care.

⁵⁹ McGee, Eileen M., R.N. M.S. (2000), "Alcoholics Anonymous and Nursing: Lesson in Holism and Spiritual Care." *Journal of Holistic Nursing* 18(1), p. 19.

⁶⁰ McGee (2000), p. 19.

⁶¹ Dunne, Tad (2001), "Spiritual Care at the End of Life." *Hastings Center Report* (March-April), p. 23.

⁶² Dunne (2001), p. 23.

Ultimately, self-transcendence can be an aspect of healing and recovery. To that end, Dunne specifically recommends that caregivers afford patients opportunity to talk about these matters by relating the narrative of their lives. In the telling of their stories, patients often realize a deeper understanding and experience of self-transcendence by coming to terms with broken relationships and unfulfilled commitments. By encouraging this kind of communication with the patient, the caregiver establishes a companionship that strengthens the patient in her struggle with ill health and impending death. ⁶³ For the dying patient, such care can lead to spiritual recovery, healing and a peaceful death.

The self-transcendence embraced by the holistic process of recovery in Alcoholics Anonymous, with its emphasis on group support and its view of health as the maintenance of a spiritual condition, offers additional guidance for caregivers who want to practice holistic therapies.⁶⁴ The ideal of AA is to provide group support and spiritual care in a compassionate, caring community without medical "orchestration". Members of AA and practitioners of holistic therapies alike are well aware of the mind/body connection, and acknowledge the concept of an undivided wholeness in the universe.⁶⁵ On this view, human beings are not tripartite entities composed of "body, mind, and spirit."⁶⁶ The holistic caregiver, in the tradition of AA, would seek to inspire patients to "sense that our lives [are] part of a much larger whole."⁶⁷ Although prayer and mediation are among the basic spiritual tools allowed and encouraged by AA to foster this sense of

⁶³ Dunne (2001), pp. 25-26.

⁶⁴ McGee (2000), p. 19.

⁶⁵ McGee (2000), p. 18.

⁶⁶ McGee (2000), p. 18.

 ⁶⁷ Newman, M. (1994), <u>Health as Expanding Consciousness</u>, 2nd ed. New York. National League for Nursing Press, p. 24.

transcendence, other healing therapies with the same purpose include the practice of humility and service to others.⁶⁸

Since the AA holistic model is grounded in patient empowerment, members never refer to themselves as victims of alcoholism.⁶⁹ Perhaps the dying patient need not see herself as a victim, inasmuch as all humans face mortality. Rather, those patients who perceive themselves as victims might find solace in imitating the newcomer to AA, who embraces the motto, "trust God, clean house and help another drunk."⁷⁰ If given love, comfort and compassion, and if viewed as a whole person by caregivers, friends and family, the dying patient may be inspired to transcend self and help another dying person.

Some holistic principles parallel to the AA model can be found in the Hospice movement as well. According to the founder of the modern hospice movement, Cicely Saunders, Hospice attempts to offer the dying person unconditional love, compassion, comfort and spiritual care.⁷¹ Hospice advocates a multidisciplinary approach to patient care that emphasizes symptom control, attending to spiritual as well as physical needs, and care of the family.⁷² Although there are residential hospices as well as hospice units in hospitals, in the United States, the emphasis is on hospice care in the patient's home. The goal of hospice in any setting, however, is to help the dying patient achieve "healing, wholeness, and hope."⁷³ To that end, hospice focuses on healing the spiritual pain, or suffering, of the dying patient. This suffering is often a complex state of emotion

⁶⁸ McGee (2000), p. 19.

⁶⁹ McGee (2000), p. 21.

⁷⁰ McGee (2000), p. 22.

⁷¹ Dunne (2001), pp. 22-26.

⁷² Emanuel, Ezekiel J., Emanuel, Linda L. (1998), "The promise of a good death." The Lancet 351(9114) p S21.

⁷³ Carr, William F. (1995), "Spiritual Pain and Healing in the Hospice." America August 12, p. 26.

consisting in "fear of dying, guilt and regret about one's life, and sadness about the imminent separation from wife or husband or children or friends."⁷⁴ In Saunders' view, the only way to help dying patients resolve their suffering and find spiritual peace is by providing a level of spiritual care that helps them find meaning in death.⁷⁵ Because only the patient can find such meaning, however, the caregiver's task is to encourage the patient in that search by creating space and time for the patient to talk about spiritual pain.

Unless a professional healthcare giver works in a hospice or has been trained in the holistic approach of hospice care, the caregiver may not feel prepared to support the terminally ill patient in her last days of life.⁷⁶ To better prepare caregivers in that regard, Fanslow-Brunjes offers the HOPE System.⁷⁷ The HOPE System is a formal spiritual assessment tool that consists in a series of questions designed to help a patient explore spiritual issues and concerns. Each of the letters in the acronym is a category of questions that the caregiver asks the patient. For instance, "H" questions concern the sources of hope, strength, comfort, meaning, peace, love and connection. "O" questions are about the role of organized religion in the patient's life. "P" questions explore the patient's personal spirituality and practices. Lastly, "E" questions center on the effects of medical care and end-of-life decisions. This system relies on the premise that dying

⁷⁴Carr (1995), p. 27.

⁷⁵ Carr (1995), p. 28. See also, Marrone, Robert (1999). "Dying, Mourning and Spirituality: A Psychological Perspective." *Death Studies* 23: pp. 495-519.

⁷⁶ For ways of providing spiritual counseling in a diverse society, see Zinnbauer, Brian J., and Pargament, Kenneth I. (2000), "Working With the Sacred: Four Approaches to Religious and Spiritual Issues in Counseling." *Journal of Counseling and Development* 78, pp. 162-171.

⁷⁷ Fanslow-Brunjes, Cathleen, RN, MA (1997), "Hope: Offering comfort and support for dying patients." *Nursing* (March), pp. 54-57. See also Anandarajah, Gowri and Hight, Ellen (2001), "Spirituality and medical practice: Using HOPE questions as a practical tool for spiritual assessment." *American Family Physician* Jan 1, pp. 81-88.

patients have three basic needs: to know they won't be abandoned; to have the opportunity to express themselves; and to maintain hope.⁷⁸ When any of these needs go unmet, the patient very likely experiences spiritual distress. This series of open-ended questions helps the patient identify the source of that distress. Resolving that distress can renew hope for the patient which might enable each dying patient to live more fully until the moment of death.⁷⁹

By the same token, the HOPE system also acknowledges that assessing the patient's level and source of hope is an important step that enables the caregiver to support the dying patient and her family. In much the same way that Kubler-Ross identified certain stages in accepting death, the HOPE system recognizes that patients and their families typically experience hope in four stages. Those stages are hope for cure, hope for treatment, hope for prolongation of life, and finally, hope for peaceful death.⁸⁰ Since patients and their families are often in differing stages of hope and acceptance, caregivers must provide honest responses to the questions of patients and their families. The HOPE system is one way for caregivers to keep the communication door open for further conversation with patients about their spiritual concerns.

Dying patients may exhibit sudden spontaneous changes in what they hope for; these changes are often triggered by perceived physiological changes, or "body wisdom."⁸¹ The caregiver should be flexible in responding to the patient's changes in hope. As a result, caregivers may find themselves in the role of mediator between the

⁷⁸ Fanslow-Brunjes (1997), p. 54.

⁷⁹ Fanslow-Brunjes (1997), p. 54.

⁸⁰ Fanslow-Brunjes (1997), p. 55.

⁸¹ Fanslow-Brunjes (1997), p. 56.

patient and her family, as the need arises for communicating the patient's changing hopes to family members who hold on to other hopes. As the patient comes to hope for a peaceful death, the caregiver must recognize that a peaceful death requires the absence of physical pain as well as the absence of emotional and spiritual suffering.⁸² Thus, in addition to attending to the patient, it is important that the caregiver help family members understand the dying process and the patient's own "body wisdom."⁸³ In this regard, caregivers can explain to family members many of the behaviors of the dying, such as no longer eating or drinking, withdrawal or reminiscing.

In addition, caregivers must stand ready to be interpreters for the family. In this regard, caregivers should understand that some dying patients who perceive that their close family members are not at peace with the imminent death will sometimes encourage their loved ones to go home for the night or out for a meal. The patient will then die while the family is gone. Upon their return, the family is often distraught that the patient died while they were away. It is at this time that the sensitive caregiver can explain that the patient chose "the moment that would spare his family the final moments of death out of love for them...[t]his...is called the 'wisdom of the dying and the choice of the moment.'"⁸⁴ "Under the HOPE System, the caregiver sees her role as helping patients and families clarify their own hopes and understand those of their loved ones, so they can be present for each other during the dying process.'⁸⁵ With this system, the caregiver helps not only the patient, but also the family, find meaning and peace.

⁸² Fanslow-Brunjes (1997), p. 57.

⁸³Fanslow-Brunjes (1997), p. 57.

⁸⁴Fanslow-Brunjes (1997), p. 57.

⁸⁵Fanslow-Brunjes (1997), p. 57.

III. Some troubling questions.

The underlying presupposition of holistic medicine mirrors Viktor Frankl's argument that each of us must give meaning to our own suffering and death. Holistic medicine promises relief, especially to dying patients, by helping them find meaning and hope. Despite that assistance, or perhaps because of it, some patients still may choose physician-assisted suicide as a way to find meaning in their lives. One reason that some patients might choose physician-assisted suicide, according to John Hardwig, is not necessarily because they are terminally ill or suffer unbearably themselves. Rather, they perceive as unfair the burdens that their illness causes others, and because relieving others of such burdens is an urgent goal for these patients, they often perceive a duty to die.⁸⁶ David Thomasma offers yet another reason, namely, that some patients might embrace physician-assisted suicide as an act of martyrdom.⁸⁷ Supposedly, each of these reasons is an effort by the patient to give meaning and purpose to her life by giving meaning and purpose to her final suffering and ultimate death. Closer analysis shows, however, that neither Hardwig nor Thomasma proves his case. As a result, the presumption stands that holistic medicine is the preferred medical response to a patient's request for assisted suicide. Because it honors the patient as a whole person, and involves community care, compassion and comfort for the patient, it can be the preferred choice for dying patients and their families as well.

⁸⁶ Hardwig, John (1997), "Is There a Duty to Die?" Hastings Center Report 27(2), pp. 34-42.

⁸⁷ Thomasma, David C. (1998), "Assisted Death and Martyrdom," Christian Bioethics 4 (2), pp. 122-42.

A. Hardwig's "duty to die".

Hardwig posits that within the health care context, under some circumstances, there is a duty to die.⁸⁸ His discussion of such a duty suggests that there are two groups of sufferers. There is the primary sufferer, namely, the person with the chronic or terminal illness or who is demented or debilitated. There are also the often unidentified secondary sufferers, namely, the family coping with the person who is ill. Hardwig's focus suggests that the amelioration of the family's suffering can come about through the self-imposed death of the primary sufferer. Given a view of suffering as involving grief, loss of self, hope and despair, spiritual distress, and the search for meaning, Hardwig's claim might seem plausible.

Hardwig develops this "other-regarding" duty to die this way. Current advances in western medicine save many lives and enable many of us to live longer. Such advances also deliver "most of us over to chronic illnesses and …[enable]...many of us to survive longer than we can take care of ourselves, longer than we know what to do with ourselves, longer than we even are ourselves."⁸⁹ Faced with becoming demented or debilitated, "there may be a fairly common responsibility to end one's life in the absence of any terminal illness at all."⁹⁰

⁸⁸ Hardwig grounds a duty to die in family relationships. He argues that "[t]he impact of my decisions upon my family and loved ones [as opposed to society] is the source of many of my strongest obligations and also the most plausible and likeliest basis of a duty to die" (Hardwig, p. 36). He states that "the fundamental insight underlying a duty to die" is found in the situation that when continuing to live will impose significant burdens--emotional, extensive caregiving, destruction of life plans, and financial hardship--on your family and loved ones (Hardwig, p. 38). Observing that the word "responsibility" "would perhaps be the most appropriate word," Hardwig clarifies that he intends "no implication that there is a law that grounds this duty, nor that someone has a right corresponding to it" (Hardwig, p.42, n. 1). This suggests that Hardwig's theory is really one of altruistic other-regarding love, rather than duty.

⁸⁹ Hardwig (1997), p. 35.

⁹⁰ Hardwig (1997), p. 35

Observing that most bioethics schools of thought share in one of the "deeply embedded American dreams: the individualistic fantasy," Hardwig notes that "[w]ithin a health care context, the individualistic fantasy leads us to assume that the patient is the only one affected by decisions about her medical treatment."⁹¹ Calling this assumption "morally obtuse," Hardwig argues that since most of us are not hermits, but rather "are affiliated with particular others and most deeply, with family and loved ones," sharing "deeply interwoven lives," we are barred from making "exclusively self-regarding decisions" about whether we should live or die.⁹² In caring for us--the demented or debilitated--the lives of our loved ones can be seriously compromised, overwhelmed, exhausted, emotionally devastated and financially decimated.⁹³ In this regard, Hardwig makes it clear that he is "not advocating a crass, quasi-economic conception of burdens and benefits, nor a shallow, hedonistic view of life."⁹⁴

He also acknowledges that, "[g]iven a suitably rich understanding of benefits, family members sometimes do benefit from suffering through the long illness of a loved one," inasmuch as "[c]aring for the sick or aged can foster growth" or "pull a family together."⁹⁵ Noting that families have responsibilities to stand by us through illness and death, Hardwig concludes that "[i]f my loved ones are truly benefiting from coping with my illness or debility, I have no duty to die based on burdens to them."⁹⁶ Family

⁹¹ Hardwig (1997), p. 35

⁹² Hardwig (1997), pp. 35-36

⁹³ Hardwig (1997), p. 36

⁹⁴ Hardwig (1997), p. 36

⁹⁵ Hardwig (1997), p. 36

⁹⁶ Hardwig (1997), p. 36

responsibility, however, is not a "one-way street."⁹⁷ Given the reciprocal nature of family solidarity, altruism, and loyalty, the primary sufferer may be called upon to make sacrifices as well, which may include abandoning her life.

Hardwig admits that there are objections to such a duty. In his view, "[T]he most serious objections to the idea of a duty to die lie in the effects on my loved ones of ending my life."⁹⁸ He also notes the most common objections, which include the following: "(1) there is a higher duty that always takes precedence over a duty to die; (2) a duty to end one's own life would be incompatible with a recognition of human dignity or the intrinsic value of a person; and (3) seriously ill, debilitated, or dying people are already bearing the harshest burdens and so it would be wrong to ask them to bear the additional burden of ending their own lives."⁹⁹

Hardwig acknowledges that these are important objections, but ultimately suggests that "[d]eath—or ending your own life—is simply not the greatest evil or the greatest burden."¹⁰⁰ Hardwig places greater weight on a family member's loss of savings, home and career as a counter to a loved one living a little longer, although he insists that this contention "does not depend on a utilitarian calculus."¹⁰¹ For this reason, he does not believe that "it would be morally permissible for me to ruin the rest of my partner's life to sustain mine or to cut off my sons' careers, impoverish them, or compromise the quality of their children's lives simply because I wish to live a little longer."¹⁰²

⁹⁷ Hardwig (1997), p. 37

⁹⁸ Hardwig (1997), p. 37.

⁹⁹ Hardwig (1997), p. 37.

¹⁰⁰ Hardwig (1997), p. 38.

¹⁰¹ Hardwig (1997), pp. 37-38.

¹⁰² Hardwig (1997), p. 38

Hardwig overstates his case in that most impending deaths surely do not have such consequences. If the scenario he presents is not representative, the question is whether it provides sufficient reason to promote a duty of such magnitude. In addition, there are some gender inequalities that he seems to overlook. For example, will a man who has been the "sole provider" for his family's financial needs perceive burdens on his family more than a woman who has not been the sole provider for her family's finances. How should we account for such gender differences in establishing who has the duty to die? Is the duty he advocates strictly a matter of perception? Hardwig suggests that the answer to a question of who has a duty to die is "very particular and contextual," and should be decided by the primary and secondary sufferers together in view of their histories and relationships.¹⁰³ In his view, however, some considerations make it more or less likely that one has such a duty.

Hardwig claims that, generally, a duty to die is more likely when continuing to live will impose significant burdens on your family and loved ones; or when you have already lived a full and rich life; or when your loved ones' lives have already been difficult or impoverished; or when your loved ones have already made great contributions or sacrifices to make your life a good one; or when the part of you that is loved will soon be gone or seriously compromised; or when you have lived a relatively lavish lifestyle instead of saving for illness or old age; or, as you grow older.¹⁰⁴ On the other hand, one condition that makes it less likely that one has a duty to die is the extent to which the

¹⁰³ Hardwig (1997), p. 38. I do not review Hardwig's discussion of whether the incompetent have a duty to die, except to note that he contends that "only those who were formerly capable of making moral decisions could have such a duty" (Hardwig, p. 39).

¹⁰⁴ Hardwig (1997), pp. 38-39.

person who is ill has made a good adjustment to her illness or handicapping condition. In this situation, the duty is less likely, because "[a] good adjustment means that smaller sacrifices will be required of loved ones and there is more compensating interaction for them."¹⁰⁵ Another feature of the situation which makes it less likely that there is a duty to die is when the ill person can still make significant contributions (not necessarily financial ones) to the lives of others, especially her family.¹⁰⁶

Hardwig also gives scant attention to the social environment that contributes to the burdens of dying when he acknowledges that promoting a duty to die may seem "a misplaced response to social negligence."¹⁰⁷ Indeed, some hold the view that "if our society were providing for the debilitated, the chronically ill, and the elderly as it should be, there would be only very rare cases of a duty to die."¹⁰⁸ He concedes that there are a number of social policies that could dramatically reduce the incidence of such a duty, but observes that our society seems unwilling to shoulder the financial burden of such programs. In his view, society instead continues to "shift the burdens of caring for the seriously and chronically ill onto families in order to save costs for our health care system."¹⁰⁹

In response to this social failure, Hardwig argues that the dying may have to pick up the slack. He attempts to soften the blow of having to shoulder this burden for society by claiming that it is important for the individual to find meaning in death, which will

¹⁰⁵ Hardwig (1997), p. 39.

¹⁰⁶ These two features call to mind my discussion of acceptance of one's condition as an antidote to suffering.

¹⁰⁷ Hardwig (1997), p. 40.

¹⁰⁸ Hardwig (1997), p. 40.

¹⁰⁹ Hardwig (1997), p. 40.

enable them to embrace death rather than fear it. He realizes that the meaning we find in death may turn on how we find meaning in life:

We do not even ask about meaning in death, so busy are we with trying to postpone it. But we will not conquer death by one day developing a technology so magnificent that no one will have to die. Nor can we conquer death by postponing it ever longer. We can conquer death only by finding meaning in it.¹¹⁰

Relying on Kant's view that "human dignity rests on the capacity for moral agency

within a community of those who respect the demands of morality," Hardwig claims that

"recognizing a duty to die affirms my agency and also my moral agency. I can still do

things that make an important difference in the lives of my loved ones."111 On this view,

"There is dignity and a kind of meaning in moral agency even as it forces extremely

difficult decisions upon us," such as choosing to die for the sake of our families.¹¹² Such

a choice affirms rather than destroys the necessary connections in our lives. To make this

point, Hardwig writes:

If I end my life to spare the futures of my loved ones, I testify in my death that I am connected to them. It is because I love and care for precisely these people (and I know they care for me) that I wish not be such a burden to them. By contrast, a life in which I am free to choose whatever I want for myself is a life unconnected to others. A bioethics that would treat me as if I had no serious moral responsibilities does what it can to marginalize, weaken, or even destroy my connections with others.¹¹³

Because "life without connection is meaningless...[t]he individualistic fantasy, though occasionally liberating, is deeply destructive."¹¹⁴ For this reason, Hardwig concludes that "We can, then, find meaning in death only through a sense of connection with something

¹¹⁰ Hardwig (1997), p. 40.

¹¹¹ Hardwig (1997), p. 40.

¹¹² Hardwig (1997), p. 41.

¹¹³ Hardwig (1997), p. 41.

¹¹⁴ Hardwig (1997), p. 41.

that will survive our death" and "for most of us, the connections that sustain us are to other people."¹¹⁵ Hardwig briefly restates his case in the following way:

If I am correct, death is so difficult for us partly because our sense of community is so weak. Death seems to wipe out everything when we can't fit it into the lives of those who live on. A death motivated by the desire to spare the futures of my loved ones might well be a better death for me than the one I would get as a result of opting to continue my life as long as there is any pleasure in it for me. Pleasure is nice, but it is meaning that matters.¹¹⁶

B. Assessment of Hardwig's case.

In this very personal account, Hardwig grounds a duty to die in familial relationships. He argues that "[t]he impact of my decisions upon my family and loved ones [as opposed to society] is the source of many of my strongest obligations and also the most plausible and likeliest basis of a duty to die."¹¹⁷ He states that "the fundamental insight underlying a duty to die" is found in the situation that when continuing to live will impose significant burdens--emotional, extensive caregiving, destruction of life plans, and financial hardship--on your family and loved ones.¹¹⁸

Ackerman critiques this sort of altruistic reasoning with "the paradox of the

selfless invalid."¹¹⁹ In describing this paradox, Ackerman observes:

...the desire to forego high-tech life-prolonging or experimental curative treatment in order to avoid being a burden specifically to one's loved ones raises an additional problem that I call 'the paradox of the selfless invalid.' That is, either the patient's loved ones want him to die quickly in order to preserve their inheritance or otherwise make their lives easier, or they do not. If they do not, the patient does them no favor by foregoing life-prolonging or experimental curative treatment for their sake. If they do, then why is the patient sacrificing what would otherwise be left of his life (or

¹¹⁵ Hardwig (1997), p. 41.

¹¹⁶ Hardwig (1997), p. 42.

¹¹⁷ Hardwig (1997), p. 36.

¹¹⁸ Hardwig (1997), p. 38.

¹¹⁹ Ackerman, Felicia (1997), "Goldilocks and Mrs. Ilych: A Critical Look at the 'Philosophy of Hospice'," *Cambridge Quarterly of Healthcare Ethics* 6, p. 318.

sacrificing his long-shot chance at a cure) for people who love him so little that they value his life less than their money or freedom from encumbrance? Wouldn't a truly loving family find such a sacrifice appalling?"¹²⁰

Although Ackerman's position may seem a bit rigid, in her view, a truly loving family would not want the loved one to die for them, as such an act would only increase their suffering in the long run, rather than relieve it. For this reason, Ackerman rejects the claim that there is a duty to die.

In all fairness to Hardwig, he makes it clear that he intends "no implication that there is a law that grounds this duty, nor that someone has a right corresponding to it."¹²¹ As a result, he suggests that "responsibility" rather than "duty" might better indicate the thrust of his argument. Despite this qualification, his other-regarding principle raises troubling questions about the role of society in creating the very burden that families must endure, which he expects the primary sufferer to shoulder. His expectation relies on a narrow view of relationship and the connections that matter. We are connected in many important ways that extend well beyond our families throughout our lives. To say that the burden of death belongs only to the individual and her family ignores the vital interaction and sustenance of those other relationships in the larger community.

As a result, it seems preferable and far more urgent to argue that society should, in the name of justice, promote a more comprehensive healthcare system, since it is inevitable that some of its members will become either demented or debilitated prior to death. It is an injustice to expect the primary sufferer to take on the additional burden of sacrificing her life in part because society will not accept its responsibility to ease the

¹²⁰ Ackerman (1997), p. 318

¹²¹ Hardwig (1997), p. 41, fn 1.

dying process for individual members. Even when the patient has other altruistic reasons for accepting that extra burden for society, the expectation that there is a duty in that regard unjustly shifts society's burden onto the family and in turn onto the most vulnerable person. His opponents might argue that, with this approach, Hardwig gives new meaning to "the individualistic fantasy" that he aims to reject.

Interestingly, Hardwig focuses on only one side of his argument. He posits that a primary sufferer who has made peace with her illness or handicapping condition may have less of a duty to die. He relies on the premise that a good adjustment means that smaller sacrifices will be required of those who suffer. The secondary sufferers, namely, the loved ones, may still be able to have worthwhile interaction with the primary sufferer, who may still be able to make significant emotional contributions to the family. This concept of making peace with one's condition is akin to the argument that acceptance serves to ameliorate suffering, which is an argument that cuts both ways. If the primary sufferer can "accept" her condition and thus ease her suffering, perhaps the secondary sufferers also can "accept" their suffering in connection with the patient's condition. In that case, suffering will decrease among all family members with a concomitant reduction in the perception of either being a burden or bearing a burden.

Many of the observations that Hardwig makes support the claim that holistic medicine is the preferred medical response to those who suffer rather than positing a duty to die. On a holistic view, the community is expected to care not only for the primary sufferer but also for the secondary sufferers, who may need respite and protection from financial ruin. Abandoning the "individualistic fantasy," however, does not have to result in a duty or responsibility to die; it can result in a communal duty to care for the

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chronically ill, the dying and their families in a holistic fashion. Paradoxically, Hardwig's observations inspire the need to change our view of others, and of ourselves, as burdens. It further inspires us to find meaning in death, and perhaps the suffering attendant to it, which, as he admits, may include affording my family the opportunity to participate in my death and suffering by caring for me until the end. My death, then, can afford meaning to the lives of my family members. Thus, it is not necessary for me to end my life prematurely in order for my death to have meaning either for myself or my family.

C. Thomasma's "martyrdom".

Hardwig is not alone in suggesting that there are noble reasons to end our lives. David Thomasma considers the possibility of taking one's life as an act faith in God, as an act of martyrdom, and examines this possibility in the context of Roman Catholicism.¹²² Thomasma asks the question, "If, in fact, conditions can be created to suspend the rule against killing, as was done, for example, in just war theory, then why could not similar conditions be developed for suspending the rule against killing in cases of euthanasia?"¹²³ In appealing to the Roman Catholic tradition, Thomasma analyzes this question from the "richer perspective" of "Christian martyrdom and what it reveals about willing one's own death."¹²⁴ He looks at the way in which the martyred saints

¹²² Thomasma (1998), pp. 122-142.

¹²³ Thomasma (1998), p. 123.

¹²⁴ Thomasma (1998), p. 123.

approached their own death and "wonder[s] aloud ... if their deaths might shed some light on the physician-assisted suicide and euthanasia debate...."¹²⁵

Thomasma begins his analysis by examining the history of Catholic/Christian pacifism. For instance, in examining the life of the historical Jesus, a social critic and a non-violent agitator, Thomasma remarks that Jesus demonstrated effectively the dignity of others through his non-violent responses.¹²⁶ In this regard, it is required of Christians "to take up the cross and follow him."¹²⁷ In Thomasma's view, the cross does not necessarily involve any and every kind of suffering, sickness or tension. Rather, the "believer's cross must be, like his Lord's, the price of his social nonconformity. It is not, like sickness or catastrophe, an inexplicable, unpredictable suffering; it is the end of a path freely chosen after counting the cost."¹²⁸ According to Thomasma, the followers of Jesus understood that the Reign of God as preached by Jesus "was a new social order of love," and that the fundamental reason for this social order of "love for all persons, friends and enemies alike, was that God is Love, and that all humans are created and redeemed by Him."¹²⁹

Thomasma contends that the first three centuries of the Apostolic Church were "marked by conscientious objection from a substantial number of Christians" evidenced by "a willingness to die rather than acknowledge a supposed divinity of the Emperor."¹³⁰ The Constantinian Church, having metamorphosed into a "principalit[y] and power" of

¹²⁵ Thomasma (1998), p. 123. Thomasma acknowledges his long-held pacifism, but "brackets out" his own convictions against killing, "like Husserl's famous methodology of *epoche*, to see where the reasoning in this analysis takes us."

¹²⁶ Thomasma (1998), p. 125.

¹²⁷ Thomasma (1998), p. 125.

¹²⁸ Thomasma (1998), p. 125.

¹²⁹ Thomasma (1998), p. 126.

¹³⁰ Thomasma (1998), p. 127.

the world, "had to accommodate to secular society and establish norms to govern it responses to new challenges about which Jesus or the tradition said nothing."¹³¹ Thomasma writes:

The accommodation to secular society eventually took the form of permitting certain forms of killing under very strict, exceptional circumstances (such as the conditions articulated for a just war). The rule against killing was paramount in its definition of the limits of personal dominion over the lives of others and oneself. It was then and still is today a form of both respecting the inherent dignity of human lives, and the divinity of a universal God.¹³²

As Thomasma points out, over time the Church struggled with the "creative tension visa-vis the world" but embraced different and potentially discordant positions. Known as the "Catholic compromise," this compromise with secular society led to the Reformation, which spawned non-violent sects such as the Mennonites and Quakers who rested their positions on the sanctity of human life.¹³³ For Thomasma, the implication is that, with respect to euthanasia and assisted suicide, perhaps another compromise may be needed.

Thomasma succinctly states the traditional Christian rule against killing, as it

relates to euthanasia and assisted suicide, in this way:

For the most part, the theological rejection of euthanasia and assisted suicide rests on the notion that any person derives his or her life from God the creator, and that therefore that life is not one which can be taken with impunity. To take life unjustifiably is to take over the role of God the creator. It is to take dominion over life, usurping the prerogative of God alone. In effect, to kill others or oneself for any reason is to deny the power and presence of God in the lives of human beings. It is a form of disbelief, another sign of the dysfunction in human life that entered with original sin and is exemplified in the Bible by the fratricide of Cain and Abel.¹³⁴

¹³¹ Thomasma (1998), p. 127.

¹³² Thomasma (1998), p. 128. As he puts it, "Essentially the rule against killing is a form of faith in God himself, a faith that God Who created and redeemed can also save those whom He will."

¹³³ Thomasma (1998), p. 148.

¹³⁴ Thomasma (1998), p. 149.

To cite a contrasting view, Thomasma points out that Kuitert, Reformed theologian and humanist philosopher, argues that "the rule against killing signifies a rule against taking life irresponsibly rather than a rule against taking innocent life," that is, "[o]ne cannot take life capriciously because it would violate the respect for God's presence and power over human life."¹³⁵ Thomasma suggests that, on Kuitert's view, "this prohibition does not rule out taking one's own life for rational and responsible reasons."¹³⁶

To support his claim, Thomasma points out that the Old Testament offers ideas about death that form part of the background of the rule against killing. These ideas include that death is an evil not originally intended by God; that death is due to human responsibility (or irresponsibility); and that death is a result of sin.¹³⁷ Alongside the Old Testament, however, the New Testament offers "a different and contrasting view of death that also feeds into the rule against killing...[but].. may provide some possible justification for suspending the rule."¹³⁸ The "new" view of death includes "death as a rebirth," and "death as a passage ...to a life of endless and unconditional love and happiness."¹³⁹ Thomasma argues that, "On this view, while death is an ontological evil for personal bodily identity, it is a spiritual good because it brings about the maturing of the Christian into a new life."¹⁴⁰ Thomasma writes:

Death may be a good, then, and intending or willing it may be a virtue (citations omitted). Note that this line or argument has little to do with personal autonomy and choice, or a concomitant argument for a right to die, but much to do with an enhanced

¹³⁵ Thomasma (1998), p. 129.

¹³⁶ Thomasma (1998), p. 129.

¹³⁷ Thomasma (1998), p. 130.

¹³⁸ Thomasma (1998), p. 130.

¹³⁹ Thomasma (1998), p. 130.

¹⁴⁰ Thomasma (1998), p. 130.

view of ordinary human persons who through redemption are transformed into mini-Christs.¹⁴¹

Having been deeply affected by the work of a Slavic Jesuit, Ladislaw Boros, entitled *The Mystery of Death* (1965), which suggested that Jesus committed suicide,¹⁴² Thomasma writes that his "interpretation of the events surrounding the passion and death of Christ has been colored by this conviction that one can and should sacrifice one's life for a higher good for the sake of others."¹⁴³ In the health care context, Thomasma suggests that "[m]ore importantly...those around such persons have obligations to assist in this sacrifice, to accedeby withholding and withdrawing their technology."¹⁴⁴ Thomasma admits that the question remains "whether this duty to stand aside includes one that sometimes requires active assistance."¹⁴⁵

Thomasma observes that in most cases of traditional martyrdom, the killing of the martyr, though with some degree of consent on the part of the martyr, stems from motives of hatred of that person and what he stood for.¹⁴⁶ But what about killing out of love or mercy, or allowing oneself to be killed out of love or mercy? Traditional martyrdom usually involves instances where the individual does not request death directly, but "is rather swept up in thoughtless, vengeful violence."¹⁴⁷ "[I]n the case of killing out of love, the individual requests death from the doctor, from a family member,

¹⁴¹ Thomasma (1998), p. 130.

¹⁴² Thomasma (1998), p. 136. Thomasma rejects the notion that Jesus committed "suicide," at least in our normal understanding of the term, that is, Jesus did not directly bring about his own death by his own hand. Thomasma accepts part of Boros' argument, however, that Jesus did will his own death and put into action a plan to bring it about. ¹⁴³ Thomasma (1998), p. 131.

¹⁴⁴ Thomasma (1998), p. 131.

¹⁴⁵ Thomasma (1998), p. 131.

¹⁴⁶ Thomasma (1998), p. 132.

¹⁴⁷ Thomasma (1998), p. 132.

a friend, or even sometimes an officially designated 'enemy,' but requests their death for a higher purpose, a symbol of some commitment to the Divine."¹⁴⁸

For Thomasma, "[t]he motive, the intent, does make a major difference in the morality of the act."¹⁴⁹ The examples offered by Thomasma to support his claim include the killings of St. Sebastian and St. Perpetua, each of whom were killed by the state (Rome). In the case of St. Sebastian, it was for the compassion he showed Sts. John and Paul; in the case of St. Perpetua, it was for her commitment to Christ. Each aided their executioners in completing their state ordered duties.¹⁵⁰ Sebastian is known for ordering his men, fellow archers, to carry out the state's order lest they meet a similar fate.¹⁵¹ Perpetua is known for guiding the sword in the hand of her reluctant executioner to her throat. As Thomasma notes that "the Christian martyrs all had one thing in common, a disregard for one's life in light of a higher principle of conscience, love of God and the Church."¹⁵²

Thomasma offers several reflections, based on his acceptance of Boros' argument that Jesus did will his own death and put into action a plan to bring it about.¹⁵³ Thomasma comments that "[t]here is an active intent and plan in Jesus' mission that is

¹⁴⁸ Thomasma (1998), pp. 132-3.

¹⁴⁹ Thomasma (1998), p. 133.

¹⁵⁰ Thomasma (1998), p. 133-5.

¹⁵¹ Thomasma is acutely aware of the Nazi conundrum, writing: "If we do not uphold the morality of the rule against killing, and morally condemn the actions of Sebastian's unit (soldier-friends who were ordered to kill him and didn't want to) then how can we condemn 'ordinary citizens' in Nazi Germany who participated in the derision, forced labor, torture, and death of millions of Jews? The horrible consequences of not resisting commands to kill are that the entire society becomes a willing mesh of evil" (Thomasma, p. 133).

¹⁵² Thomasma (1998), pp. 135-6. Thomasma discusses the deaths of other martyrs such as St. Ignatius, Archbishop of Antioch, who reflected on his forthcoming martyrdom; St. Peter, the Dominican priest, who asked his killers for a painful death as a sacrifice for Christ; St. Timothy, Paul's companion, who, in his old age, went looking for a martyr's death; St. Thomas More, who refused to acknowledge Henry VIII as head of the Church, and who, from his cell window marveled at two monks laughing and rejoicing on their way to their death for their similar resistance.

¹⁵³ Thomasma (1998), p. 136.

missing in those who think we should shun willing and acting to bring to pass our own death or the death of another."¹⁵⁴ Acknowledging that some may object that there is no need for further redemptive acts on the part of others because Jesus alone was destined to die "once for all," he points out that from the Christian martyrs' perspectives, they did just that: "they imitated Christ's death and through that imitation considered their deaths a gain."¹⁵⁵

Another reflection centers on death as a good. In terms of physiological survival, Thomasma admits that death "truly is an evil."¹⁵⁶ "Clinically speaking, however, death is often seen as a friend, a rescuer from suffering, and a relief."¹⁵⁷ More to the point, "Theologically speaking, death is for the Christian a new birth into the resurrected life promised through Christ and already experienced in the world."¹⁵⁸ For these reasons, he argues that discussions of euthanasia should "distinguish among the many meanings of death, as many perhaps as life itself."¹⁵⁹ For those considering assisting death, "[t]he morality of assisting death requires a complete analysis of this meaning for the person who is dying."¹⁶⁰ He concludes that because such a death may be "a participation in the redemptive act of Jesus, such a death may contain sufficient good to overcome the usual philosophical analysis of evil intent and outcome."¹⁶¹

¹⁵⁴ Thomasma (1998), p. 136.

¹⁵⁵ Thomasma (1998), p. 136.

¹⁵⁶ Thomasma (1998), p. 137.

¹⁵⁷ Thomasma (1998), p. 137.

¹⁵⁸ Thomasma (1998), p. 137.

¹⁵⁹ Thomasma (1998), p. 137.

¹⁶⁰ Thomasma (1998), p. 137.

¹⁶¹ Thomasma (1998), p. 137.

As a final reflection, Thomasma focuses on the participants themselves and suggests:

If death can be a good, and one can will that death in favor of a higher purpose, then those who assist in bringing it about can conceivably participate in this good act if their own motives are those of love and devotion to the person and/or that to which the person is dedicated.¹⁶²

Concerned about good intentions and good ends being confused with good acts, Thomasma cautions, however, that "[i]t does not follow automatically that a good intent and a good end are sufficient to make an act good. If the action itself is evil, then a good intention and a good end cannot redeem it. This is where the ethical analysis can be enriched by the stories of martyrdom."¹⁶³

Without question, however, Thomasma places all of this discussion in the context of the Christian faith when he writes: "[t]he point to underline here is the redemptive and courageous motive of giving up one's life for one's faith."¹⁶⁴ Thomasma is careful to point out that his reflections are not based on standard autonomy. Unlike Hardwig, Thomasma does not engage in a benefits/burdens analysis about how the suffering or dying of the primary sufferer is affecting the secondary sufferers emotionally, physically or financially. Instead, Thomasma suggests the following analysis:

...it seems too facile to interpret the rule against killing as implying that one could never intend the death of another. If one can so under certain circumstances, when death is perceived by the dying person as a good, or by the family and loved ones attendant upon the suffering of someone they love, then that death is a good thing, and intending it is also a good, perhaps even a virtue. If death can be sometimes seen as a good, then it can be virtuous to will or intend such a death. As the martyrdom stories suggest, actively

¹⁶² Thomasma (1998), p. 137.

¹⁶³ Thomasma (1998), p. 137.

¹⁶⁴ Thomasma (1998), p. 138.

assisting in that death may sometimes but rarely be subsumed in to God's greater redemptive plan.¹⁶⁵

Ultimately, Thomasma remains a pacifist because he "think[s] that is what Jesus asks of all of us," and is cautious about assisting death of any kind.¹⁶⁶ Aware of the "brutalities" of "a highly technologically-dependent civilization," however, he poignantly concludes:

...it is a brutality to the sacredness of human life to extend it unduly, to deny its origins and its ends, and to manipulate it in the person of the dying for the sake of legal fears, new and unusual interventions, and technological misperceptions about fundamental human acts like eating and drinking. To wish to say "no" to all of this may be a grace given by God, and to help may be an act of faith in the invisible hand of God."¹⁶⁷

D. Assessment of Thomasma's case.

With all due respect, it seems that Thomasma has been overly influenced by Boros' view of the death of Jesus. It is a misreading of the Gospel accounts to suggest that Jesus willed his own death in the sense that he wanted to die and put into place a plan to bring it about. Indeed, the Gospel of Mark, for example, reports that Jesus prayed to be relieved of his impending suffering and death if possible, but accepted God's will in that regard rather than his own. Later, Mark's account relates that Jesus foresaw that he would be handed over to the power of sinful men, indicating that, under their control, his condemnation and death would be their responsibility.¹⁶⁸ Although his divine power of omniscience gave Jesus foreknowledge of his human death, it does not follow that he willed that death or sought to bring it about.

¹⁶⁵ Thomasma (1998), p. 137.

¹⁶⁶ Thomasma (1998), p. 139.

¹⁶⁷ Thomasma (1998), p. 139.

¹⁶⁸ Mark 14:41

Jesus' intended mission all along was to carry out the will of God, which was to preach the message that God loves his people and calls his people to love each other. In the course of carrying out this mission, it became clear to Jesus that such a message and the following that it generated were threatening the secular government and the religious establishment. What Jesus did despite that awareness was to remain "on message" and true to his mission. Considering his mission in purely human terms, he must have sensed, much like Martin Luther King, Jr. and Ghandi, that if he did not shrink from his mission and message, his personal safety may be at risk at the hands of those who chose to hate him. In fact, as it turned out, he was killed. This does not mean, however, that he willed his death. It only means that others decided to kill him in order to end his "cause." His triumph was that, even in the face of death and in the course of his ignominious death, he remained true to his calling to do the will of the Father, namely, preach the Father's message of love and forgiveness.

Thomasma similarly misconstrues the actions of Sebastian and Perpetua when he suggests that they engaged in self-killing. Each of these martyrs was killed by orders of the state either because of their faith or compassionate actions. The fact that they did not resist their executioners, and for the temporal sakes of their reluctant executioners even "aided" them, does not mean that they engaged in self-killing. In the United States, persons sentenced to death in capital punishment cases usually courageously or cooperatively walk down the hall and either step into the electric chair or lay down on the execution gurney without resistance. It does not follow that these persons are engaging in self-killing. Rather, they are submitting themselves to the authority (albeit questionable) of the state.

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Thomasma's thesis that the martyrdom of Jesus and certain of the saints amounts to a kind of self-killing is similar to an interpretation often applied to the circumstances surrounding the death of Socrates in ancient Greece. Plato reports on those circumstances primarily through the dialogues. In one of those dialogues, the *Apology*, Plato describes the charges brought against Socrates by the Athenian government, and reveals the testimony during the subsequent trial that ended in a sentence of death for Socrates. According to this account, Socrates devoted himself to the pursuit of truth and knowledge through careful inquiry and analysis, and taught his method of philosophy primarily to young students. Eventually, the Athenian government charged him with the treasonous crimes of "corrupting the minds of the young, and of believing in deities of his own invention instead of the gods recognized by the state."¹⁶⁹ In his own defense, Socrates testifies at trial that he is an emissary of god, and that he would, and indeed must, resume the practice of philosophy were the court to set him free. He describes his philosophical mission in terms of a commitment to persuade others to care for their souls by making truth and understanding their chief concern and goal in life. In that regard, Plato relates the following testimony given by Socrates:

And if any of you disputes this and professes to care about these things, I shall not at once let him go or leave him. No, I shall question him and examine him and test him; and if it appears that in spite of his profession he has made no real progress toward goodness, I shall reprove him for neglecting what is of supreme importance, and giving his attention to trivialities. I shall do this to everyone that I meet, young or old, foreigner or fellow citizen...This, I do assure you, is what my God commands, and it is my belief that no greater good has ever befallen you in this city than my service to my God. For I spend all my time going about trying to persuade you, young and old, to make your first and chief concern not for your bodies nor for your possessions, but for the highest

¹⁶⁹*Apology*, <u>The Collected Dialogues of Plato</u>, Edith Hamilton and Huntington Cairns, eds., Bollingen Series LXXI, Princeton University Press (1961), 24b.

welfare of your souls, proclaiming as I go, Wealth does not bring goodness, but goodness brings wealth and every other blessing, both to the individual and to the state.¹⁷⁰

Despite Socrates' appeal to such a noble cause, in the end, the court condemns him to death, and imposes a method of execution that requires Socrates to drink hemlock by his own hand. This deliberate act on the part of Socrates has given rise to the suggestion that he committed suicide.¹⁷¹ Those who favor this interpretation argue as Thomasma does regarding the death of Jesus, that is, both had a way out of the circumstances that led to their execution. In the case of Jesus, the implication of Thomasma's reasoning is that, since Jesus instituted the plan that led to his own death and because he had foreknowledge of such results, he controlled his own fate to some extent. In the case of Socrates, had he accepted the limitations which the Athenians wished to impose on him, his life would have been spared.¹⁷² The conclusion is that, because Socrates refused such limitations and eventually drank the hemlock as the state ordered, he engaged in self-killing. In other words, "Had the Athenians hanged [Socrates], there would have been less doubt about the State's responsibility for his death; but the method actually invites suspicion of complicity on Socrates' part. In fact, the moral ambiguity entailed is probably just the reason why the Athenians afforded him this means of execution," so as to avoid the suspicion that they unjustly killed Socrates.¹⁷³

One way to resolve the uncertainty about the participation of both Jesus and Socrates in their own executions is to place responsibility for that process where it

¹⁷⁰*Apology*, 29e-30b.

¹⁷¹Walton, Richard (1980), "Socrates' Alleged Suicide," Journal of Value Inquiry 14, pp. 287-88.

¹⁷²Walton (1980), p. 289.

¹⁷³Walton (1980), p. 292.

belongs, which is on the state in both cases. Neither Jesus nor Socrates intended to die, even though that outcome was quite certain for both. Rather, Jesus intended to remain faithful to his mission and overcome death by overcoming the devil,¹⁷⁴ while Socrates intended to persist in his commitment to the philosophical life, even if that meant that each would die at the hands of the state for their faithfulness. In this sense, both Jesus and Socrates "died heroically, a martyr to truth, a victim of prejudice, fear and resentment."¹⁷⁵ Paul Shorey claims that this interpretation of the circumstances surrounding Socrates' execution is "…the overwhelming impression which the *Apology* still produces on the minds of sensitive undergraduates…"¹⁷⁶ No moral uncertainty attaches to Socrates' act of drinking the hemlock, just as none attaches to the condemned prisoner's act of stepping into the electric chair or of laying down on the execution gurney. In such cases, the prisoner's last act, however deliberate and intentional, is merely part of an unavoidable, state-ordered execution for which the state must accept full responsibility.

Lastly, Thomasma cites several exceptions to the rule against killing, and relies on the Roman Catholic tradition that supports these exceptions to suggest that altruistic suicide might be a valid addition to the list. The exceptions that Thomasma cites are just war, capital punishment, and self-defense. The Catholic tradition that he relies on, however, limits the scope of the underlying moral premise in these exceptions. In each exception, killing or bringing about the death of another human being is acceptable only as a foreseen but unintended consequence of exercising a moral right of defense, which

¹⁷⁴ Hebrew 2:14

¹⁷⁵Walton (1980), p. 288. Walton makes this claim with respect to Socrates only.

¹⁷⁶Shorey, Paul (1933), <u>What Plato Said</u>. Chicago. The University of Chicago Press, p. 85.

belongs to both an individual and the state. This limitation derives from Aquinas' discussion of self-defense as a kind of homicide.¹⁷⁷ For Aquinas, the morally acceptable goal in self-defense, though not obligatory in itself, is never to kill the attacker. Rather, the intention always must be to defend against an attacking force with an equal or lesser repelling force. When a force sufficient to ward off an attack results in the attacker's death, the attacker's death must be an unintended, although foreseen, consequence.

Even in the case of capital punishment, Aquinas contends that the justification rests on protection of the community. As he puts it, "the killing of malefactors is legitimate in so far as it is ordered to the well-being of the whole community. And so this right belongs only to those who are charged with the care of the whole community, just as it is the doctor who has been entrusted with the health of the whole body who may amputate a gangrenous limb. But the care of the whole community has been entrusted to the rulers who exercise public authority, and so it is only they, and not private persons, who may execute malefactors."¹⁷⁸ Such a qualification is further reason to reject Thomasma's suggestion that it is morally permissible for private persons to kill themselves, on the assumption that doing so will promote their spiritual well-being.

Some may view the distinction between foreseen and intended consequences as practically and psychologically, and thus morally, untenable. If Thomasma means to set aside this distinction, he needs an argument to that effect. As it now stands, however, the Catholic tradition that supports just war, capital punishment, and self-defense does not

¹⁷⁷ Summa Theologica, Q. 64, a. 7.

¹⁷⁸ Summa Theologica, Q. 64, a. 3.

support suicide for any reason, much less as an act of martyrdom. Neither does it support physician-assisted suicide.

IV. Conclusion.

Holistic medicine does not promote self-killing as a means of ameliorating suffering, or as an act of altruism, or as an act of redemptive martyrdom. Instead, it offers patients an alternative to the belief that they want to die now through assisted suicide,¹⁷⁹ or have a duty to die for the sake of their families, or need to embrace martyrdom as a spiritual discipline. To effect relief without hastening death, the holistic approach to patient care relies on a basic premise similar to Viktor Frankl's claim that a crucial step in resolving all suffering depends on the meaning and value that each gives to our own experience in that regard. For this reason, Eric Cassell claims that there are two primary ways to relieve suffering in the clinical setting. One is to guide patients to assign meaning to their medical condition, which often resolves the suffering associated with that condition. The other is a spiritual focus that assists patients in developing a sense of transcendence, which is most effective in restoring a sense of wholeness after injury to an individual's self or personhood.

The fundamental notion behind Cassell's approach is that caregivers must focus on fostering the best interests of the sick person rather than on merely treating a disease. In his view, sick persons usually know better than others what their best interests are, what aspects of function matter most to them, and when they are suffering. This

¹⁷⁹ Stream, Carol and Thomaas, Gary L. (1997), "Deadly compassion." *Christianity Today*. June 16, pp. 14-21. The authors explain that Pellegrino argues that the demand for PAS is a shortcut that attempts to address legitimate concerns in illegitimate ways. Pelligrino takes issue with those who see PAS as an act of compassion; instead, he suggests that it is often more compassionate for the frustrated physician or hurting family than it is for the patient. In fact, he maintains, assisted suicide is really a noncompassionate form of moral abandonment (see especially pp. 15-16).

approach includes the patient's knowledge as a vital element in the care process, which requires physicians to work more closely with patients and their families than is customary in traditional medical practice. Cassell's approach minimizes this limitation by focusing on a patient's suffering as a psychological condition that involves the whole person, rather than as a physiological condition that involves primarily the patient's body.

In this sense, Cassell offers a holistic approach to patient care that emphasizes unconditional acceptance of the patient by the caregiver, who may be friend, family, spiritual guide, or professional health care provider. His method relies on honest communication between caregiver and patient, which can relieve the patient's feeling of being a burden. Outside the bounds of conventional medicine, medical holism is often viewed as a radical alternative to patient care that emphasizes preventive and therapeutic self-healing strategies, which aim at enhancing one's own biological mechanisms with natural rather than artificial means.¹⁸⁰ Within the bounds of conventional medicine, however, holistic medicine can refer to techniques that complement and augment, rather than supplant, traditional medical practice.

A holistic approach to patient care relies on acceptance as a less onerous method of assisting patients in their search for relief of suffering. Acceptance is not to be confused with giving in to despair, which does not bring relief. In despairing, the sufferer merely gives up the *belief* that "what should be" is attainable without giving up the *desire* for that outcome.¹⁸¹ Confusing acceptance with despair is due primarily to the manner in which acceptance can have either positive or negative results for the sufferer. Positive

¹⁸⁰ Eskinazi (1998), p. 1622.

¹⁸¹Frankl (1986), pp. 108; 112.

results occur when acceptance derives from courage and self-determination, which can lead to wisdom and peace. Negative results occur when accepting a particular situation or outcome derives from indolent or cringing resignation, which can lead to resentment and bitterness. Such an attitude is often perceived and described in terms of despair, when a more accurate description would be as a different form of acceptance. In any case, relief of suffering follows either from having hope fulfilled or from acceptance, but never follows despair.

Regardless of how one finds relief, however, suffering itself remains an inescapable part of the human condition, and in some cases, is nothing less than unmitigated misery. Compassion for those who must endure such misery often motivates efforts to help them find relief. Such a response by the observer at times can become a natural duty based on the dignity of human beings.¹⁸² The medical profession itself long ago expressed a compassionate regard for others in adopting the relief of suffering related to disease and illness as one of its professional goals. This ideal, along with compassion and a benevolent regard for others, often motivate the individual physician to accept the healer's role and accompanying duty to relieve medically relevant suffering within reasonable limits.¹⁸³ As a result, medical holism functions on the premise that an adequate healthcare system responds to patients as persons who are ill and fully recognizes the need to integrate the many parts of their lives. Even for the individual,

¹⁸²James, S. (1982). "The Duty to Relieve Suffering." *Ethics* 93: 4021.

¹⁸³Pellegrino, Edmund D. (1983). "The Healing Relationship: The Architectonics of Clinical Medicine." <u>The Clinical Encounter: The Moral Fabric of the Physician-Patient Relationship</u>. E. A. Shelp. Boston and Dordrecht, D. Reidel Publishing Company, p. 163.

doing so promotes health, while evading that integration can lead to sickness.¹⁸⁴ If the medical profession were to embrace the claims of medical holism, a very different kind of academic and clinical training for physicians and other healthcare providers would become necessary. Hopefully, the end result would be a radical change for the better in the current orientation toward patients and the physician's responsibility regarding the relief of suffering.

¹⁸⁴ Alster (1989), pp. 48-49.

Chapter 5

Summary

Nothing at all makes sense, unless we admit, with John Donne, that: "No man is an island, entire of itself; every man is a piece of the continent, a part of the main."

Thomas Merton No Man is an Island

I. Summary of Chapter 1.

A major premise of this dissertation is that suffering is a pervasive and inevitable consequence of human existence. Among the many kinds, the suffering that stems from a medical condition can be especially perplexing, because most persons do not have the skills and resources to effect their own relief. As a result, they often turn to physicians for healing. Since relief of suffering is a traditional goal of medicine, the aim in Chapter 1 is to outline the nature of an appropriate clinical response to a patient's suffering from a physician's perspective.

An underlying assumption of the answer provided is that a physician's clinical response must be guided primarily by the principles of beneficence and respect for patient autonomy. For these principles to work in conjunction, however, the physician must respond with medically appropriate care and provide that care in a proportionate manner. According to this standard, the physician offers medical care that is backed by the scientific and clinical data relevant to the patient's medical condition, and equally important, provides such care in a manner deemed acceptable by the patient.

An indispensable aspect of providing medically appropriate care specifically aimed at relief of suffering is an understanding of the nature of suffering itself. Nonetheless, most physicians are at a disadvantage in this regard, because the medical profession itself does not yet have an adequate clinical understanding of suffering *per se*. To compensate, physicians often rely on their own personal and professional instincts and clinical experience to effect relief of suffering, especially at the end of life. The physician's professional limitations in this respect can be a disadvantage, and in some cases, might even harm the patient. The disappointment that follows for both physician and patient can lead to serious and sometimes irresolvable, tragic conflicts.

II. Summary of Chapter 2.

To avoid such consequences, the analysis in Chapter 2 develops a clinical concept of suffering, based primarily on the works of Freud, Bakan, and Cassell. That analysis shows that suffering is an existential problem associated with the person, in contrast to physical pain, which is a physiological problem associated with the body. Specifically, suffering is a state of emotion, consisting in an unrelenting tension between hope and despair, caused by the perception of a serious and unacceptable disruption in important personal matters. As Frankl explains, when one suffers, one perceives a gap between the way important matters are at the moment as compared to how such matters ought to be.

The matters are important and personal because they involve something that the sufferer holds dear. The gap is unacceptable because the consequences of not overcoming that disruption are potentially devastating. The sufferer's desire and belief that the situation will be resolved in a favorable manner gives rise to hope, while the thought of being overwhelmed by those circumstances gives rise to despair. The intensity and duration of the tension between these simultaneous and contradictory states of emotion are a function of various subjective factors, as well as the involvement of others and the particular circumstances that cause the suffering.

Given this description, it follows that relief of suffering results from eliminating or reducing the tension between hope and despair. In this sense, there are two avenues of relief. One avenue corresponds to the realization of a desired outcome that represents fulfillment of the sufferer's hope. The other avenue corresponds to a change in the tension between hope and despair that reflects the sufferer's acceptance of the situation. In acceptance, the sufferer relinquishes or modifies the desire and belief about a certain kind of outcome, and substitutes an alternative goal. As a result, the perceived gap between the "what is" and the "what should be" closes. Because there is no longer a perceived gap in expectations, the sufferer experiences relief.

III. Summary of Chapter 3.

In the clinical setting, it sometimes happens that all medical efforts fail to bring relief to the patient. Such a result can be most troubling at the end of life. In such cases, some terminally ill patients come to view hastening death by suicide as the most effective way to relieve their own suffering. To address this issue, the analysis in Chapter 3 highlights the moral complexity surrounding physician-assisted suicide. Developed in two stages, the conclusion is that physician-assisted suicide is a disproportionate medical response to a patient's suffering, and must be rejected by physicians as inappropriate medical care.

The first stage explores the claim espoused by Pellegrino and Thomasma that physicians must provide medically appropriate care in a proportionate manner. The second stage develops their principle of proportionality, based on a classical interpretation of that principle provided by Aquinas, and a modern interpretation provided by the works of Gury and Knauer. Each interpretation is then applied in turn to

the question of physician-assisted suicide, with the result that it fails to meet the requirements of either a classical or modern interpretation of proportionality.

Based on a classical interpretation of proportionality, the physician's agreement to assist a patient's suicide is morally impermissible for three reasons. First, it is contrary to the physician's duty to heal. Traditionally, a physician's professional commitment involves caring for human life with medically appropriate care as determined by the scientific and clinical data relevant to the patient's medical condition, quality of life, and personal preferences regarding that care. On this view, to heal does not necessarily mean to cure. As a result, physicians can fulfill their commitment to heal even when cure is not possible, the patient has a poor quality of life, and death is imminent. This standard of professional conduct reflects a long-standing medical, ethical, and legal tradition that bars the practice of physician-assisted suicide.

Second, physician-assisted suicide is contrary to the public good. The physician's participation in that practice renders it medically acceptable, which, due to its inherent and unavoidable potential for abuse, perpetuates harm to the common good. Support for this claim relies on evidence from the Dutch experience with euthanasia and from the U. S. criminal justice system in regard to the death penalty. Such evidence also serves to refute Brock's claim that safeguards are an effective way to prevent abuse of vulnerable persons. Based on such considerations, the prohibition of physician-assisted suicide must be maintained as a matter of prudence.

Third, despite the autonomous nature of a request for assisted suicide, the physician's agreement to provide that assistance is contrary to the virtuous practice of medicine. The virtuous practice of medicine requires the physician to provide medically

appropriate care, based on relevant scientific and clinical data. There is no such data that shows physician-assisted suicide as an effective way to relieve suffering. In the absence of such data, some physicians are led to substitute their own subjective evaluation of the patient's quality of life as warrant for their agreement. This substitution deviates from established medical protocol and exceeds the physician's expertise. Moreover, their agreement in particular cases goes to the level of medical principle for all other patients similarly situated, which renders physician-assisted suicide a *de facto* social policy. Yet, there is no reason to accept a physician's idiosyncratic approach to suffering as the basis of a social policy of this radical nature.

Physician-assisted suicide is also morally impermissible on Gury's interpretation of proportionality, because a predominance of good in the immediate outcome is unknown and incalculable. From a medical perspective, this lack of knowledge on the physician's part rules out the possibility of calculating the immediate net effect of physician-assisted suicide. As a result, the clinical basis for the claim that physician-assisted suicide indeed relieves suffering is lacking.

For this same reason, physician-assisted suicide also fails as a proportionate medical response on Knauer's account. Because he adds the claim that the realization of the values sought in the long run and on the whole must not undermine those or equally important values, there are two additional reasons for this failure. First, in the long run, physician-assisted suicide undermines autonomy and self-determination due to its potential for abuse. Second, on the whole, it creates an injustice for patients with fewer resources in that such patients may be forced to opt for physician-assisted suicide sooner than those patients with greater resources.

Even were the inequity that results from such disparity to be eliminated, the voluntary nature of a request for assisted suicide may be compromised by psychological factors as well, which ultimately raises a question of competency. Although a request for assisted suicide is not necessarily irrational, such a possibility demands exploration of the motivation behind such a request, which includes evaluating the patient's competency as an important safeguard against abuse. Despite that need, however, the guidelines and standards to aid in such evaluations have not been developed. Without standardized measures, there is no benchmark against which to assess the validity of actual evaluations. In that case, claiming that physician-assisted suicide in the long run and on the whole promotes autonomy and self-determination is without warrant.

The second additional reason that physician-assisted suicide fails as a proportionate medical response on Knauer's account is due to his claim that there must be no less onerous method of realizing the values sought. In the case of physician-assisted suicide, however, where the value sought is relief of suffering, there is a less onerous method of relief available, namely, acceptance. Although not always possible, acceptance is more likely when physicians treat patients as whole persons. In the clinical setting, physicians promote acceptance by inspiring hope for the good that is yet to come, even when no remedy or cure is available. The physician inspire hope with an explicit or implicit promise that the patient will not be abandoned to die alone, and if possible, will not suffer unbearably or go without adequate pain management in the final days of life.

A promise of professional non-abandonment raises yet another question about those "hard cases" in which every available treatment has been carried out, and still some patients cannot achieve acceptance, their pain management is no longer effective, and their suffering is unbearable. Some proponents argue that such an outcome is an outrage that should be avoided, especially in cases of terminal illness. As a result, they advocate allowing the practice of physician-assisted suicide (and voluntary active euthanasia for that matter). Others who oppose establishing physician-assisted suicide as a formal social policy nevertheless favor allowing it in some "hard cases" on an informal basis.

In contrast to these proposals, there are three reasons that physician-assisted suicide should not be allowed even in hard cases. First, allowing the practice is an inadequate and premature medical response, because doing so will lead physicians to accept such a request at face value without exploring and treating the underlying issues that cast doubt on its voluntary nature. Second, it is difficult to control the expansion of this kind of social policy that allows exceptions, simply because other exceptions are likely to emerge, along with the pressure to extend the outer boundaries to accommodate those new cases. Third, specifying exceptions entails the adoption of criteria and guidelines and the establishment of safeguards to protect against abuse. That process can transform physician-assisted suicide into permissible social policy, but "hard cases" cannot transform physician-assisted suicide into acceptable medical practice.

IV. Summary of Chapter 4.

The claim that physician-assisted suicide is a disproportionate medical response to patient suffering and thus must be rejected by physicians might seem counterintuitive. Nevertheless, the view defended herein is that the principles of respect for patient autonomy and beneficence must remain in balance with one another so as not to endanger vulnerable members of society, which precludes physician-assisted suicide. Instead, as the analysis in Chapter 4 shows, physicians must treat patients, especially the terminally

ill, in a holistic way. On a holistic model of medicine, patients are viewed as situated persons with spiritual and intellectual as well as physical needs, all of which vitally influence and determine an illness experience and an experience of suffering. By paying attention to all of these aspects of a patient's life rather than to just the physical, physicians are better able to treat the whole person, and thus better able to relieve the patient's suffering without causing death, even when the patient's underlying medical condition cannot be cured.

A holistic approach to patient care does not mean, however, that physicians must treat all aspects of a person's life. This model merely acknowledges that there are other dimensions to a patient's life—mental, spiritual, and emotional—in addition to the physical that at times need special attention. Nevertheless, neither physicians nor other caregivers can heal everything or be all things to all patients. The limited connections in a patient's life yield a partial set of meanings useful for interpreting and coping with disease and suffering. Although some needs will go unmet on this model, viewing patients holistically makes it possible to meet their needs more fully, which in turn, makes it possible to relieve their suffering more effectively.

From this perspective, Cassell offers two specific ways of relieving suffering in the clinical setting. One is to guide patients to assign a meaning to their medical condition, which often brings relief. The other is to focus on the spiritual aspects of the patient's medical condition, and to assist patients in developing a sense of personal transcendence. Since illness and disease are a kind of injury to the self, Cassell claims that a spiritual focus best enables patients to recover a sense of wholeness after injury.

A holistic approach to patient care requires physicians to sustain a compassionate presence with the patient. Physicians fulfill this commitment best by refusing to leave their patients alone and isolated in their illness. The compassionate physician also insists that those who can and should provide comfort and care to the patient, regardless of professional standing, should do so as an integral part of the healing process and as the patient desires. This is especially true at the end of life, where suffering can be difficult to relieve. In addition, the compassionate physician relieves all unnecessary pain of any kind or intensity when remedy is available, even if such measures hasten an unintended death, on condition that the patient desires that kind of relief. When cure is not possible, the compassionate physician aids the patient's continued life in a reasonable manner so as to avoid postponing an inevitable death against the patient's will.

Holistic medicine is centered in community, caring, compassion, and comfort. Its aim is to inspire patients to view themselves as persons of value even at the end of life. It places a special emphasis on spiritual concerns, because spirituality is an integral part of every individual's character and personality. Holistic medicine is one approach to patient care that attempts to meet the inherent need we all have to find meaning in life, in illness and disease, and especially in death. Works Cited

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