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UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

THE ADJUDICATION OF UTILITARIANISM AND RIGHTS IN THE SPHERE OF HEALTH CARE

A Dissertation

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment of the requirements for the

degree of

DOCTOR OF PHILOSOPHY

By

Harry L. Moore
Norman, Oklahoma
1998

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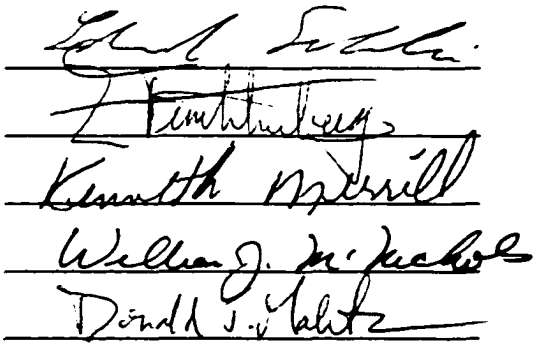
THE ADJUDICATION OF UTILITARIANISM AND RIGHTS IN THE SPHERE OF HEALTH CARE

A Dissertation APPROVED FOR THE
DEPARTMENT OF PHILOSOPHY

BY



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The following work is dedicated to the memory of my dad, Harry Moore, who died in November of 1995. It was he who initially taught me the meaning of ethical values and conduct, and to let my "yes" mean "yes," and my "no" mean "no."

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THE ADJUDICATION OF UTILITARIANISM AND RIGHTS IN THE SPHERE OF HEALTH CARE
Moore, Harry L., Ph.D. *The University of Oklahoma*, 1998, 204pp.
Chair: Edward Sankowski

This dissertation serves as a monograph on the moral and social implications of a utilitarian-based system of health care which recognizes and takes rights seriously. Though the design and claims are stated primarily in terms of utilitarianism, admittedly, there are elements of communitarian, deontological, and rights theories which have been incorporated.

Such a commingling of theoretical elements, under the claim of being utilitarian, may seem ambiguous, however, it is my contention that such inclusions only serve to enhance the plausible nature of this sphere-specific form of utilitarianism and the adjudication of rights. Additionally, though there are other components of theories included, the basis of utilitarianism still serves as the foundation by which all other actions, decisions, and values are judged.

While it is true that utilitarianism offers a standard for all areas of life, the idea of examining a sphere or environment of utility, in this case, the utility associated with the sphere of health care, allows for the good to be clearly defined. One primary weakness of classical utilitarianism is that it ignores, or at least does not do full

justice to, the notion of personal responsibility or sense of obligation. If the only duty or requirement is to produce some obscure sense of the "greatest good" or the "greatest happiness," the question of how the good is identified and who is to have the good remains unanswered by the traditional utilitarian construct.

The classical view of utilitarianism is too broad in its scope of defining "the greatest good" or realm of value. But to narrow the area of value to a particular sphere or environment allows for the utility and associated rights in question to be identified, the value measured, and the success more easily interpreted.

While maintaining the general premise of utilitarianism, that is, "the greatest good for the greatest number," the notion is not from some nebulous concept or subjective position about life or feelings in general. This sphere-specific position also acknowledges and defines the "rights" of the individual within the particular sphere being considered, in this case, the sphere of health care.

Chapter 1

Introduction

The whirlwind advancement of health care over the past fifty years may best be epitomized in a written statement from Wilbur Wright. Referring to the multiplicity of events he experienced while flying the first airplane, he writes, "With the machine's moving forward, the air flying backward, the propellers turning sideways and nothing standing still, it seemed almost impossible to find a starting point from which to trace various simultaneous reactions."[1]

Medical knowledge, procedures, pharmaceuticals, and technology continue to advance, driving up costs at astronomical rates. Expectations and demands by health care consumers continue to escalate, and the administration of the system seems out of control.

In addition, there is minimal agreement among the key players (e.g., hospital administrators, politicians, and insurance companies) on how to correct or control the health care system. The technologic explosion in medicine makes it almost impossible to find a point of reference from which to explore the problems and potential resolutions, if any, of such a system in a constant state of change and confusion.

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[1] This quote comes from the Wilbur Wright exhibit at the Aerospace Museum, San Diego, California.

Additionally, many health care policies, proposed economic solutions and various types of health care reform have been laid on the altar, built by the health care industry, and offered up in smoke in an attempt to appease this behemoth god of medicine. Philosophical arguments and intricate theories have attempted to design plans which would minimize or eradicate the associated ethical problems of justice, rights, and equality for the recipients of health care.

For example, one theorist has proposed that the problem lies in a pluralistic society's attempt to address biomedical/ethical issues from too many fragments of varying moral perspectives. He contends that the solution may be found only by identifying a common ground or point of reference based on what he calls a "content-full morality,"[2]

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[2] H. Tristram Engelhardt, Jr., *The Foundations of Bioethics*, Second Edition, (New York: Oxford University Press, 1996), 1-17. Engelhardt argues that there must be a common ground of ethics from which moral and medical decisions are made. The identified arena for such kindred spirits and common ground source is found only from the Judeo-Christian tradition. While it is true that the Judeo-Christian tradition may provide a common source of identification for an ethical and moral position, it can be argued that even among this group there is frequent disagreement regarding major ethical issues. Theologians, ethicists, physicians, scientists, and other contributors to the field of medical ethics, who align themselves as like-minded and coming from the Judeo-Christian tradition, fail to agree on what constitutes a moral/ethical foundation for addressing such ethical issues as euthanasia, abortion, terminating life support, and artificial tube feedings.

which is grounded in the Judeo-Christian moral tradition.

More specifically, Engelhardt views the Roman Catholic version of the Judeo-Christian tradition as the ideal framework within which to make moral, medical, bioethical judgements and decisions. Coming from a Roman Catholic tradition, Englehardt has reduced his theoretical position, concerning bioethics, to one theological in nature. While his claim for a "content-full morality" is commendable, to add a theological position does not offer "the" common ground for a moral position; it only offers "a" common ground which is further limited by one's conservative or liberal position.

Another theorist, John Rawls, has advocated a theory which, while theoretically and philosophically appealing, could hardly begin to support or adjudicate the issues of equality, rights, and/or justice associated with the real scenarios found in life, in general, and more specifically, the medical/ethical issues in health care. And to impose a "veil of ignorance,"[3] whereby everyone is in the same blind position, fails to acknowledge the individuality of each person. Such an idealistic scheme denies a sense of personal history and the unique psychological makeup of the individual, which even in theory seems meaningless.

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[3] John Rawls, *A Theory of Justice* (Massachusetts: The Belknap Press of Harvard University, 1971), 136-37.

Admittedly, there are a multitude of theoretical positions regarding health care and related ethical issues. This dissertation, however, serves as a monograph on the moral and social implications of a utilitarian-based system of health care which recognizes and takes rights seriously.

Though the viewpoint is utilitarian, it is different from other forms of utilitarianism in that it is focuses on a particular sphere.[4] That is, it focuses strictly on the sphere of health care and the adjudication of rights within this sphere.[5] It is acknowledged up front that no single theory can provide a solution or even a universally acceptable position. But, perhaps, the continuous reformulation of a particular theory can provide an additional grain of intellectual and pragmatically relevant ethical truth.

Though the design and claims of this dissertation are stated primarily in terms of utilitarianism, admittedly, there

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[4] The idea for the term "sphere-specific" comes partly from the title and content of Michael Walzer's book, *Spheres of Justice: A Defense of Pluralism and Equality*, (United States: Basic Books, A Division of Harper Collins Publishers, 1983), and partly from the notion that life is lived within spheres of experience.

[5] While the focus is on health care, the idea behind the notion of sphere-specific utilitarianism is that any number of other life or "human" spheres may be plugged into the calculus. With modifications to meet the specific needs in a particular sphere, the theoretical dynamics of this sphere-specific utilitarianism should be met.

are elements of communitarian, deontological, and rights theories which have been incorporated. While the inclusion of these theoretical components may provide an impure form of a utilitarian theory, it is acknowledged that there are and will be decisions and standards of conduct independent of, or seemingly in conflict with, classical utilitarianism, or any other theory for that matter. And while the major premises are utilitarian, it is my hope to retain some features of these theoretical constructs and reconcile them with a more communitarian outlook.

Such a commingling of theoretical elements, under the claim of being utilitarian, may seem ambiguous. However, it is my contention that such inclusions only serve to enhance the plausibility of this sphere-specific form of utilitarianism and the adjudication of rights. Additionally, while there are other components of theories included, the basis of utilitarianism still serves as the foundation by which all other actions, decisions, and values are judged.

Accordingly, while it may be acknowledged that individuals have rights beyond "life and liberty," such rights do not follow from some ideal conception of societal justice or humanity, but from a shared conception of social goods.[6] For "the idea of distributive justice has as much to do with

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[6] Walzer, xv.

being and doing as with having, as much to do with production as with consumption . . .[and the] multiplicity of goods is matched by a multiplicity of distributive procedures, agents and criteria."[7]

The sacrifice of a community or nation's infrastructure and well-being in the distribution of created goods, for the sake and sanctity of the notion of autonomy and the individual's perceived right to this or that, in this case health care, is a no-win situation.[8] Justice in the distributive process calls for some social controls and "defined limits of freedom"[9] within the particular sphere of goods or services being distributed. The intersection of autonomy and interdependence, individual rights and mutual obligation, calls for a "natural sensibility which impels us to see ourselves in relationships of interdependence with other people and take responsibility both for our own lives and for what happens to others as well."[10]

"All goods with which distributive justice is concerned

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[7] Ibid., 3.

[8] Willard Gaylin and Bruce Jennings, *The Perversion of Autonomy: The Proper Uses of Coercion and Constraints in a Liberal Society* (New York: The Free Press, 1996), 6.

[9] Ibid., 7.

[10] Ibid., 4.

are social goods.. . .[which] have shared meanings, because [the] conception and creation [of these goods] are [defined by] social processes."[11] It is from these social processes that social goods and personal qualities have their own spheres of operation, in which they work their effects "freely, spontaneously, and legitimately."[12]

It is from this notion that *Spheres of Justice*, by Michael Walzer, has been a major influence. I agree with his notion of a "distributive logic" which claims that "[health] care should be proportionate to illness and not to wealth."[13] I do, however, disagree with his view that "no single principle of distributive justice can govern all social goods and their distribution."[14] The principles of utilitarianism can serve as the benchmark by which all distributive actions, values, and consequences are judged.

However, even with the supposition that the traditional view of utilitarianism offers a standard for all areas of

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[11] Walzer, 7.

[12] Ibid., 19. It is from this statement that the notion of spheres of utility came to fruition.

[13] Ibid., 86.

[14] Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, Fourth Edition (Oxford: Oxford University Press, 1994), 338. (See Walzer's discussion in *Spheres*, pp. 3-10).

life, it fails to take into account the specific rights and responsibilities connected with the area of life being evaluated. The idea of examining a sphere or environment of utility, in this case, the utility associated with the sphere of health care, allows for the good to be more easily defined and translated into success.

One primary weakness of classical utilitarianism is that it ignores, or at least does not do full justice to, the notion of personal responsibility or sense of obligation. If the only duty or requirement is to produce some obscure sense of the "greatest good" or the "greatest happiness," the question of how the good is identified and who is to have the good remains unanswered by the traditional utilitarian construct.[15] Even with the assumption that the "greatest good" applies to any and all areas of life, the good or value intended must still be defined.

Another problem with the classical view of utilitarianism is that it is too broad in its scope of defining "the greatest good" or realm of value. But, to narrow the area of value to a particular sphere or environment allows for the utility and associated rights in question to be identified, the value measured, and the success more easily interpreted. Again, it

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15 Ross, W.D., "What Makes Right Acts Right?," *Ethical Theory: Classical and Contemporary Readings*, Louis P. Pojman, ed., (California: Wadsworth Publishing Co., 1989), 256.

is here that Walzer's notion of social goods having their own spheres of operation[16] comes into play, when identified with the rights contained within the particular sphere or environment of utility being evaluated.

It is my contention, therefore, that the "greatest good," in association with specific rights, must necessarily be defined or examined from within a particular sphere or environment, which serves as the focal point in which the theory is grounded. While maintaining the general premise of utilitarianism, that is, "the greatest good for the greatest number," the notion is not from some nebulous concept or subjective position about life or feelings in general. This sphere-specific position also acknowledges and defines the "rights" of the individual within the particular sphere being considered, in this case, the sphere of health care.

To put it another way, what kind of algorithm can be applied in order to know if the results or the desires to achieve "the greatest good" is successful? For example, the value of any medical activity is to restore some semblance of health; it is not the thing (i.e., the medicine, test, procedure, or surgery) itself which defines the "good" or value, but it is the sphere or environment within a particular context which gives or defines the value.

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[16] Ibid., 7.

Another example might be the availability or use of a CT scan (Computerized Axial Tomography) machine. The utility or value will be determined by the sphere or environment in which it is used, that is, it is the identified sphere or context which determines the value. Suppose there are three circumstances or arenas: one involves a person, the next involves the legal system, and the last involves a business. How will the value or utility be determined?

For the individual brought into the emergency room, after being injured in a motor vehicle accident, the CT scan may be of benefit in determining internal injuries not visible by routine x-rays. In this case, while the CT scan is important, it is not the machine which has value, but the results it produces. These results allow for the identification of certain sustained injuries, which provides the physician with the means to better know what treatment is needed, which, in turn, will help the person to regain a state of health.

From the perspective or sphere of the legal system, the use or availability of a CT scan machine has no value, unless it happens to be relevant to a particular case involving malpractice, which could have been avoided by the results produced by the test. However, if such a test was not warranted, then it is of no consequence to the value or sphere of litigation.

The last arena mentioned, the business environment, will

have a totally separate means of determining the utility, based on the production of a particular product, good, or service, in this case, the production of the CT scan machine. If a particular company produces the CT machine, then the value, success, or utility to be measured will be the number of machines sold, not the number of CT scans, or the reason it was or was not used.

While there are some goods that are needed absolutely, such as medical care, "there is no good such that once we see it, we know how it stands vis-a-vis all other goods and how much we owe to one another. The nature of the need is not self-evident."[17] But, such need is somewhat determinable by virtue of the identified or particular sphere of utility, with its different conceptions, associated rights and experiences. This, in turn, leads to "different patterns of provision"[18] and notions of distributive justice related to that specific sphere of goods or services needed or in demand.

"Despite the inherent forcefulness of the word, needs are elusive. People don't just have needs, they have ideas about their needs;"[19] they have degrees and various priorities

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[17] Ibid., 65.

[18] Ibid.

[19] Ibid., 66.

associated with their perception of need. These degrees and priorities are related not only to the concept of human nature but also to the history and culture of a particular society.[20]

"Since resources are always scarce, hard choices have to be made.. . ;"[21] and while such choices are subject to philosophical elucidation, the idea of a need or a communal commitment to meet such a need does not yield any clear calculation of degrees or priorities. Clearly, every need cannot be met to the same degree, "or any need to the ultimate degree,"[22] but, by examining needs and the goods or services associated with those needs, in relation to the specific sphere in which the needs exist, perhaps a more precise form of distributive justice may be attained.

Utilitarianism and a Right to Health Care

One particular advantage of utilitarianism over other theories is that the principle of utility is the ultimate and guiding principle by which all other principles, morals, ethical positions, and virtuous actions are measured. In defining this utilitarian system of health care and in an

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20 Ibid.

21 Ibid.

22 Ibid., 66-67.

attempt to address some primary issues associated with health care, the major focus will be to adjudicate the internally coherent ethical theory of utilitarianism with the issue of rights. That is, to achieve the greatest good for the greatest number of health care recipients while recognizing and supporting one's right to accept or reject the health care offered by this system.

The ethical implications of such a system, which acknowledges, defines, and supports the individual's right(s), will by necessity include the individual's responsibility in connection with the entitlement or right. Pragmatically, the reasons for a utilitarian designed system of health care are as follows. First, since utilitarianism is closely linked to economics, the rational and efficient use of resources is by necessity a primary component.

Second, since the function of morality is to serve as a guide to ethical human conduct, and utilitarianism is a consequence-based ethical theory, the value or utility of the actions associated with health care are to achieve the greatest benefit for the largest number, with the resources available. This, of course, does not mean that there are no negative or less than desirable outcomes, but the utility, intent, or "greatest good" or "benefit over burden" of the sphere of health care is maximized, decision-making or *prima*

facie obligations[23] becomes clearer, and the resolution of conflict is strengthened. Such action calls for a reduction in the continued use of scarce medical resources for cases which are deemed futile, based on clinical evidence of prognosis and ability to respond to treatment.

Third, as argued by David Hume, the obligation to benefit others comes from the principle of reciprocity. That is, if there are benefits received from society, then by virtue of this principle, society can expect and the individual has an obligation in return to promote or contribute to that society's well-being or best interest.

Fourth, associated with the intent of medicine is the principle of beneficence, that is, to do good with the health care resources available. Fifth, patient participation in his/her care has become a recognized right associated with the principle of autonomy, allowing greater involvement to accept or decline further treatment and use of health care resources.

While there are many topics associated with this participation in whether to allow or decline a treatment or procedure, the focus will be restricted. The primary discussion, associated with patient autonomy, will address the ethical question a right to health care and whether an indi-

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23 W.D. Ross, *The Right and the Good* (Oxford: Clarendon Press, 1930), 19-36.

vidual can morally demand medical treatment even if such actions are deemed futile by the physician and the patient has failed to respond to care already received.

Economics and Ethics

Health care expenditures rose from nine percent of the Gross Domestic Product in 1980 to more than fourteen percent in 1992, with an expected increase to more than nineteen percent by the year 2000.[24] Regardless of one's philosophical framework or theoretical position, economics is a vital part of the equation in health care.

Currently, there are more than two million Americans who lose their health care coverage each month; some will get it back, but the numbers continue to add to the more than 37 million who already go without health care coverage.[25] Many who have health insurance will lose their benefits due to unemployment, some because of their inability to continue making payments for medical insurance, and still others because benefits have been cut by their employer due to rising costs. Out of this 37 million, there are more than nine million children who are not covered under any form of a

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[24] Office of the Press Secretary, The White House, "Health Security: The President's Report to the American People," 1993.

[25] Ibid., 2.

health care plan.[26]

In addition, procedural costs and technological capabilities have seemingly outstripped the affordability of health care for many individuals within the U.S. The system has also advanced to such complexity that the ethics of humane and reasonable treatment seems to have been lost to defensive medicine, triggered by a litigious society. Just because the potential exists for prolonging the physiological characteristics of a person, do such possibilities and acts of vitalism always constitute the preserving of "life," thereby negating the responsible and realistic use of medical resources? I think not.

While many may choose to ignore the economic considerations of receiving and providing health care, it is by necessity a relevant factor which must be given equitable consideration. The issues of one person's so-called "right" to health care, that is, to receive the resources and equitable treatment must be evaluated in terms of benefit and burden.

Ethical concerns and health care reform have been, and continue to be, major political and economic "hot topics" of discussion. Attempts have been made to ensure that every citizen can access the system and receive medical treatment,

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[26] Ibid.

regardless of the prognosis or ability to pay. The down side is that many individuals have come to view this as a guarantee of a "right" to health care, when in reality, health care in the current market is a commodity to be purchased and is not and never has been a "right" in the United States.

Only in the event of an emergency or evidence of some type of guaranteed financial reimbursement has medical care been considered a "right." The up side, and only clearly defined "right," which is recognized and supported legally and clinically, is the right of the individual to have input into his or her treatment. This right also includes the individual's right to decide whether or not to even receive treatment, and the right to declare, in advance, what he or she would want if in a terminal or persistently unconscious condition.[27]

In spite of the shift to respect patient autonomy, provide quality health care, and effectively utilize the technological advances by which to cure illnesses and prolong life, we are still burdened with a system that is seemingly inequitable, unjust, and does not serve the greatest number or achieve the greatest good. The reality is that health care

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[27] These rights have been acknowledged and made a part of the legal system by the Patient Self-Determination Act of 1991, and are expressed in the Advance Directive, as related to the withholding or withdrawal of medical treatment if diagnosed as being terminally ill or persistently unconscious.

has costs and the current system does not guarantee a "right" to health care.

Additional problems are created by the unrealistic expectations by "consumers" which lead to the false assumption that health care is a right. This is due, in part, to earlier decades when health care costs were lower, and health insurance coverage paid for most, if not all, medical expenses. The fact remains, that the delivery of health care in the U.S. is, and always has been, based on a market-driven, fee-for-service system. It is only within the past ten to fifteen years that consumers have begun to realize the actual costs involved in medical care received, resulting in an increase of uncompensated care costs and "bad debts" by consumers.[28]

None of the current plans and policies being considered for health care reform propose a feasible plan of economic and equitable revision. While a change in the health care system is essential, to identify some of the key issues may help to

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[28] For additional information on the problems associated with uncompensated care, and the various distinctions, see the following articles. Joyce M. Mann, Glenn A. Melnick, Anil Bamezai, and Jack Zwanziger, "A Profile of Uncompensated Hospital Care, 1983-1995," *Health Affairs*, vol. 16, no. 4, (July/August, 1997): 223-232. Linda E. Fishman and James D. Bentley, "The Evolution of Support for Safety-Net Hospitals," *Health Affairs*, vol. 16, no. 4, (July/August, 1997): 30-47. Peter J. Cunningham and Ha T. Tu, "A Changing Picture of Uncompensated Care," *Health Affairs*, vol. 16, no. 4, (July/August, 1997): 167-175.

better understand how and what kind of theoretical and applicable reform will be necessary.

Policies and Politics

A critical discussion of issues may make it possible to design a workable system, rather than the usual tactic of designing a system and then examining the issues. However, as the myriad of experts discuss the various policies of recommended change, they "seem not only to be talking about different matters but even speaking different languages."[29]

Not only do the experts fail to agree on the central points of what is being discussed, but also they disagree on who will be identified as the target group(s), e.g., the elderly, children, or unemployed that must be considered and will most likely be affected by the revisions. In their failure to agree upon or identify the recipients, they miss the means and methods of designing a reasonably just and equitable system of health care distribution. As a result, the various players instrumental in the design and development of policies for a health care system talk at rather than to one another without establishing an agreeable agenda for reform.

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[29] Davis B. Bobrow and John S. Dryzek, *Policy Analysis by Design* (Pittsburgh: University of Pittsburgh, 1989), 4.

In October of 1993, President Clinton's "Report to the American People" called for reform of the health care system with universal access and health care security to be provided for all citizens. His statements brought to light the well-known reality that the American health care system is itself critically ill. It lacks competent administration, coherent organization, and ethical vision, and has become "intolerably expensive," shamefully inefficient, and definitely unjust.[26]

A progression of theories, policies, and procedures have attempted, and failed, to meet the needs of this leviathan system. The rationale of medicine is to promote the health and welfare of the patient and to help ensure the general health of society, but somewhere along the way, this goal has been lost. In the evolution of the health care system, an illusion has emerged that medical care is a "right" rather than a commodity within the United States.

Such persistent demands for treatment, whether efficacious or not, reflect the prevalent idea that as long as someone will pay, there is an entitlement or "right" to health care. This misperception includes the notion of having a "right" to have "everything done," regardless of the ethical considerations, futility of treatment, or cost. In part, this

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[26] Ron Hamel, "Issues & Currents," *Second Opinion* (July 1991): 126.

is due to the fact that as late as 1987 close to three-quarters of individual "health care expenses were paid by a private or public third party program,"[27] with minimal to no out-of-pocket expense being borne by the consumer. However, by 1994, uncompensated care costs had risen to an estimated $21 billion,[28] due to individuals losing or being unable to afford health care insurance.

With a major focus on the idea or principle of patient autonomy, many individuals have seemingly become confused about the genuine meaning of autonomy. The assumption seems to be that autonomy serves as a guarantor of any and all demands placed upon the resources of medicine; for example, a family demands that everything medically possible be done to sustain the patient's "life," even when such measures are deemed futile by the physician.[29]

On the positive side, the emphasis on autonomy and patient self-determination has evolved to serve as a corrective measure to physician and family paternalism,

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[27] Jack E. Fincham, Ph.D., Albert I. Wertheimer, Ph.D., *Pharmacy and the U.S. Health Care System* (New York: Pharmaceutical Product Press, 1991), 108.

[28] Cunningham and Tu, 169.

[29] For a more thorough discussion of the negative side of autonomy, see Willard Gaylin's and Bruce Jenning's book, *The Perversion of Autonomy.*

allowing the patient to refuse unwanted or futile treatment. Another consideration is that while the sick individual is a patient with rights to accept or reject treatment(s), he/she is also a citizen with responsibilities associated to that right. That is, the acknowledged right to make health care decisions should not be seen as an absolute or guaranteed right outside a given context. This context is bounded by the reality of the patient's ability to respond to the care received, the reality of limited resources and a society which recognizes the competing rights of others.[30]

Part of the problem is perpetuated by technology and the availability of potential life-prolonging procedures (e.g., heart, liver, and kidney transplants), which lend themselves to the often unrealistic expectations, by the patient and/or family, from medicine. Another major concern is found in the system itself; attempts are to keep everyone happy while trying to fix the system with Band-Aids.

Policies have been designed which attempt to achieve valued outcomes through programs which are supposedly sensitive to the context of time, place, and perceived need,[31] but fail to address or adapt to the constant changes in health

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30 Larry Churchill, "Autonomy and the Common Weal," *Hastings Center Report* (January-February, 1991): 28.

31 Bobrow, 19.

care demands. The tendency is to create policy after policy, resulting in a system so complex and unclear that values and perceived needs are perpetually in conflict.

Surely such attempts cannot be viewed as legitimate means of providing an equitable system of health care. To continue to provide medical care where minimal success is the expected outcome, while allowing others to be subjected to receiving substandard care or go without basic care is unequitable, unjust, and unethical.

In the development of these various schemes of policy design there has been an establishing, then mixing and mingling of "Welfare Economics," "Public Choice," "Social Structure," "Information Processing," and "Political Philosophy."[32] The attempt to achieve some semblance of order, equity and justice has resulted in a mishmash of policies, procedures and political disputes with no viable ethical and equitable resolution in sight.

Much of what happens might be analogous to building a house with multiple floor plans, numerous builders, and various types of nonuniform materials. The end product may be called a house, it may somewhat resemble a house, but it is functionally compromised. These policy designs will be examined in more detail in Chapter 2.

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[32] Ibid., 27-101.

Utility, Rights, and Health Care: Toward a More Equitable System

The purpose of my dissertation will be to examine the health care system within the United States and propose a utilitarian[33] system of health care. While a redesign of the health care system is needed, it will only be generally alluded to in order to address more specific issues related to health care.

In particular, the issue of what constitutes the good in health care, defining a "right" to health care, adjudicating the theory of utilitarianism with the issue and rights, and the idea of the patient's responsibility in the context of utility and rights, will be critically examined and discussed.

The primary intent, therefore, is to develop a theoretical and practical model which will address and adjudicate a theory of "rights" within a sphere-specific utilitarian system of health care. Some of the key concerns relevant to a more equitable system of health care

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[33] From this point on the term "utilitarian" will be used to equate with the idea of "the greatest good for the greatest number." That is, the whole concept of this writing is that health care is a "good", something to be received like a commodity, and this commodity should serve to perpetuate the "good", namely, beneficence, which is measured by the "good" or primary principle of utility. The right to this good is guaranteed by genuine need, with the associated responsibility of not abusing the system and helping to maximize the use of scarce resources, especially towards the end of life.

distribution will also be explored.

The general assumption is that "utilitarianism cannot support or yield a system of rights with moral force."[34] Such a supposition presupposes a "conflict of interest" and a "conflict of welfare" among the recipients because of the potential for perceived injustices and inequalities in benefits afforded to individuals by the system.

In the various interpretations of utilitarianism, it seems those "states of mind" and "perceptions of happiness or pleasure" have predominated, rather than proposing the idea that "[T]he moral impulse of utilitarianism is to define the right as good consequences and to motivate people to achieve [them]."[35] The utilitarian dictates for right action, in the sphere of health care, are based on the principle of beneficence and the need of the patient. Whether the person has a "right" or entitlement to this service is the question at hand.

It is my contention that the issue of "rights" must be defined in conjunction with the idea of a particular system and an established or clearly defined set of rights rather than merely from the individual's perspective and the claim

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[34] Russell Hardin, *Morality within the Limits of Reason* (Chicago: The University of Chicago Press, 1988), 77.

[35] Ibid., 3.

for an assumed right. One important element which is seemingly overlooked in most theories addressing the issue of rights is the participant's responsibility; the tendency is to discuss rights without mention of the recipient's obligation in relation to that particular, identified right.

Given the complexities of the concepts of equality and rights, the idea of distributive justice should be pursued only within a particular sphere. The nature and limits of a sphere being determined by the general and specific needs or purpose of the identified sphere (for example, the sphere of health care, education, community, and workplace). The sphere of health care, for example, has the general criteria of monitoring and providing the means to ensure community health and safety through public health clinics which provide inoculations for various types of diseases. More specifically, the particular goal of medicine is to provide health care for the individual.

Another example is found in the sphere of education. In most countries public education for children is considered a need which is provided through the efforts of communities establishing schools. In the United States, the need of public education for children, in general, is met through such community efforts. More specifically, private schools have been established to meet other identified needs or demands for a different quality or level of education.

Naturally, the development of policies which address the sphere specific needs will not work strictly within the micro realm of the individual or the macro realm of society at large. Clearly defined boundaries and consequences must be established within the particular system or policy being examined.

Utility in the sphere of health care, as a clearly defined system of distribution, could create a genuine right to needed care at a more objective and equitable level. The idea of "justice" and "fairness" in our current system becomes obscured, self-serving, and totally subjective for a particular individual or family, especially when there is no accountability for demands made and no financial responsibility for care received.

In Mill's treatises *Utilitarianism* and *On Liberty*, he briefly touches on the idea of proper education, in particular for the "youth." His notion is that such action would provide the means of ensuring each individual's ability to cognitively identify, appreciate, and experience the higher pleasures. This in turn would ideally enhance the sum happiness of the aggregate.

While such hedonistic idealism may be theoretically proposed, there is no practical outcome to be realized, and obviously with Mill's minute mention of such education, he too

might have sensed it to be an exercise in futility. Part of the problem in attempting to educate the masses is that such idealism does not affect people where they live, and pleasure or happiness is a very subjective experience.

Another identifiable problem is that while utilitarianism is concerned with maximizing consequences and achieving the greatest good for the greatest number in general, my theory is more narrowly defined and sphere specific. That is, the intent is to maximize the good or greatest benefit over burden in the distribution and utilization of health care resources for the greatest number.

Most theories addressing principles of utility seem to put the cart before the horse, that is, they want to define the individual within the system, rather than defining the system and educating the individual about reasonable expectations, responsibilities and acknowledged rights within that particular sphere or system. The "greatest good" must necessarily be defined from within a particular arena, not from a position about life in general; there must be a point of reference from which the theory can be grounded in order to work.

Being an ethical/moral theory based on utilitarianism, the parallel-grounding principles for this sphere-specific form of utility, and from which all other axioms are deduced or measured, are beneficence, nonmaleficence, autonomy and

justice.[36] In other words, the utility or the good to be achieved in the sphere of health care is supported and ideally realized by these secondary principles.

Any system of health care, in particular, a liberal system of health care, does not mean carte blanche for each and every individual. Such a system recognizes the individual as autonomous with certain previously defined rights and responsibilities, as a member of that society. Not only is the person responsible for what he does, but also, for what he does not do.

Utility of health care recognizes the physical and mental well-being of each citizen, with the greatest "good" being the right of every citizen in the U.S. to receive needed basic health care[37] in order to maintain some semblance of quality of life. Such a system also acknowledges that certain individuals will be or are limited in realizing "good health" by virtue of congenital defects, life style choices (again the issue of responsibility) and injury related physical limitations. This liberal, utilitarian-based health care

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[36] Beauchamp and Childress, 38.

[37] While the terms "reasonable" and "basic" may seem very subjective, the ideal in this context is that everyone individual is guaranteed the right to health care and treatment that is efficacious in eliminating the condition and will help restore the individual to a reasonable or realistically achievable state of health.

system recognizes the right of the individual to live how he or she might choose to live, with the understanding that there will be no discrimination or refusal of reasonable care should medical treatment be needed.

For example, the person who contracts the AIDS virus would receive whatever treatment is needed, but must also realize that in the end stages of the disease only comfort care would be available. The cancer patient who has had numerous treatments of chemotherapy and radiation therapy, with no evidence of remission, would be kept comfortable and as free of pain as possible.

Further futile treatment would no longer be an option, regardless of patients wishes or the coercion of a paternalistic, egocentric doctor who takes the patient's death as a personal affront to his skills as a physician. Neither would the family or a family member be able to serve as the interloper of the patient's fate, refusing to accept the realities of the situation. This system would also do away with "free" clinics which provide substandard care.

In such cases where an individual is born with no hope of survival, or a person becomes terminal because of a certain type of disease (e.g., cancer, AIDS, and renal failure) or physical injury or condition (e.g., stroke, anoxic brain injury, and head trauma) treatment is often futile and only serves to prolong the dying process, giving a pseudo

appearance of life which is sustained only by machinery, tubes, and medications.

Reasonable and efficacious medical treatment should be used when there is hope for the individual to recover to some form of sentient and reasonable quality of life. But, the reality is that such recovery is not always possible. In these cases, the resources could be used for another person's potential recovery.

One identifiable problem is, of course, who will decide what constitutes the idea of "right," "good," "quality," "futility of treatment," or "who lives and who dies?" Another major concern is how the system will be established to ensure some semblance of justice and equality, without becoming bogged down in bureaucratic red tape associated with the various governmental forms, policies, and procedures.

There is also a problem associated with the phrase "right to health care." This cliche encompasses a cluster of moral concerns often used to solicit support of some social program; but it is also a phrase which contains no clear sense of a moral foundation or content.[38] If health care, or access to the health care system, is a "right," regardless of ability to pay for services rendered, then can it be considered a more

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[38] H. Tristram Engelhardt, "Rights to Health Care: A Critical Appraisal," *The Journal of Medicine and Philosophy*, vol. 4, no. 2, (1979): 113.

legitimate right than the need for the basic necessities of life such as food, clothing, and shelter? Clearly, health care is a need, but the question of whether it is a right must be more clearly defined.

It is my proposal that health care can be considered a "right" only in a utilitarian-designed system of health care; of course, this will call for a clearer understanding of what the system entails and what is entitled to in such a system. These issues will be addressed and more thoroughly defined in succeeding chapters.

In chapter 2 there will be an overview of the health care industry during the 20th century within the United States, exploring some of the contributing factors which have helped to create such a problematic and unjust system. In particular, this chapter will address some of the social and political problems associated with various policies found within the current system. While this chapter may not seem immediately relevant to the sphere specific utilitarian theory development in later chapters, its purpose is to provide insight into the ethical concerns and inequities which exist.

Chapter 3 will present the idea of equality and responsibility of access to the proposed system of health care reform. Cries of "equality" are heard throughout the nation, but there is little talk of responsibility connected with those demands. A liberal system of health care is not a free

ride, but neither should it provide a multi-tiered system of health care which meets the needs of some and ignores the needs of others.

Chapter 4 will attempt to define some of the basic characteristics of a more equitable system of health care reform and delivery from the general premises of a utilitarian system, that is, "the greatest good for the greatest number." This will necessarily include defining what is meant by the word "good," and how it is to be incorporated into a utilitarian theory of health care. The basic premise is that the "good" or common good in health care is a societal experience, based on some notion of equitable access to basic, quality health care.

Another element of design in this theory of the common good is the idea of both positive and negative responsibility on the part of the individual and the collective whole. That is, we are not only responsible for our actions, but we are also responsible for our decisions not to act. The concept of utility does not negate concern for the individual, his desires, wishes, or acts of self-fulfillment, but it does call for a recognition of certain responsibilities and considerations to the general welfare of others within the community.

Addressing the issue of rights will be the theme in Chapter 5. More specifically, the issue of "rights" within the context of health care will be examined. It seems the

term "right" has become mistakenly associated with the idea of receiving any and all medical care. An analysis of the meaning of the word "right" must be given and the term examined and clearly defined in order to determine what kind of right is offered and supported by the health care system and society at large. While most theorists do not hold to the idea of utilitarianism being compatible with rights, it will be the intent of this chapter to argue for a utilitarian health care system which recognizes and honors a person's right to medical care.

The intent of Chapter 6 will be to explore the issue of medical futility and propose a system of distributive justice which serves in conjunction with rights and responsibilities in this sphere form of utilitarianism.

Chapter 7 will serve as the conclusion, attempting to put the whole theory in perspective. Trying to balance the theoretical and practical elements of a theory is never easy, but is a necessity when attempting influence and bring change to a society.

Adjudicating the theory of utilitarianism and the issue of rights in health care does not, and cannot serve as a solution to the associated problems in health care, but can possibly help overcome some of the limitations of previous

"formulations of ethical responsibility."[39] While seemingly idealistic, I believe that this form of utilitarianism is the most plausible theory to provide a more just and equitable system of health care, and contributes to the notion that rights and utilitarianism can be adjudicated.

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[39] Beauchamp and Childress, 3.

Chapter 2

A Brief Historical Overview of Health Care Advancement in the 20th Century: The Social and Political Implications

At the beginning of the 20th century, a large portion of the American population consisted of young adults and children. Health care was relatively inexpensive, generally ineffective, and focused primarily on acute illnesses. As the century and technology advanced, more effective health care was made available, which necessarily increased the cost of care received due to the expenditures for research and technological advancement. Still, health care costs, resource allocation, and priority-setting were not primary economic issues.

By the 1930s, scientific progress and the depression created a shift in concern for economic issues due to the mounting and unpayable bills by both patients and providers. In an attempt to address some of the rising economic concerns, talk emerged of developing a national health care system and consumer-owned medical cooperatives. In an attempt to reduce health care costs as political/economic issues, private hospitals and physicians invented state medical societies and Blue Cross and Blue Shield, initiating a financial scheme which allowed providers to maintain control, calming the political waters and discussions of government-controlled

health care schemes.[40]

The Forties and Fifties saw a big push to increase access to health care resources through programs such as the Hill-Burton Act, which promoted an increase in hospitals, clinics, long-term facilities, and other sites for the provision of health care services. Antibiotics and the advancement of medical and surgical skills, learned on the battlefields of World War II, began to affect the practice of medicine across the country.

New techniques in emergency treatment, trauma care, and other valuable interventions learned in the Korean War, further contributed to the advancement of medical technology and skills in caring for patients. Tax-exempt health care benefit plans gained increasing popularity for workers and employers, creating the illusion that health care costs were and would remain stable, i.e., the consumer did not realize the full cost of medical care received.

In the Sixties, attention focused on ways to improve access to health care through new government programs to pay for care and ways to address shortages in health care services by increasing the number of physicians and other health care professionals. In 1967, Medicare benefits were initiated for

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[40] Doug Henwood, "Paying-for-health," *Left Business Observer #57*, (February 1993): 1. This article was retrieved from the Internet; the LBO is a newsletter on economics and politics.

services provided in extended health care facilities, after the third day of hospital stay. Social Security amendments also mandated studies, experiments, and demonstrations of alternate systems to control rising health care expenditures. As billions were fed into the medical-industrial health care machine, inflation continued to escalate.

In response to rising medical costs and in an attempt to introduce cost-control and rationing, President Nixon implemented a policy which would encourage competitive-corporate-medicine. From this plan, subsidies were made available to create health maintenance organizations (HMOs); all businesses who provided health care benefits were required to offer this plan as an option to their insured workers.[41]

Successes of public and private programs began to cause a different set of concerns to surface in the 1970's. Incentives placed before the health care field by public and private purchasers of health care resulted in increases in the number of health professionals, services, resources, and technological advances. Funding programs to expand the number of sites for health care services and attempts to remove financial barriers to improve and create universal access resulted in increased utilization and expenditures.

The proliferation and duplication of services and

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[41] Ibid.

equipment, the progression in quality of care, the necessity of services, and an increase in defensive medicine practices and tort reform caused the health care system to become ripe for utility studies. As a result of these deliberations, action plans were developed to meet the growing costs and demands for health care.

The Eighties witnessed the convergence of technological advances in the health care system which enabled more sophisticated tests and procedures, previously provided only in the acute care setting, to be performed at ambulatory or outpatient sites. At the same time payment programs were developed which provided incentives to encourage this shift. Medicare reimbursement shifted from retrospective payment for costs to prospectively determined prices.

In the past two decades medical technology has progressed by such leaps and bounds that costs have become astronomical. With this high tech advancement has come the possibility to prolong life, even to the point of anatomical vitalism, i.e., keeping the body alive when no hope of recovery is present.

With the advent of the 1990s, most medical care is provided to the growing population of elderly patients with chronic diseases. Though a conceivable balance between the rising costs and seemingly insatiable demands for high-tech health care may have been anticipated, they have not been adequately addressed by either health care professionals and

planners, or economists.

Many health insurance companies attempt to control costs by setting limits on the amount covered and the length of a stay allowable for a particular illness or type of surgery. For those patients who are irreversibly ill, with little or no quality of life to be experienced or enjoyed, families often demand that every possible test, procedure, and treatment be performed on the patient, even if it is against the patient's expressed wishes. Such a violation of an individual's rights has become a major focus in ethical debates concerning patient autonomy and the right to refuse treatment.

Often these demands are with little or no consideration of the expense incurred by the medical institution and society when there is limited health insurance, finances, or nothing but Medicare to cover only a minimal portion of the patient's bill, for which the family is not responsible. That is, in the case of Medicare law dictates that the family is not financially responsible for anything beyond the established deductible not covered by Medicare.

However, in most cases the family refuses or cannot afford to pay the deductible, or that amount of the bill not covered by insurance. It then becomes necessary for the hospital to "write-off" this bill as a "no pay," or compound the expense by turning the bill over to a collection agency.

Public Policy by Design: An Attempt to Meet the Needs in Health Care

Though there is no particular order in the evolution of these policy designs, a brief overview will be given in order to better understand the intent of each model.

"Welfare Economics" attempts to "replicate for the public sector the decisions that would be made if private markets worked satisfactorily."[42] Such an attempt to realize aggregate net benefits [or utilities] which are accruing to individuals would necessarily require "distributive value judgments [and cost-benefit analysis] about the relative worth of individuals."[43] The self-serving, rational rich man, genius, or noted politician would receive a greater share of the benefits than the pauper, the mentally retarded, the person of average intellect, or the blue collar worker.

By virtue of its design, and in order to realize the "aggregate net benefit," distribution of desired goods would be based on the axiom of "the more valuable the citizen, the greater the benefits received." While this may not be the original intent of such a policy, the reality is that those who understand and control the system gain the most.

The "Public Choice" model is similar to welfare economics

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[42] Bobrow, 33.

[43] Ibid.

in that it too recognizes the realities of rational, self-serving, maximizing individuals, in particular, the political leaders who are in charge of design and the making of policies. "Unlike welfare economics, though, public choice admits of no benevolent, public-spirited, unitary government."[44]

The system tends to be controlled at a higher level of government, rather than at a lower and possibly more responsive level, with the idea that equity between persons and regions will be ensured.[45] While the spirit of this model may present the idea of intended equity, the reality is that the rich get richer and the poor get lost in the shuffle.

In the "Social Structure" approach, there are a number of social theory models which establish its foundation:

> **Functionalism** explains individual and collective behavior; . . . **.Symbolic action** theory interprets behavior; . . . **.Role theory** assumes that people adopt the roles that promote their social acceptance; . . . **Socioeconomic determinism** regards behavior as being determined by social and economic conditions; . . . **.Interest Theory** contends action is based on a rational pursuit of real interests; . . . and **Action Theory** sees rationality only in terms of subjective perception and attitudes.[46]

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[44] Ibid., 50.

[45] Ibid.

[46] Ibid., 69.

This structure has been utilized in areas such as health care, public education, law enforcement, urban policy, antipoverty programs, and the criminal justice system. While seemingly beneficent in its intent, there has been a large gap between what it offers in principle and what is received in practice. Part of the problem is identified in the "frequent lack of policy applicability." While focusing on the advancing of "disciplinary knowledge," effective public policy is left undone.[47]

Two other major contributing factors are that: (1) demographic variables often play a larger role than variables open to manipulation by public policy; and (2) even when manipulable factors loom large, they often lie outside the jurisdiction of the institutions responsible for the issue or problem at hand.[48]

While the social structure model may have had its beginnings in the 1960s, it is still a working model which fails to adequately provide for an equitable and workable system of practical social reform. It has helped to establish a growing mind set of "rights" centered expectations by individuals from government-sponsored programs and services in

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[47] Ibid., 73.

[48] Ibid.

general, with health care services being a prime example.

Similar to the social structure, the "Information Processing" model utilizes many subspecialty disciplines from the natural and social sciences. "Individuals are seen as making decisions based on some internal, simplified model of an external situation."[49] This approach views the government as a collection of various structures with their own agendas, but unlike the public choice model, these structures are not considered as means of aggregating the preferences of "rational utility maximizers."[50]

This system is comprised of so many varying theories and agendas that no one particular group is willing to take responsibility for the weighing of values and the making of decisions. This model is the epitome of the typical bureaucracy associated with government agencies, where no one (individual or department) seems to be aware of what anyone else is doing. To get a straight answer is extremely difficult.

The "Political Philosophy" model is comprised of political science, philosophy, law, and an "offshoot in economics and sociology."[51] On the plus side, this system

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[49] Ibid., 84

[50] Ibid.

[51] Ibid., 105.

views the individual as someone who merits moral consideration and therefore is central to the models' design, directing its intent toward the individual's interests and rights. The negative is that while man is considered a moral, sentient being with various needs, there are little consensuses on how these needs are to be defined or met.

Individual preferences that tend to conflict with the principle of human dignity are excluded before being entered into the utilitarian calculus. Part of the problem common to this policy formation is that there is a conflict between the ideas of equality, utility and rights, with a minimal consensus on the identity or potential resolution of any of these issues.[52]

The Rising Cost of Health Care: Who's Going to Pay the Bill?

The reality is that there is a price tag on health care which must be paid for by someone--i.e., individuals with insurance, private pay, or government programs. Perhaps to better understand the economic factors involved, a cost shift model description, based on the following figures, will serve to illustrate the inequitable distribution of costs of health care to society.

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[52] Ibid., 109.

Type of Coverage	Average Cost Per Patient Day	Patient Days
Medicare	$759	35,585
Medicaid	$872	4,313
Self-Pay	$660	4,137
Commercial (Insurance)	$956	3,692
All Others (HMO's,PPO's)	$994	14,011

Before getting into the analysis of the Cost Shift Model, a background is needed in how hospitals are currently being paid for the services rendered. Medicare reimburses hospitals a fixed amount based on the principal diagnosis of the patient. These classifications are known as Diagnostic Related Groups, DRG's. There are 492 total DRG's presently used by Medicare.

Initially, the DRG program was designed to reward efficient providers of health care and force the inefficient to improve their delivery systems or face closure; however, it has turned into a budget reconciliation tool for Congress. Medicaid reimburses hospitals on a per diem rate, a fixed amount per each day in the hospital and caps the total number of days per diem at twenty. Charity and uncollectables are the accounts not collected due to the financial limitations of the patient.

With this background, the Cost Shift Model will demonstrate the impact each of the groups noted above have on the charges hospitals make to the insurance companies and charges incurred by those individuals without insurance

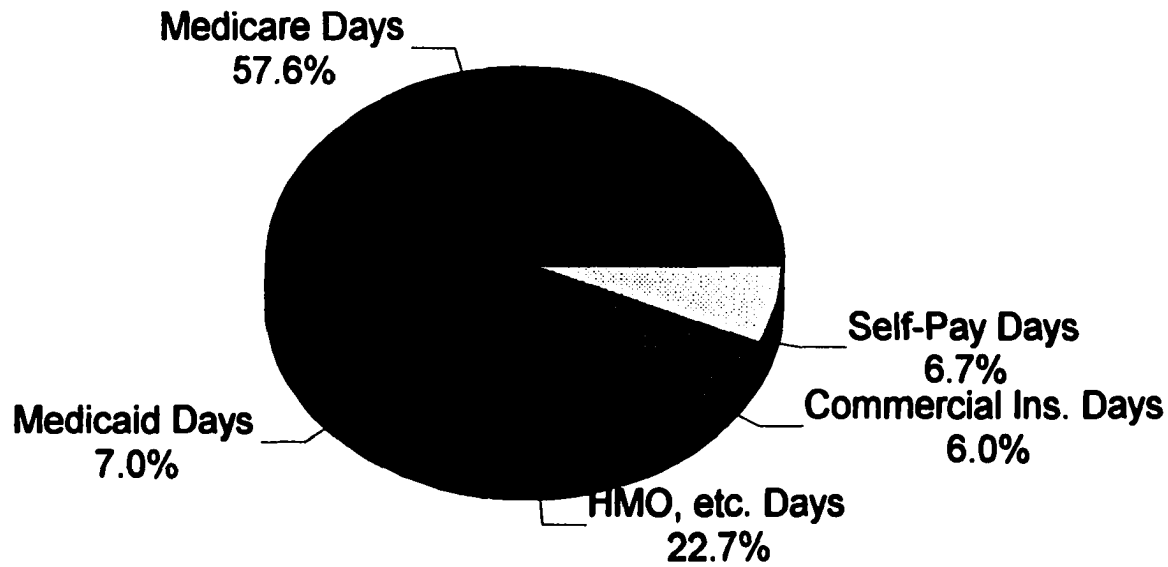
coverage.

The first graph reflects the average number of days, per payer group, over the fiscal year 1995. The total number of days for each payer group indicates the total average of patients for that year. That is, the daily census of patients in a particular hospital is calculated. At the end of the fiscal year, the daily censuses are totaled to give the number of patient days. The daily census can be broken down to reflect payer type. For example, Medicare reflects 35,585 days, which indicates approximately 100 Medicare patients were in a particular hospital on any given day. This average is determined by dividing the total patient days (according to payer group) by the number days in a year.

The second graph reflects the average cost of $848 per patient day, assuming that the cost to provide the care is equal for all patients. The graph also reflects the payer mix based on patient days and, as can be seen, Medicare represents the largest payer group for the hospital.

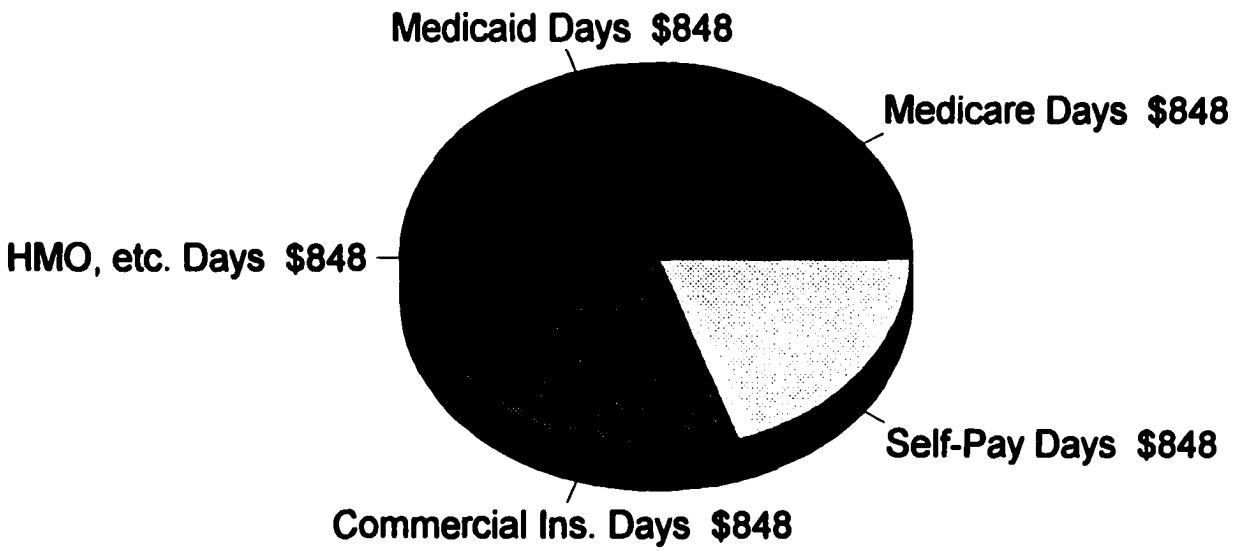
Graph 3 represents the cost per patient day for all payers, assuming all payers are paying billed charges while in the hospital and that the hospital's net income from operations is 8% (a "profit" is needed by hospitals--even the "not for profit" hospital--to generate the cost needed to keep facilities and equipment updated). Assuming this 8% net income, the charge per patient day would be $916.

Graph # 1
Cost Shift Model

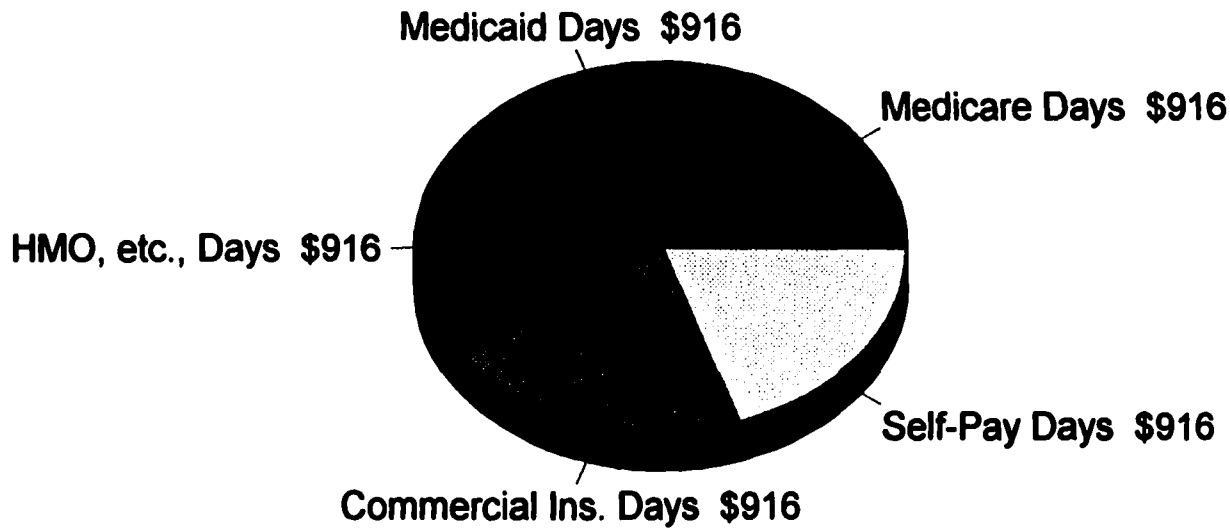


Medicare Days = 35,585
Medicaid Days = 4,313
HMO, etc. Days = 14,011
Commercial Ins. Days = 3,692
Self-Pay Days = 4,137

Graph # 2
Cost Shift Model
$848 Represents the average cost per patient day, assuming all payers are billed equally



Graph # 3
Cost Shift Model
$916 Represents the needed 8% increase in net income to maintain the facility and equipment

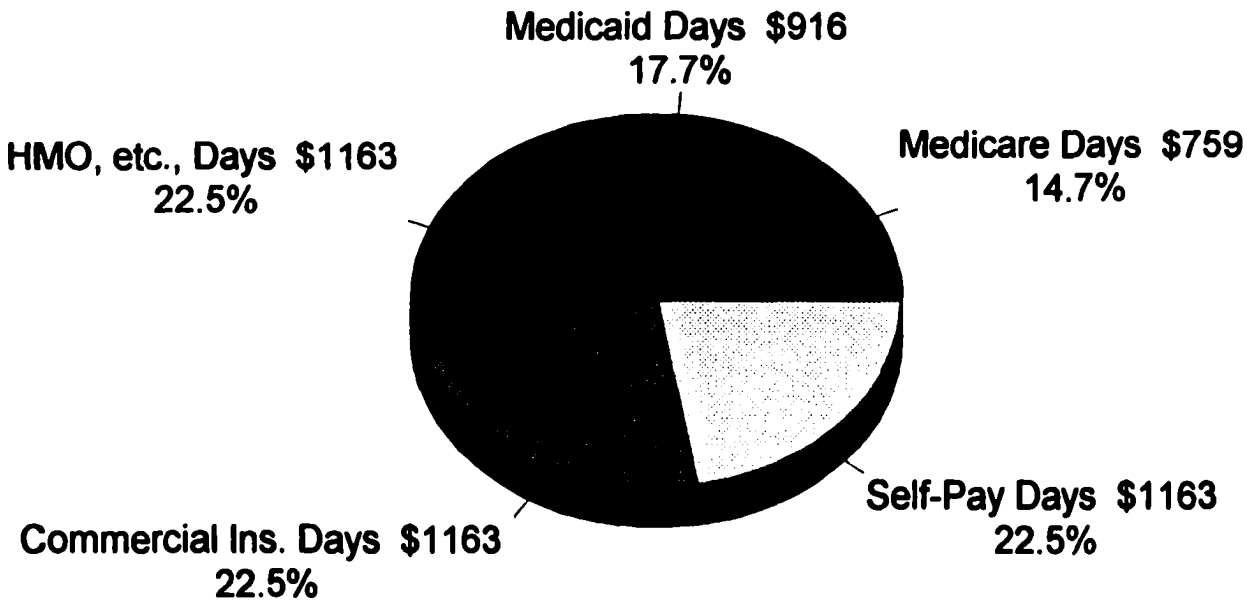


Graph 4 focuses on the average amount of $759 which Medicare reimburses per patient day, in comparison to the total average charge of $916 per day. The amount not paid by Medicare must be shifted to the other payer groups, if the hospital is to achieve its 8% net income. Distributed evenly over the other patient days, the amount not paid by Medicare results in charges increasing from $916 per day to $1163 per day to cover costs and gain the necessary 8% net income. Even if the hospital wanted to just break even, the financial considerations would still require the hospital to shift the burden to other payers since Medicare reimburses at less than cost.

The next graph reflects the amount Medicaid actually pays in relationship to the new charges of $1163. Since Medicaid pays only $484.04 per patient day there is a $679.00 per patient day shortfall, which, again, must be redistributed to the remaining payer groups. This results in an average increase of $195 per patient day.

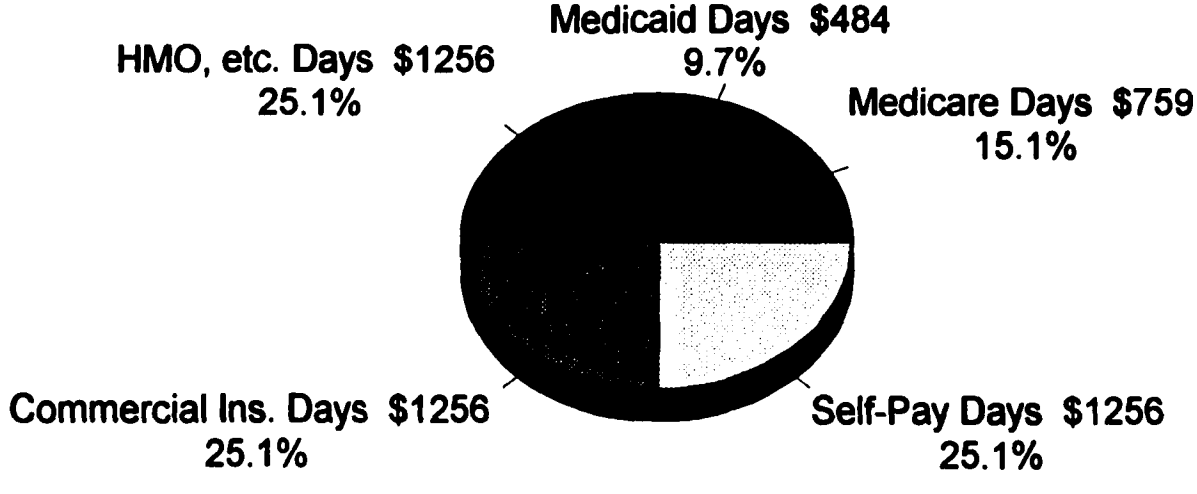
Graph 6 illustrates the additional 21% cost shift to other payer groups due to the shortfall from Medicare and Medicaid reimbursements. Additional factors include charity write-offs and those who do not pay their bill; these are not reflected in the chart because they are in a totally different account. They are mentioned only to indicate the additional burden passed on to the primary payer groups. As can be seen,

Graph # 4
Cost Shift Model
$1163 Represents a 27% increase which is shifted to the other payer groups since Medicare reimburses at less than cost and nothing further can be shifted to Medicaid

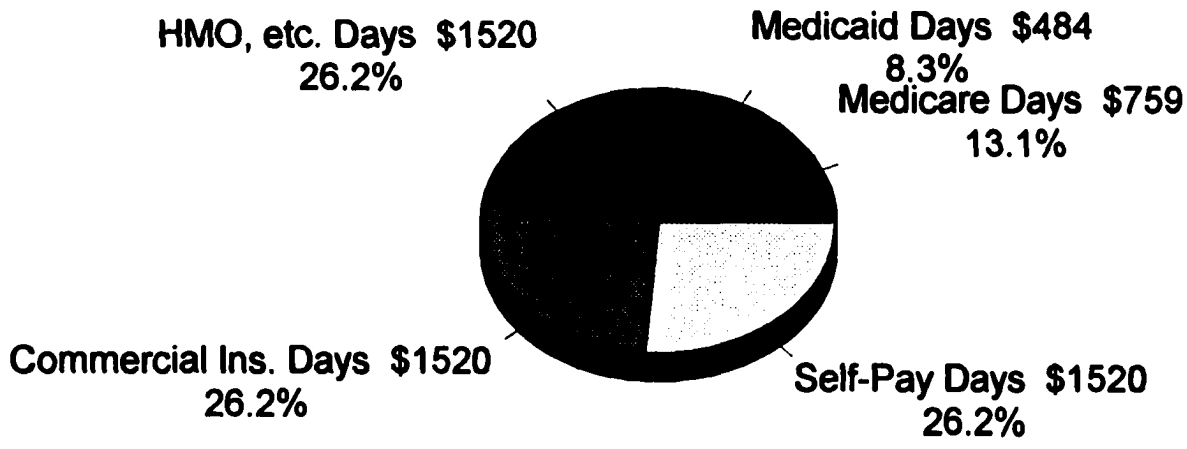


Graph # 5
Cost Shift Model

$1256 represents the additional cost shift amount needed to provide the 8% net profit. The $484 reflects the actual per diem rate provided for each Medicaid day and the $759 is an average of the DRG reimbursement for Medicare



Graph # 6
Cost Shift Model
$1520 represents a 21% cost shift to other payer groups due to the shortfall realized by Medicare and Medicaid reimbursement, charity write-offs and uncollectibles



the total burden has to be shifted to the remaining groups made up of those insured[53] and self-pays, resulting in the average cost of $1520 per patient day.

The Cost Shift Model clearly demonstrates the burden that Medicare, Medicaid, charity and no-pays have placed on health care costs. The shift in these costs increased prices almost 100% over costs to provide the care claimed as a "right," and by shifting this burden to the insured and self-pays, there has been, in effect, an implementation of another tax on those paying for health care. This "tax" burden will continue to grow as the government (state and federal) uses this reimbursement system in an attempt to keep the budget deficits from growing.

One possible solution to the real dilemma in health care allocation was found in the proposed reform in Oregon, in 1989. "The Oregon Basic Health Services Act mandated universal access to basic [health] care, but also included rationing services to those individuals who are Medicaid recipients."[54] If no new resources or funding were added, the

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53 While the HMO, etc. group reflects an increase in realized costs, the actual amount paid will depend upon the fixed terms of the contract.

54 Norman Daniels, "Is the Oregon Rationing Plan Fair?," *Journal of the American Medical Association*, (May, 1991), Vol. 265, No. 17: 2232.

Medicaid recipients would be worse off, but the current inequality between the poor and the rest of society would be reduced. As pointed out by Dr. Kitzhuber, in his paper presented to the Estes Park Institute:

> The Oregon Health Plan should not be viewed as a solution, but rather as a political strategy--a process to achieve consensuses on the policy objective and principles of reform and a framework in which resource allocation and reallocation can take place.[55]

With the Oregon Plan came the systematic rationing of health care services. In a country that has adhered to a social principle of universal access, the question of health care rationing seemed almost inconceivable. The truth is that in the past the reality of costs and limited resources has never been based on a conscious public policy but on a cost shift basis which was allowed by the willingness of third party payers to absorb the actual cost incurred.

"Widespread third party insurance coverage and the ability to cost shift created the illusion that health care was free, since both providers and consumers were insulated from the true cost of treatment decisions."[56] With this misconception came the expectation, by consumers, that not

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[55] John A. Kitzhaber, M.D., "Speech to The Estes Park Institute," (January 28, 1992): 1.

[56] Ibid., 4.

only access but everything the health care system had to offer, including high tech and experimental procedures, were theirs for the asking. Health care providers were also allowed to enjoy the luxury of "employing all treatments available, regardless of the cost, as long as some potential benefit, however slight, might result."[57]

A cogent argument could be made that the cost of universal access was being paid for by society. But, with more of the costs being shifted to the provider community, i.e., hospitals and physicians, by the "cost containment" measures instituted in the 1980's, they were soon unable to absorb them. What was once subsidized care in an institution or practice began to show up as uncompensated care. And when a provider or institution reached a point of being unable or unwilling to absorb any additional uncompensated care, they began to require that individuals pay the costs themselves.[58]

One of the great ironies of the health care system in the U.S. is that the more money is pumped into the system, the more people are squeezed out of the system. One of the great hypocrisies of this system is that those who are most likely to be "squeezed out" are not those who are unemployed or

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[57] Ibid., 5.

[58] Ibid.

retired, but those who are working.

If an individual doesn't have health care insurance or private resources to pay for health care, access to the health care system is likely to be lost. This is because the individual is forced into a growing coverage gap, either because there is a delay or avoidance in seeking treatment out of concern for how to pay for it, or the inability to find a provider who will see the individual as a patient.

Currently, this coverage gap encompasses approximately 35 million people on any given day, the majority of them workers with dependents.[59] Individuals between the ages of 19-24, account for 20.3% of the population who are currently uninsured, and an additional 13.6% of the uninsured population falls between the ages of 55 and 64. In 1991, health care expenditures constituted 12.4% of the GNP, and for the beginning of 1992, the figure was in excess of $750 billion for the first quarter alone.

To better illustrate the reality of this dilemma: Assume a person earns an annual salary of $7,500 to support a family of four. He is not eligible for Medicaid because he makes too much money. His rent is $250 a month and food and utilities cost another $300 a month. This takes $6,600 of his annual income of $7,500, leaving only $900 a year for clothing,

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[59] Ibid.

miscellaneous expenses, health care, and transportation.

What happens when he or one of his family members gets sick? One trip to the emergency department at the local hospital could easily consume one-third of the family's annual discretionary income. It is difficult for him to find a physician who will take a new patient--particularly a medically indigent patient. What is he to do? He waits. He waits until the problem is so severe he can't wait any longer. As a last resort he goes to the emergency room, where the cost for treatment has increased because the condition has worsened.

Emergency rooms are becoming a primary source of health care intervention for many people. As a result, what we are seeing is a direct consequence of implicit social and legislative rationing decisions for which there is no accountability. Premature infants are dying from respiratory distress because their mothers did not receive prenatal care. Young adults are brought in in a diabetic coma, with serious wound infections, and pneumonia all because they delayed treatment and have never been educated in self-care with diet and insulin. These situations are a result of individuals waiting for treatment because they did not know how they were going to pay for the treatments received. This is rationing of health care in a very real and negative sense.

In addition to the tragic and dramatic impact on

individuals, the health care crisis is also affecting the major payers of health care, i.e., the government and business community. In spite of efforts to protect themselves from the cost shift, both sources are buckling under the sheer magnitude of expenditures for health care. Federal spending has increased by approximately 13% per year over the past twenty years, accounting for the second fastest growing deficit after interest on the national debt.

While the Oregon Plan did not propose to solve the health care dilemma, it did incorporate the primary principles that: "(1) there is a social obligation to guarantee universal access to a *basic level* of health care, (2) reasonable or necessary limits on resources mean that not every beneficial service can be included in the basic level of health care, and (3) a public process, involving consideration of social values, is required to determine what services will be included in the basic level of health care."[60]

The current trend in attempting to provide medical care for a reduced price is found in the concept of managed care. While there are certain basic elements which help reduce costs and provide coverage for more people, it does not provide universal access. It limits choices and services to recipients, what doctors can offer or even inform their

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[60] Daniels, 232.

patients about regarding options of treatment, and the administrators and insurance companies are getting richer.

While the term "managed care" has a ring of better utilization, the reality is that what is being managed is money and people, offering less coverage for a greater profit. The shift in health care delivery has gone from a patient-based to payer-based system, with the "ideal client" as one who never submits a claim. In reality, what managed care describes is a variety of price and use control strategies designed by private insurers and health-care-provider conglomerates.[61]

According to one prominent health maintenance organization (HMO) executive, people are seen as numbers, not patients, which makes decisions about services provided much easier. "Just like Ford, we're a mass production medical assembly line, and there is no room for the human equation in our bottom line. Profits are king."[62]

While reductions in cost and the utilization of resources are necessary, by necessity limits must be placed on rampant use of health care resources, "managed care" does not provide an equitable or ethical plan of providing health care.

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[61] Henwood, 3.

[62] Malcolm Berko, "HMOs Don't Have a Patient's Health in Mind," *The Sunday Oklahoman*, August, 25, 1996, p. 2.

Where Do We Go From Here?

Health care and the common good can only be adequately and equitably realized from a utilitarian perspective. The question of "fairness" may be raised, but is not the issue in this or any other proposal for restructuring the health care system. If the objective is to provide health care, we must recognize that health care is not synonymous with health--it is a means to an end, not an end in itself.[63] Access to basic health care may be a positive right for individuals, and in keeping with the welfare of the common good, but not an exclusive right for some at the expense of others.

Reducing health care to claim rights is an absurdity, especially if the system continues to be saturated with demands equated with rights--at no realized cost for some. The reality is that rights may be claimed, but when economic and resource factors are ignored, the system will not and cannot bear the burden. When a system collapses, there is nothing left to claim as a right. The health care "source" is not an eternal fountain of youth, it can and will run dry of funding, resources, and accessibility.

"The problem with most health care proposals today is that they start at the bottom of the matrix with a completed

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[63] Ibid., 10.

'plan' and then try to 'sell' it."[64] None of these "proposed solutions" have been grounded in or built around a consensus of objectives and principles. Rather, they seem to be founded on politics rather than policy, offering a "quick fix" based on short term economic interests.

The common good and health care is not an easily definable term, but a societal experience, based on equitable access to basic health care. We will continue to advance in medical technology and capabilities, however, the reality is that all individuals are not equal in their ability to pay the price for high-tech medical care.

Perhaps the most valuable, just and ethical solution for the common good is to develop a system which recognizes that providing preventive care for thousands of people is more efficacious than one experimental procedure, costing $200,000, which benefits one. "We must sacrifice the freedom that has allowed us to avoid the reality that we have become obsessed with providing health care as opposed to improving health."[65]

To date, perhaps the best or closest model of a universally accessible and utilitarian form of health care provision is found in Hawaii. In 1974, the "Prepaid Health

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[64] Ibid., 9.

[65] Ibid., 16.

Care Act (PPHCA)" was enacted in Hawaii, establishing an extremely successful law which mandates employer health care coverage.[66] This PPHCA plan ensures that costs are shared between employers and employees, with the employee paying as much as fifty percent of the premium cost.

By law, the employer must provide a minimum of basic services as defined in Section 393-7 of the mandate. This section covers the basics associated with hospitalization, surgery, after care, necessary home, office, and hospital physician visits, necessary laboratory and radiology tests necessary for diagnosis and treatment, and maternity benefits. Under this basic-standard benefit plan, no employed person can be rejected, and the PPHCA's "indirect coercion of the insurers to more effectively treat patients with chronic disease rather than reject them, . . . result in a more cost-efficient system."[67]

By comparison, Hawaii's overall health care costs are lower than the rest of the nation (7.8% of the gross state product compared to the U.S. gross domestic product of 11.2%), but also lower than Sweden (9.0%), Canada (8.6%), Germany

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[66] John C. Lewin, M.D., Peter A. Sybinsky, Ph.D., "Hawaii's Employer Mandate and Its contribution to Universal Access," *JAMA*, (May 19, 1993) vol 269, no 19: 2538.

[67] Ibid., 2539.

(8.2%), and the Netherlands (8.5%).[68] The key seems to be that everyone must pay and play; the young and the healthy must pay into the plan along with those who have a greater need for health care and medical services.

Concerning the medical indigent, the Department of Health estimates the "gap group in financial need" to be approximately 3.5% of the population, or about 35,000 people.[69] In essence, what this plan has done is to reduce the number of uninsured and provided health care coverage for virtually all employees in Hawaii, creating a legitimate "right" to health care, and in turn, reducing the costs related to those uninsured. This plan, as related to maximizing the good or greatest benefit and the issue of rights, will be further examined in a later chapter.

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[68] Ibid.

[69] Ibid., 2540

Chapter 3

Liberalism in Health Care: Equality and Responsibility of Access

Since president Clinton's proposal for health care reform in 1992, hospitals, businesses, and individuals have turned their attention to the various presented plans designed to meet the health care needs of the public. The President states that his intention is for every American to have access to a health care system with comprehensive benefits that can never be taken away.[70]

Such a system calls for equality and justice as a primary component of access to a liberal health care system,[71] raising

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[70] Health Security: The President's Report to the American People, October 27, 1993.

[71] The idea of a liberal health care system, as presented in this paper, is based on the utilitarian concept of equality in which each person's happiness and well-being counts as one unit, no more and no less, with the consequence being the realization of the greatest benefit for the greatest number of people. Autonomy is recognized and the idea of the self is realized in that each individual is capable of critically reflecting on the values that govern his socialization. (Michael Walzer, "The Communitarian Critique of Liberalism," *Political Theory*, Vol 18 (1990): 248). This theory is not independent of some concept of the good for man or a particular conception of the good life and what it is that gives value to that life. In this theory the good requires having equal access and treatment to health care which will help to restore a person's health when possible; that which gives value to his life is the realization or hope of physical or mental well-being and the ability to resume a productive life, as determined by the individual, allowing him to contribute to the aggregate good. The main goal of such a health care plan is that an individual can access the system

the question, "How is this to be accomplished?" The major difference between the present reality and the President's proposal for the future is that those who currently have no insurance would have coverage and insurance companies would pay for the health care received, rather than hospitals writing off the bill, if the patient doesn't qualify for Medicaid.

One problem not addressed in all the various proposed plans is how to avoid the expenditure of health care resources and dollars on futile treatment. That is, medical care which is ineffectual, which will be of no physical benefit to the individual, may or may not be covered by any insurance plan and will certainly not be paid for by the individual, his estate or his family. The purpose of this chapter will be to describe the current realities of health care, and examine the positive and negative attributes of a liberal approach to

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with the expectation of being treated equally for physical or mental conditions, but cannot expect preferential treatment which would deprive others of the same type treatment. The principle of utility presented in this theory contains not only a sense of responsibility for individual actions but holds the individual responsible for his nonactions, that is, an unwillingness to make changes or concede to the inevitability of a particular situation. For example, the person with AIDS who continues to have sex with whomever, jeopardizing the lives of others. Or, the family member who refuses to allow intensive care medical treatments to be stopped when all such treatments are futile. (This additional notion of responsibility for nonactions is based on Kai Nielsen's, "Against Moral Conservatism," *Ethical Theory: Classical and Contemporary Readings*, Louis P. Pojman, ed., (California: Wadsworth Publishing Co., 1989), 181.

health care, with the primary focus on those cases which call for extraordinary or futile care and treatment with no hope of the individual's recovery.[72]

I will address the inequalities perpetuated by the futility of some treatments, (e.g., in the case of Baby K, an anencephalic born in 1992, and Helga Wanglie, an eighty-five year old female who suffered severe anoxia in 1990). In these two cases alone, such futile treatment takes intensive health care resources and dollars away from, not only those with insurance, but also those who can't even afford basic health care. In addition, such inappropriate continuation of medical care must be paid for through higher costs in premiums and health care expenditures by others.

I will then describe how a liberal, sphere-specific utilitarian health care system can provide equal access to medical treatment. Such action, not only respects the rights of the individual to reasonable health care, but also, it takes a realistic and humane approach to minimizing or eliminating futile medical treatment. The question then is, "How is a liberal system to address this problem?"

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[72] References to a liberal health care system will mean that all individuals have access to the system, and each individual is to be treated equally within the system, according to his ability to respond to treatment. Futility of treatment will refer to medical intervention that cannot and will not achieve the goals of its action, that is to restore a general state of health.

The Current Realties of Health Care

In spite of the various claims by different factions of both the liberal and conservative camps, every individual does have access to health care in some form or fashion. Those individuals and families who still have health care insurance realize the benefits either as part of an employment package or as a result of paying premiums for health care insurance. But an increasing number of people have lost or will lose their health care insurance benefits due to unemployment, not being able to continue making payments for medical insurance, or because benefits have been cut by their employer because of rising costs.

Currently, it is estimated that more than two million Americans will lose their health care coverage every month; some will get it back, but ultimately the numbers will add to the more than 37 million who will go without health care coverage.[73] Out of these 37 million, more than 9 million are children who will not be covered under some form of health care plan.[74]

In spite of these increasing numbers, and the claims that health care is not accessible to many Americans, health care

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[73] The President's Report: 2.

[74] Ibid.

is available, on a more limited basis, to individuals who cannot wait for some more equitable plan which will allow them to maintain their health care benefits, pride, and dignity. Currently, only a fraction of the cost of treatment by those individuals without medical insurance is being covered by Medicaid.

Regardless of the decrease in health care coverage, medical treatment is still needed. However, more individuals, most without insurance, come to emergency rooms to seek treatment for various physical ailments and symptoms. Then there are those who, because of an accident and injury, are brought to the hospital. In addition, most of those individuals without medical insurance coverage or money to pay for treatment, wait until they are so ill that hospitalization is required, which adds to the bill which they cannot pay. The reality is that health care costs, and this care must be paid for by someone.

Part of the current problem is perpetuated by the rapid advancement of medical technology, life-prolonging procedures (e.g., heart, liver, and kidney transplants), which lends itself to the public's frequent unrealistic expectations of medicine and technology, which has outstripped the affordability of health care and the ethics of humane and reasonable treatment. Just because the potential exists for prolonging the physiological characteristics of a person, do such

possibilities negate the responsible and realistic use of medical resources?

"Between 1980 and 1992, American health care spending rose from 9 percent of Gross Domestic Product (GDP) to 14 percent. Without reform, spending on health care will reach 19 percent by the year 2000."[75] The question then is, "Does a view that 'life' is sacred and should be maintained at all costs warrant an open ended ticket to an already overextended system?" This, of course, would depend upon with whom you are talking.

Such instances raise the additional question, "Who's being treated in such cases where there is no hope for the individual's recovery," yet treatment continues because of family wishes? Certainly this cannot be considered an equitable and just system, one which neglects the needs of basic health care for children and the elderly, while allowing hundreds and thousands of dollars to be spent daily on individuals whose sole existence depends on tubes and machines.[76]

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[75] The President's Report.

[76] Two such cases involve Baby K, who by court order is still being treated, and Helga Wanglie, who eventually died, In spite of her husband's success in obtaining a court order to continue futile treatment.

Liberalism, Autonomy and Health Care

In one of Bob Dylan's songs he sings that "The times, they are a changin'..." and so it is within the health care system. We have seen technology advance at a tremendous rate of speed and machinery become outdated before it hits the market. We have come to recognize the right of autonomy of the individual to have input into his treatment or whether to even receive treatment.

Physician paternalism, "Dr. knows best," has been challenged and treatment on demand has become a current reality. For example, a patient is seen in an emergency room for a minor head injury; x-rays are taken and the individual requests a CAT scan, so the doctor orders it for fear that he may return with his lawyer claiming that "not everything was done to make sure my head was okay."

With every positive there is always the possibility for a negative, and in spite of the shift to respect for patient autonomy, all the technological advances, and the possibility to prolong life, the reality is that people are born and eventually die. There are some things that individuals demand and technology cannot fix or cure. This is where the breakdown occurs in our current system of health care, and most likely in any of the plans currently being considered in the President's proposed health care reform.

A liberal system of health care and the notion of autonomy does not mean access to unlimited resources for everyone. Such a system does, however, acknowledge the individual as valuable member of that society, with certain rights and responsibilities. In this context, the "right" is to have access to needed medical care, with the "responsibility" of not abusing the system or expecting unwarranted or continued futile treatment.

The utility to be realized is the physical and mental well-being of each citizen by providing the means to maintain reasonably good health of all its members. Such a system also takes into account the realization that certain individuals will be or are limited in realizing "good health" by virtue of physical limitations and abnormalities.

This sphere-specific utilitarian based health care system recognizes the right of the individual to live how he or she might choose, with the understanding that there will be no discrimination or refusal of reasonable treatment should medical treatment be needed. For example, the person who smokes runs a greater risk of contracting lung cancer. While every reasonable or efficacious treatment would be made available, in the end stages of the disease process, only comfort care and hospice would be available.

Another example is the cancer patient who has had numerous treatments of chemotherapy and radiation therapy,

with no evidence of remission. Ideally, the patient would receive palliative care and kept as free of pain as possible, without being subjected to further painful and futile treatment. Realistically, many patients do not want additional treatment but agree to such treatments by the coercion of a paternalistic, egocentric doctor, or family members who often attempt to usurp the patient's stated wishes, refusing to give up hope.

In those cases where an individual is born with no hope of survival, or a person becomes terminal because of a certain type of disease process (e.g., cancer, AIDS, renal failure), physical injury, or persistent vegetative condition (e.g., stroke, anoxic brain injury, head trauma) treatment is often deemed futile and only serves to prolong the dying process. In such cases, the continuation of ineffectual medical intervention only serves to give a false sense of hope or the appearance of life which is sustained only by machinery, tubes, and medications. While efficacious and reasonable medical treatment should be used when there is hope for the individual to recover to some form of sentient and reasonable quality of life, the reality is that such recovery is not always possible.

Case One: On October 13, 1992, a baby (referred to as Baby K) was born at Fairfax Hospital, in the Washington DC

suburb of Falls Church, Virginia. The baby was born anencephalic (i.e., born without a brain) and was immediately placed on a mechanical ventilator because of respiratory distress. Baby K's condition had been diagnosed prior to her birth, but her mother refused to terminate the pregnancy because of strong religious beliefs.

Within a few days after the birth, hospital medical personnel approached the mother about issuing a DNR order ("Do Not Resuscitate Order") and allowing them to withdraw ventilator support, arguing that the treatment given was futile and inappropriate in this case where no cure or hope of reversal of the condition was possible. Again, the mother refused on religious grounds, claiming that all life is sacred and should be protected, and that only God "should decide the moment of her daughter's death."[77]

Over the first year of her life, Baby K required mechanical ventilation, on numerous occasions, in order to breathe, and she required a total of four months in the hospital's pediatric intensive care unit. In spite of hospital officials, physicians, and an ethics committee recommendations, Judge Hilton of the United States District Court, Alexandra Division, ordered that the hospital must

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[77] Michael McCarthy, "Anencephalic baby's right to life?," *The Lancet*, Vol 342, (October 9), 1993: 919.

provide aggressive life-sustaining treatment or be in violation of state and federal laws prohibiting discrimination against the handicapped, child abuse, and the Emergency Medical Treatment Act.[78]

Hilton cited the Fourteenth Amendment as extending to guarantee the right of parents to make medical decisions for their children. He "concluded that the First Amendment, which guarantees the free exercise of religion, also applied, because the mother's decision was based on a religious conviction that all life is sacred."[79]

Regarding Hilton's citing of the Fourteenth Amendment, there is no constitutional right or provision for the use of all possible medical technology in sustaining anyone's life; "the Fourteenth Amendment says that a state may not deny equal protection of the laws."[80] Concerning the mother's arguments related to her religious conviction, the moment of her baby's death was when she was born.

If it was not for mechanical ventilation to sustain her

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78 The decision by Judge Hilton was that the hospital was legally obligated to provide any and all emergency medical treatments, including ventilator support. For additional information see: Baby K, **832 F. Supp. 1022** (E. D. Va., Alexandria Div., 1993).

79 McCarthy.

80 Richard B. Brandt, *Morality, Utilitarianism, and Rights* (Cambridge: University Press, 1992), 356.

nutrition and hydration, Baby K's life would cease. Her "life" would end not because the machinery was turned off but because there is nothing there physiologically to support her life functions on its own.

Three months later, the case was heard in the United States Court of Appeals, Fourth Circuit. Judge Hilton's decision was affirmed by a panel of the Fourth Circuit, with the opinion written by Judge Wilkins. The panel did not, however, affirm Judge Hilton's rulings concerning discrimination against the handicapped or state and federal child abuse laws. Its decision only affirmed Hilton's ruling that failure to provide emergency treatment needed by Baby K would violate the federal Emergency Medical Treatment Act. It also held that the "hospital was not authorized to decline to provide stabilizing treatment which it considered morally and ethically inappropriate."[81] There was, however, a dissenting and filed opinion by Senior Circuit Judge Sprouse, which essentially stated that Baby K's unique medical condition, though tragic, "should be regarded as a continuum, [and] not as a series of discrete emergency medical conditions to be

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Baby K, **16 F. 3d 590** (United States Court of Appeals, Fourth Circuit, 1994); appeal denied. See Baby K through Mr. K and Ms. H, **513 U.S. 825, 115, S. CT. 1026** (October 3, 1994).

considered in isolation."[82]

Case Two: Helga Wanglie was an eighty-five year old, well-educated and active woman who on December 14, 1989, tripped over a rug, fell and broke her hip. She was hospitalized at Hennepin County Medical Center, Hennepin, Minnesota, underwent surgery, and began rehabilitation over the next five months. During this time she suffered several cardiopulmonary arrests, and on May 23, 1990, after another cardiac arrest, suffered severe anoxia (i.e., lack of oxygen to the brain). She remained unconscious in a persistent vegetative state (PVS), her breathing sustained by a ventilator, and her nutritional and hydrational needs being met by artificial means (i.e., tube feedings and IVS) until her death on July 4, 1991.

In December of 1990, the physicians involved with Mrs. Wanglie's case determined that her condition was irreversible and approached Oliver Wanglie about withdrawing treatment. Mr. Wanglie indicated that his wife had not indicated her wishes prior to hospitalization, but that she had always been a very religious person, she considered life sacred, and he felt she would want life-support continued. A petition was filed with the Minnesota District Court by Dr. Steven Miles, a gerontologist who served as an ethical consultant to the

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[82] Ibid.

physicians caring for Mrs. Wanglie, requesting that another guardian be named.

On July 1, 1991, Judge Patricia Belois "ruled that 'Miles has offered no evidence that Oliver Wanglie is incompetent to discharge the trust as Conservator of the Person of his wife. Judge Belois therefore denied Dr. Miles' petition and granted the [counter] petition filed by Mr. Wanglie. . . .'"[83]

Helga Wanglie's medical treatment served only to preserve her persistently unconscious state and dependence upon intensive medical care; therefore, further medical treatment was futile. There is also the issue of valuable resources being used that might have served to benefit a patient who would recover. The money spent on Mrs. Wanglie could have well provided immunization for thousands of children.

The list could continue, but the main issue is that valuable resources and finances were taken away, not only from those who are covered by insurance, but also, by those with no coverage. In intensive care units, sometimes the emergency demand for beds, adequate staffing, and available resources can exceed the need, and physicians can only provide intensive

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83 Alexander Morgan Capron, "In Re Helga Wanglie," *Hastings Center Report*, (September-October, 1991): 26. In re Wanglie, No. PX-91-283 (Minn. Dist. Ct. 1991), reprinted in 7 Issues L. & Med. 369 (1991).

care to some patients only by denying it to others.[84]

In both cases presented, the futile use of health care dollars and resources is an ethical injustice to those who could benefit from the financial and medical resources expended on just these two individuals alone. It could be argued that if health insurance was paying the bill (which there is no indication of private insurance in either case), it is the right of the covered recipient to receive the benefits of the insurance.

This would be true if there was a probability of successful response to treatment and recovery from the illness. But, there is no indication in either case:

> the goal of medical treatment is not merely to cause an effect on some portion of the patient's anatomy, physiology, or chemistry, but to benefit the patient as a whole.. . .the ultimate goal of any treatment should be improvement of the patient's prognosis, comfort, well-being, or general state of health.[85]

The goals were not obtainable in either case.

Though every effort was made to restore Helga Wanglie's

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[84] Tom L. Beauchamp, James F. Childress, *Principles of Biomedical Ethics*, Third Edition (New York: Oxford University Press, 1989), 297.

[85] Lawrence J. Schneiderman, MD; Nancy S. Jecker, Ph.D.; and Albert R. Jonsen, Ph.D., "Medical Futility: Its Meaning and Ethical Implications," *Annals of Internal Medicine*, Volume 112, Number 12, (June 15, 1990): 950.

health and life, ultimately the court decision and continued treatment was for her husband. That is, it only delayed the inevitable of his having to say his final good-byes to his wife of fifty-three years.

It could be argued that the time allowed him to adjust to the reality that his wife could and would not recover, and he could begin his grieving process. But, this is hardly an adequate or ethical response, when the man-hours, resources, and intensive care bed could have been used for someone who would recover, or at least had a chance for recovery.

The same is true in the Baby K case. Does the mother's claim that "all life is sacred" warrant the ignoring of the reality of the situation? There was no higher brain function in her baby; there was only minimal lower brain function--as indicated by the necessity of sustaining her breathing by a ventilator.

According to Robert Veatch, Ph.D., who testified as an expert witness on the medical/ethical issues connected with this case at the court hearing, "Baby K's mother is searching for a neurologist and plastic surgeon who can construct a skull and cover it with skin in order to make her baby look normal."[86] Obviously, the continued sustaining of Baby K's

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[86] This statement was made by Robert Veatch at the Health Care Ethics Forum '94, in Arlington, Virginia, in March of 1994.

body is not for the baby, it only serves to perpetuate the mother's false hopes of normalcy for her baby. Such action only delays the inevitable realization that her baby is not and will not "be alive, and normal," while continuing to increase the medical bills for which other individuals will ultimately be responsible.

Sphere-Specific Utilitarianism and Health Care: Equal Access to Medical Care

Because health care is of fundamental importance in reducing pain and suffering, minimizing the risk of premature death, and helping to protect an individual's opportunity to pursue life goals, it is viewed as a primary good. Morally, the ideals of equality and justice require "that the health care system be universal, comprehensive, and equitable in the sharing of benefits and costs."[87]

To most effectively meet the health care needs of individuals in the United States, without sacrificing other important goals, the system must manage and treat effectively, allocate wisely, and ensure quality. "Controlling costs without unduly compromising quality is a moral, not just economic, imperative; it is how we achieve the most good for

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87 Dan W. Brock, Ph.D., Norman Daniels, Ph.D., "Ethical Foundations of the Clinton Administration's Proposed Health Care System," *JAMA*, (April 20, 1994), Vol 271, No 15: 1189.

the members of our society with our limited resources."[88] This would also call for insurance companies to restrict their range of health care premiums, offer greater subsidies to smaller and lower-income groups, and require "health alliances and the national health board to ensure comparable quality and benefits in all plans."[89]

A liberal system of health care, based on the principles of utilitarianism, would provide such an equitable system. The terms "equality," "justice," and "fairness" should be relative in all medical situations, and not be left to or be influenced by the subjective definition given by the person who demands and pleads for continued futile intensive medical care for his/her family member.

Quality care, effective treatment, and efficient management will ensure that individual health care needs will be met with high-quality care while minimizing the use of medical resources that fail to secure positive benefits for patients.[90] The failure to secure positive benefits does not mean that if the prognosis is poor for the recovery of a patient, all further treatments should be deemed futile and

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88 Ibid., 1190.

89 Ibid., 1193.

90 Ibid., 1192.

the individual be sent home to die.

What this does mean is that when the evidence clearly indicates that further treatment will not alter the person's condition, or will only prolong the dying process, or necessitate that the individual will be maintained on life-support indefinitely, educated discretion should be used, such treatment should be withdrawn, the patient kept comfortable and be allowed to die with dignity.

While the concept of futility has been more narrowly defined, both clinically and legally, in my theory, futility is more broadly defined as medical intervention that cannot achieve the goals of its action. That is, to restore a general state of health, allowing the person to be capable of consciousness and feelings for life. Such medical futility may be measured qualitatively and quantitatively, each independent of the other.

The qualitative notion is when "any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive care should be regarded as nonbeneficial and, therefore, futile.[91] The quantitative perimeters are when the physician(s) concludes from previous experience, the shared experiences of colleagues in similar type cases, and evidence from empirical data that medical

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[91] Schneiderman, 952.

treatment is and will be useless.

With respect to autonomy, equality, and justice, if the patient expresses, or has given evidence that he wishes everything to be done that is medically possible to sustain or prolong his life (e.g., in a living will), even when terminal or in a PVS state, then the physician is honoring the patient's wishes. Such care and treatment may be a direct affront to the principle of utility and equality, but this would depend upon the physician's willingness to adhere to such principles.

However, when futile treatment is being given or continued at the request or demands of the family or significant others, such treatment, if against the wishes of the patient, is a direct act of paternalism against the patient, and an infringement upon the equitable availability and distribution of medical resources to other individuals.[92]

Cases where futile treatment is being continued at family insistence confuses the issue and purpose of medical intervention. The argument of "fairness" is totally subjective, and irrelevant in such cases; for example, in the case of Baby K. While such a case is unfortunate, it is the mother's emotionally charged interpretation of "fair" and the

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[92] Such circumstances brings in the issue of substituted or proxy judgment, which will not be discussed in this paper.

court's order to continue the care realistically deemed futile by the medical staff. Such a decision genuinely violates the true sense of "fairness," "justice," and "equality," in a utilitarian based theory of liberal health care.

Liberalism in Health Care

A liberal, sphere-specific utilitarian based theory of health care could and would provide a system of health care that every American would have access to with comprehensive benefits that would not be taken away. That is, if the terms "equality," "justice," and "fairness" were objectively defined, and the current health care system were restructured administratively to include "that the health care system be universal, comprehensive, and equitable in the sharing of benefits and costs."[93]

Insurance companies would be required to revamp their systems to allow for more equitable and competitive rates for health insurance coverage, with expanded benefits. Basic health care plans would need to be universal, with all businesses subsidizing the system, and allowing the option for supplemental insurance coverage for those who can and wish to purchase it.

In the sphere-specific utilitarian system I am proposing,

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[93] Brock, 1189.

it is a privilege with equal access. Health care is a service whose aim is to maintain the physical and mental wellness of individuals, which when they are physically well allows them to be self-actualizing (i.e., to be able to realize their potential, however limited that may be), and, in turn, contribute either directly or indirectly to the greatest happiness or good for the greatest number of people. If there is a "right" involved, it is the right to access, not to expect or demand tests that are not necessary (e.g., a CAT scan for a minor head injury) or the gross misuse of health care resources, such as in the cases presented.

Liberalism in health care is not a free-ride system. Neither does it ignore the needs of individuals who cannot afford to pay for services rendered. A utilitarian system of health care recognizes these needs, and with reform hopefully will provide a service that the individuals in society can live with and benefit from, on a more equitable basis.

Such reform will not please everyone, and the system will certainly not meet the expectations and demands of some who will claim their "rights," or the "rights" of their family member, have been violated because the treatment has been deemed futile and stopped. Along with access comes responsibility, and sometimes the responsibility involves the realization that people die, and no amount of intensive medical treatment can reverse or alter the reality.

Chapter 4

Establishing a Theory of Moral Value Within a Sphere-Specific Form of Utilitarianism

Sphere-Specific Utilitarianism

While classical utilitarianism is basically defined as achieving the "greatest good or happiness," it is further equated with achieving or experiencing the greatest "good," over the potential "bad," for the greatest number. The general concept of the "greatest good for the greatest number," however, is too obscure when not defined from a particular or intentional point of utility to be achieved.

Even when a particular scenario is presented, for example, sacrificing one individual for the benefit of several others, this context still omits two major elements. One is that while it is true that the initial defining of utilitarianism must start with the general and proceed to the more specific, the sphere of life or context in which the situation may take place has been ignored.

Second, while social utility is of primary importance in a utilitarian theory, the individual need not be sacrificed for the greater good or net benefit. The reason is, the scope of moral action is not fixed but fluid and based on a multiplicity of events, with varying degrees of moral interest which are relevant only to the participants' proximity of the

sphere of utility being examined.

It is my contention, therefore, that the "greatest good" or benefit must necessarily be defined from within a particular arena, not from some nebulous concept or subjective position about life or feelings in general. In other words, there must be a point of reference from which the theory can be grounded in order to be plausible. While certainly not new, my proposal is an ethical/moral theory which is sphere specific, based on the general notion of utilitarianism, and acknowledges the "rights" of the individual within the particular sphere being considered, in this case, the sphere of health care.

In this context, the premise of utility serves as the ultimate foundation from which all other principles are evaluated within the specific sphere or environment of health care. The principles deducible from and measured by the utility desired, and which serve as parallel-grounding notions, are beneficence, nonmaleficence, autonomy and justice.[94] In turn, the utility or the good to be achieved in health care is realized or produced by compliance with these secondary or supporting principles.

As previously stated, though the theory presented is based on utilitarianism in general, it is different from other

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[94] Beauchamp and Childress, Fourth Edition, 38.

forms of utilitarianism in that it is sphere-specific. That is, it focuses strictly on a particular sphere which has or may have a direct effect on a person's life and the lives of individuals within a particular society, again, in this instance, the sphere of health care. However, any other major sphere of life could theoretically be plugged in and the same end realized, that is, the "greatest good" is achieved for the individual and society, not only in theory but also in practical application.

Admittedly, each primary sphere of life will have its own unique set of circumstances, calling for some modification of the theoretical and practical utilitarian applications in order to meet the ethical and moral dynamics of that particular sphere. In the sphere of health care, each individual would have access to equitable and comprehensive medical care conditioned only by his or her ability to respond to treatment. That is, futile medical care which no longer achieves the goal of its actions and does not restore the individual to a general state of health would be discontinued. In this case, only comfort or palliative care would be provided. Also, since utilitarianism is closely linked to economics, the efficient and rational use of resources is given primary consideration.

Another example is the sphere of public education, which will have its own set of relevant considerations in attempting

to meet the primary good of providing education to the children of a particular society. In this sphere there is not only the general educational needs of children, but an additional factor is the special educational requirements of some which must be considered. Similar, in some respects, to the chronically ill person, the child with distinctive educational needs is still entitled to the same right of educational opportunities.

Another "human" sphere which has a principal affect for the individual and the community is the legal system. While the good to be realized is generally apparent, the dynamics of the system itself is, in many ways, similar to that of the health care system. A need exists; and while the precipitating events leading to the need may vary, the goods (legal representation, legal and criminal justice, etc.) and services (law enforcement agencies, public defenders, etc.) are made available.

Any number of other human spheres with primary utilitarian considerations could theoretically be plugged into the principal formula and worked out to meet the needs and provide the same ethical considerations.

Two major components associated with my sphere-specific theory focus on: (1) the responsibility of the individual and society which play an important role in defining and achieving the "greatest good", and (2) the "right" of the individual is

recognized in accessing the health care system. These ideas will be further developed and defined in subsequent chapters.

A New Approach To Utilitarianism

While no one theory can provide a solution or even a universally acceptable position, perhaps the continuous reformation of a particular theory can provide an additional grain of intellectual and pragmatically relevant moral and ethical truth. I also readily admit that my account of utilitarianism is of an "impure nature," when judged according to Anne Maclean's classification,[95] and J.S. Mill's definition.

If the ideal notion is that the moral rightness or wrongness of an action is measured by the utility of maximizing the greatest happiness or "satisfaction of desires," then my version of utilitarianism falls short. For the reality is that there are and will be decisions and standards of conduct independent from or seemingly in conflict with the ideal notion of classical utility.

This diagnosis of "impure" is rendered in light of the "classical" or "pure" definition of utilitarianism, which "admits only utility as the measure of conduct, and. . . defines utility in terms of the satisfaction [or realization]

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95 Anne Maclean, *The Elimination of Morality* (New York: Routledge, 1993), 15-16.

of preferences or desires."[96] However, when examined in relation to the sphere-specific notion of utility, the theory becomes grounded by the identified sphere of utility, not some generalized or abstract terms such as "happiness" or "desires." Apart from its own internal linguistic struggles, one particular advantage of utilitarianism over other theories is that it is the ultimate and grounding principle by which all other principles, morals, ethical positions, and virtuous actions are measured.

In general, the utility in a particular sphere is purposefully created or adopted to serve as a universal measure for the purpose of moral decision making and the resolution of conflict. In particular, the utility in the sphere of health care is to maximize the use of medical resources, e.g., equipment, procedures, medications, and health care providers, which serve to achieve the greatest good in helping to maintain and provide the health care needs of the members of a particular society.

Practical Reasoning and Utilitarianism

While theoretical support for a utilitarian system of medical care is of primary importance, pragmatic reasons for a sphere-specific utilitarian designed system of health care

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[96] Ibid.

are just as vital. Five such reasons are as follows. First, since utilitarianism is closely linked to economics, the rational and efficient use of resources is by necessity a primary component.

Second, the function of morality is to serve as a guide to ethical human conduct, and the value or utility of health care is to achieve the greatest benefit for the largest number of people with the available resources. This, of course, does not mean that there are no negative or less than desirable outcomes, but the utility, intent, or "greatest good" of the sphere is maximized, decision-making or *prima facie obligations*[97] become clearer, and the resolution of conflict is reduced.

Third, the obligation to benefit others comes from the principle of beneficent reciprocity. That is, if there are benefits received from society, then by virtue of this principle, society can expect and the individual has an obligation or responsibility in return to promote or contribute to that society's well-being or best interest.

Fourth, the specific intent of medicine is based on the principle of beneficence, that is, to do good, with a counter-point of nonmaleficence, which is, to do no harm. The good desired, namely, providing health care and helping the sick

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[97] Ross, 19-36.

return to some semblance of good health, when possible, calls for the reasonable or prudent use of medical resources.

Fifth, patient participation has become a recognized right, allowing greater involvement by the patient to accept or decline treatments and the use of health care resources. Such participation, while adhering to the ethical construct of autonomy, does not mean that autonomy is the sole driving principle, with a kind of egoistic utility as the underlying basis for the applicability of the principle.

Because health care touches so many lives and shapes so many experiences, important intrinsic and instrumental ethical values are at stake in determining and defining a health care system. While beneficence is a primary factor, the concept of justice in distribution must also be a consideration in determining the greatest good for society.

On Defining the Good

To define what the "good" means to an individual or society often results in as many definitions as people asked. Naturally, the context of the term will further define and clarify what it is and how or why that "some thing" is desired and a particular action or consequence is considered "good." In this sphere-specific form of utilitarianism, the "good" is used to describe that which is positive and serves as a

foundation for moral value and judgment in establishing guidelines and principles in the distribution of health care.

The basic premise of utility asserts that the ultimate criterion for morality is the maximizing of the social or aggregate utility, which, in turn, serves as a function for establishing moral values. In attempting to define that which is "good," as opposed to that which is "bad," the meanings of these words are often vague and controversial.

For example, Dan Brock lists four concepts which he considers to have value or good consequences: (1) happiness; (2) the satisfaction of desires or preferences; (3) the promotion of welfare or interest; and (4) a notion associated with "ideal utilitarianism," that is, the morality of an action and its consequences are either intrinsically good or intrinsically bad.[98]

While Brock considers these terms mainly from a linguistic viewpoint, and the idea behind each term or phrase may convey an ideal consequence(s), the first two principles are more expressive of feelings or psychological states of satisfaction for the individual. Take, for example, the word or idea of "happiness." To attempt to equate happiness with

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[98] Dan Brock, "Chapter 9: Utilitarianism," *And Justice for All: New Introductory Essays in Ethics and Public Policy*, ed. Tom Regan and Donald VanDeVeer (New Jersey: Rowman and Littlefield, 1982), 217-240.

the good, in relation to the aggregate, is automatically limited by its purely subjective nature. The same holds true for the principle of achieving satisfaction of desires or preferences. It is not clear what preferences or desires are being satisfied or defined as the good.

The third notion, "the promotion of welfare" is more in line with the intent of a sphere specific utility, but is still subject to further clarification. The fourth point, however, "the morality of an action and its consequences are either intrinsically good or intrinsically bad," ignores the fact that morality is flexible and is often subject to the aggregates perspective and the legal status of some actions.[99]

One of the major problems associated with the idea of good in general is that there is no societal sense of good or well-being. Many have become so self-focused, it seems society has lost the attention of others in comparison to the self. While it may be true that man is an end in himself, the realization of this "end" is and can only be in relation to others. Therefore, the conceptual context in which the "goodness" ("badness") of an action is defined can only be relative when there is more than one person.

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[99] For example, when abortions were given legal sanction, this in turn made it morally acceptable for many. This idea of the legal status providing a moral position will be examined in a later chapter.

On Moral Flexibility and Ethical Values

"There are no ethics!" "There are no morals!" At least this is so in the sense of Plato's "The Forms," or some nebulous set of ideals. It could be argued that from a theological perspective, the Ten Commandments set some standard for societal ethic, but what if a person(s) is not familiar with or does not accept the Old Testament writing? Perhaps the concept or some "innate" premise of the Golden Rule or sense of the ideal of common decency sets the stage for a societal ethic. What ever the answer, a claim that some set of moral constructs are well established is negated by the historical fact that there seems to be a continuously developing ethic(s) which expresses the moral development and attitude of a given society.

The "good" of utilitarianism in the context of this writing is based on the ideal or ethic of "the greatest good" or "benefit over burden," for the largest number of people within a particular society, the United States, and within the specific sphere of health care. It is further defined by the considerations of limited resources, limited funds, the realization of the realistic limits of the art of medicine. There is also the cold, hard reality that medicine, physicians, technology, and individual wishes do not and cannot fix every disease, illness, or reverse the ever present

process of dying.

More specifically, the procedure at hand is how to adjudicate the principle of sphere-specific utility with the concept of rights, which will be the theme in Chapter 5. Historically, the idea of rights associated with the theory of utilitarianism has been disputed as improbable as well as impossible.

Additionally, while many theorists have attempted to cause the demise of utilitarian theory, the fact remains that it is alive and well; the reality is that it is not easy to refute any moral theory completely. In truth, utilitarianism is well established, for it makes common sense and serves as a guide to moral human conduct, having both theoretical and practical viability.

While I do not intend to reject other ethical theories in opposition to my utilitarian position, I still believe utilitarianism to be the most plausible position, even in light of the attempt to adjudicate utilitarianism with the issue of rights. And, while the theoretical opposition to a utilitarian approach to validating rights has a long history, I believe there are two pragmatic reasons which offer support to my theory; these are: (1) the ultimate value or utility realized appeals to man's common sense, and (2) the economic utility to be realized in health care is of primary importance to all concerned.

While arguments may be leveled at the economics of health care, with claims that a life, for example, is not about money, the reality is, when we price ourselves out of affordable medical care, even for the wealthy and those who have some insurance, all arguments become mute. If the genuine concern by physicians and the public is with providing health care in a reasonable and just manner, in a way that will benefit the greatest number at an affordable rate of cost, then it seems that "utilitarianism is the only ethical theory consistent with the modern theory of rational behavior and a full commitment to an impartially sympathetic humanitarian morality."[100]

My proposal is a theoretical and practical approach to a sphere-specific form of utilitarianism, which acknowledges and takes the individual's right to health care seriously, and produces a moral foundation for action which genuinely enhances the utility of a particular society. It must also be stated that utility will be society specific, for each country will have certain unique elements which will identify the spheres of utility to be achieved.

The greatest good to be realized in the United States, in relation to the specific spheres unique to this country, will

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100 John C. Harsanyi, "Morality and the Theory of Rational Behavior," *Utilitarianism and Beyond*, edited by Amartya Sen and Bernard Williams (Cambridge University Press, 1991), 61.

certainly be achieved in a somewhat different fashion than in another country. While there may be some similarities of desires, the history of establishing values and the moral fibre of that society will cause a difference in cultural recognition of the "good."

THE COMMON GOOD AND HEALTH CARE: A UTILITARIAN PERSPECTIVE

In Plato's Republic, Socrates speaks of various types of education and comes to speak of a mythical doctor figure, "Asclepias," who:

> Introduced medical treatment for those who have a good constitution and lead a healthy life. If they get some specific disease, he gets rid of it by drugs or surgery, but tells them to go on leading their normal life so as not to make them less useful to the community. But, he makes no attempt to cure those whose constitution is basically diseased. . . which can only lead to an unhappy prolongation of life. . .. [H]e thought that no treatment should be given to the man who cannot survive the routine of his ordinary job, and who is therefore of no use either to himself or society.[101]

While this may seem an extremely archaic and nihilistic view of providing health care, there is a sense in which the basic principle is still relevant to medical care today. Particularly in keeping with the proposed definition of the common good as "that which provides the greatest benefit for

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101 Plato, *The Republic* (New York: Penguin Books, 1985), 171, 407d-e.

the greatest number of people," there is some relevance to limiting treatment and procedures in certain cases.

Realistically, there comes a point and time when no additional surgery, medication, treatment or high-tech gadgetry will ensure or provide any possible positive outcome or recovery for the patient, but will only delay the inevitable--i.e., death. Such exercise in futility only serves to enhance the physical and emotional suffering of the patient, and the family, not to mention the financial expenditures and depletion of valuable resources. But, even with a clearer description of the sphere and utility desired, certain difficulties are still present.

Identified Difficulties with Utilitarianism

As a consequence-based theory, utilitarianism provides that a decision will be reached by weighing the projected consequences of various actions and then deciding which action will produce the best possible moral consequences or net benefits. While this sphere-specific theory of utilitarianism can rightly be understood as a form of "situational ethics" and has many of the same general principles of *act utilitarianism*, it more clearly defines the sphere in which the good or benefit is to be achieved. This, in turn, sets the parameter which qualifies and quantifies the desired

utility, and determines the efficacy of treatments in certain cases.

While the sphere of utility may be more clearly defined, one problem exists in that while it is generally assumed that the utility is for others, i.e., "the greatest benefit for the greatest number," the question remains whether or not the individual agent should be included in the utility equation. It would seem that based on the concept of equality and as a member of the identified society, the individual should be considered.

Utilitarianism acknowledges the general ethical principle of obligation, rights, and autonomy, in relation to the best possible good or benefit of identified utility. Accordingly, we will be better served if we allow the situation to determine the action employed or consequence desired.[102] For example, a physician may withhold information or even lie about a patient's condition in order to give hope to that patient.

From a positive perspective, depending upon the individual/patient, i.e., the emotional state, or prognosis, the lack of explicit diagnosis may allow time for more tests and a better idea of a prognosis for the patient. In other

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102 J.J.C. Smart, *An Outline of a System of Utilitarian Ethics* (Melbourne: University Press, 1961).

words, rules should sometimes be obeyed, and other times disobeyed, depending upon the best prediction of beneficence or the good to be achieved.

From a *rule utilitarian* position, particular judgments and actions are or should be guided by moral rules such as, "Do not lie," which are justified by the principle of *rule* utility. Again, take the example of a patient and physician--except now the physician does not withhold information about the patient's condition. The good or beneficence achieved is, or would be, respect for the right of knowledge by the patient, respect for autonomy, and allowing the patient to begin dealing with or processing the facts and the possible prognosis or outcome (e.g., additional surgery, chemotherapy, or imminent death).[103]

It is this writer's opinion that a sphere-specific utilitarianism best serves the needs arising in health care, and more specifically, addresses the issues of justice and equal access associated with health care. This view is based on the nature and method of health care and medicine in this society, and on the principal or consideration of consequences relevant to a specific set of circumstances. Case by case decision making, i.e., in relation to a patient, the prognosis

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103 Worthington Hooker, *Physician and the Patient* (New York: Baker and Scribner, 1948).

or recommended treatment, and whether to begin a new procedure, or protocol, or discontinue treatment, is the only just avenue of providing health care.

This position necessitates the question, "What will be the maximum gain or consequence of doing the most good or, at least, the minimum of harm to or for the patient?" In regard to an individual, the general ethical principles of obligation, rights, and respect for autonomy, utilitarianism seems most congruent with consideration for the individual needs and situational assessment, providing the most good, i.e., health care, for a patient or the most number of patients, based on standard methods of practice in medicine.

Though the most reasonable or equitable consequences are desired, no theory is without its complications. First, as with any consequence, there are no certainties. Second, an analysis of the predicted consequence must be made to assess the potentially positive or negative results of the consequence desired. With this element comes the dilemma of whose values will be used to assess the "goodness" or "badness" of the results achieved.

Another "potentially serious problem with the consequence-based [theory] is that it is possible for the good of some to be gained at the expense of others, provided that

the good outweighs the bad."[104] In turn, this may create "what is known as the problem of justice, namely, it is possible to have a morally correct action (in terms of consequence analysis) which is nonetheless unjust, thus violating a basic principle of ethics."[105] In addition, there is the problem of "trying to determine what constitutes the good and whether there is a single good for everyone or whether each person determines his or her own good."[106]

In his book, *A Theory of Justice*, John Rawls addresses the idea of a society as a rightly ordered group of people in which its institutions are organized in such a manner as to achieve the greatest balance of good or satisfaction for those belonging to that particular society.[107] From the individual's perspective, based on the utilitarian model, his attempt is to achieve the greatest good or benefit for himself. Holding to this formula, the greater good for society would be based on the same principle, calling for the individual to acquiesce to

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104 Ibid.

105 Ibid.

106 Ibid.

107 Rawls, 22. In this particular definition of utilitarianism, Rawls uses Henry Sidgwick's *The Methods of Ethics*, to summarize the development of a utilitarian moral theory of justice.

the greater good or satisfaction of that particular society.[108]

According to Rawls, ". . . a society is properly arranged when its institutions maximize the net balance of satisfaction."[109] The idea of choice for the individual is enlarged to consider the choice of the aggregate. In relation to social justice, the principle is still equated to the sum of the whole, i.e., that which best benefits that particular society.[110]

Concerning the principles of ethics, equated with the concept of a morally virtuous person or society, the two primary considerations are those of the "right" and the "good." Based upon this premise, the ethical theory is then determined by these two basic notions, i.e., the "right" and the "good." "The simplest way of relating them is taken by teleological theories: the good is defined independently from the right, and then the right is defined as that which maximizes the good."[111]

Keeping in mind that in a teleological based theory the good is defined independently from the right. It then follows

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[108] Ibid., 23-24.

[109] Ibid.

[110] Ibid.

[111] Ibid.

that those value judgments which are considered "good" are intuitively distinguishable by common sense, and the right is that which maximizes that which is considered good. In relation to health care, this would equate to the good being discriminatory decisions being made by the individual or family, giving consideration to the prognosis and potential for the patient's response to treatment and the probability for recovery.

These decisions would also give consideration to whether the continuation of treatment would only prolong the suffering of the patient. The expenditure of resources (i.e., medicines, lifesaving equipment, money) would also be a relevant consideration if the good of others would be better served by a decision which maximizes the benefit for society in relation to health care made possible by more conservative and rational decision making. Certainly these are emotionally charged decisions that must be made, but there is a certain amount of common sense and realistic resolve that goes with these choices.

The reality is that people die regardless of technological advances; the other side of this is that technology often only delays the reality of human finitude. The bottom line is that the best possible decision is "essentially a question of efficient administration," where

the distinction between persons is not a consideration. [112]

A few case studies may best illustrate the viability of the sphere-specific utilitarianism methodology in relation to health care.[113]

Case One: Juanetta is a 23-year-old female in end-stage renal disease (i.e., her kidneys have ceased to function). Because of complex medical problems, Juanetta is not a candidate for a kidney transplant, from either a relative or cadaver. Juanetta comes to the clinic several days a week for dialysis, which takes several hours each visit. One day, during dialysis, Juanetta says that she is not feeling well and it seems that the dialysis is becoming less effective (which is often the case with end-stage renal failure patients). She says that this is the last time she will be in for treatment, for she has decided to let the disease end her life. There are many factors involved with this case, e.g., Juanetta's competence, her quality of life at this time, and the right of a patient to refuse further treatment.

Based on the principle of my sphere-specific utilitarianism, and if Juanetta's right to autonomy is taken seriously, her decision will be respected after some further

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[112] Ibid., 27.

[113] The following cases are cited in Beauchamp and Childress, *Principles of Biomedical Ethics*, Third Edition, 1989, 400-454.

clarification of the grounds and thought processes of her decision. With consideration for the principle of doing no harm and minimizing suffering, there comes a point in time for some patients that honoring the decision to end treatment is more beneficent than continuing the treatment.

Naturally, there are always additional factors to be considered, but the length of treatment and realization that end-stage renal patients ultimately succumb to the disease, if transplantation is not a viable option, is a primary factor in some cases. There is also the issue of respect for the patient's right to decide for or against further treatment, which reflects the primary ethical principle of respect for autonomy.

Case Two: In 1980, Massachusetts General Hospital assessed the feasibility of a heart transplant program at their institution. Upon the decision of the twelve trustees of the board, the program was vetoed in favor of further evaluation of new procedures which would allow for further technological advancement and the potential for providing the good for the greatest number of patients at a later time.

Case Three: A five-year-old girl has been a patient for three years because of progressive renal failure. Dialysis has been the method of treatment, with consideration for transplant as a possible option. Her mother proves to be

incompatible, her two younger sisters are too young to be considered as possible donors. However, her father proves to be compatible.

It is the opinion of the medical staff that the transplantation is questionable, at best, and it is possible that the transplanted kidney will undergo the same disease process. The doctor met with the father and gave him the prognosis of minimal success of permanent reversal of his daughter's condition, even with his healthy kidney.

It is the father's painful decision not to donate, after considering the prognosis, the pain already suffered by his daughter, and admitting to his own fear. He asked the doctor to inform the other family members that he too (the father) was not histocompatible. The doctor was uncomfortable with honoring the father's request, but consented to inform the family that for "medical reasons" the father could not donate.

There are many factors to be considered in this case, both morally and medically. First, honoring the father's right to autonomous decision making must be recognized. There are also the issues of beneficence (doing good) and nonmaleficence (doing no harm), and truth telling. One argument, in the father's favor, is from the standpoint that the greatest good is realized from a financial consideration for his wife and two other children. This is over and against the potentially poor prognosis given of his daughter

benefiting from receiving his kidney.

From a strict rule utilitarian view, the principle of "Do not lie" is compromised; however, from a sphere-specific position of utilitarianism, the father's position is morally justified. While it may not be the decision that someone else would make, the father's decision seems based on the lesser of two evils or burdens, given his daughter's prognosis.

In this particular case, there is the problem of whether the daughter has the right to receive her father's kidney. If she were of age, 18 years old or older, it would be her choice, if a kidney was known to be available. Of course, given the same scenario, it would still be the father's decision of whether or not to donate. While the argument could be made that the right to receive the kidney should be present regardless of age, the issue is still the girl's prognosis of benefiting from the transplant.

Each case is unique in its own right, and each represents an element(s) addressed from a utilitarian perspective. But, what of the rights of such patients, or prospective patients in case number two? Are there certain rights associated with health care? This topic will be explored in Chapter 4.

While these examples address some individual issues in a utilitarian system, what of society as a whole? As previously stated in Chapter 2, the Hawaiian system of health care provision seems to best epitomize the criteria set forth in my

sphere-specific theory of utilitarianism.

Hawaii's Prepaid Health Care Act (PPHCA) meets both the theoretical and pragmatic qualifications of utilitarianism, in general, and my sphere-specific utilitarianism, in particular. First, it takes into account and meets the criterion for delivering the "greatest good," to the "greatest number," i.e., providing universal access to health care. Second, it acknowledges the needs of the individual, and endorses a "right" to access the health care system. And, while it is designed to cover virtually all employees in the state, provisions are made for those who are unemployed and uninsured.

Chapter 5

Adjudicating the Issue of Rights and Utilitarianism: Concerning The Language and Legitimacy of Rights

Since the time of Thomas Hobbes, individuals have employed the language of rights to buttress social, political, and moral arguments to make claims for reforms, and demand recognition and respect of the individual.[114] This language of rights is even more prevalent and congenial to the liberal individualism pervasive in our modern society.[115]

Regardless of their origin, rights are generally of two kinds, either liberty or claim rights,[116] the distinction being that liberty rights are those which people have whether they request them or even know they exist. For example, the Declaration of Independence guarantees that individuals have the right to "life, liberty, and the pursuit of happiness." It attributes to us the right to pursue happiness, not to happiness per se.

In the same way, the right to life is the right to self-preservation. Accordingly, the right not be physically

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114 Beauchamp and Childress, Third Edition, 55.

115 Ibid.

116 Richard A. Wright, *The Practice of Ethics: Human Values in Health Care* (New York: McGraw-Hill Book Company, 1987), 35.

attacked or harmed need not be requested in order to be enforced. There are established laws which ideally, in principle anyway, protect the individual from being physically assaulted, ensuring one's safety, or at least having the right to protect oneself or the right to legal recourse in the event of being physically harmed.

Claim rights, on the other hand, require that an individual "specifically request whatever they have a right to, in order for it to be received."[117] The right to vote serves as an example of a claim right, i.e., the individual must be of legal age, request and register in order to exercise this right. Incorporated into this broad category are welfare rights which more explicitly involve the idea of rights of access to goods; for example, a right to food, shelter, and education, and in this writing, the idea of a right to health care.

More clearly, a theory of rights specifies something which an individual should be free to have or do, invoking a sense of entitlement and equality.[118] This does not mean, however, that there are no boundaries or circumstances in which the right may be strictly defined, limited or withdrawn.

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[117] Ibid.

[118] Charles Fried, "Equality and rights in medical care," *Hastings Center Report*, vol. 6 (February 1976): 30.

Neither does the term "free" mean free just for the asking or without cost. Even under the guaranteed right for an individual to pursue life, liberty, and happiness, or ownership of property, there may be certain limitations found within the exercise of these rights.

There also exists, in this notion of rights, a rather seemingly precarious relationship between the identified rights and the concept of equality. While a person may not actually be "entitled" to a particular thing, by virtue of the notion of rights and equality, he is entitled to equality in respect to that thing, "whether or not it is efficient to do so."[119]

For example, under the First Amendment of the Constitution, there is the right to freedom of speech. The guarantee is the right to speak freely; a right to be equally free of constraints and impositions on whatever speaking one might wish to do, should the person be able to find anyone to listen. The right does not guarantee, however, that each speaker will be afforded the same arena or media coverage for getting their ideas across, or that they will even be heard, believed, or applauded.

The relation between the notion of rights and equality, therefore, suggests the need "of being very clear and precise

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[119] Ibid.

about how a particular right is conceived: . . ."[120] In regards to health care, while there may be agreement that it is the right of all people to have equal access to health care, the right and what that equality entails must be precisely defined.

Take the example of freedom of speech; while someone may argue that such a claim right actually implies a right to be heard by the masses, such an argument is ludicrous. The same type argument holds true for health care. While the notion may be that whatever right exists in regards to health care is some how synonymous with a right to health, such a claim is equally absurd.

The design and function of the health care system will also be very different depending upon whether the right is considered a claim right or an automatic right. The current design of the health care system, in the United States, is based on the theory of a market driven claim right, i.e., the person must request the exercise of that right by setting an appointment with the physician or be admitted to the hospital by the physician. The patient must then make arrangements to pay for the services rendered, either by submitting proof of insurance, filing claim for services rendered, submitting proof of Medicare or Medicaid coverage, or making other

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[120] Ibid.

arrangements to pay the bill.

There are those who, of course, cannot pay for medical service, these are accepted by the physician and hospital as a percentage of a write-off--especially if the hospital is a public hospital, though private and for profit hospitals also have a certain percentage of charity or "write-off" cases.[121] Whereas, if it was an automatic right, the patient could exercise the right to health care coverage, regardless of insurance or ability to pay. This would be somewhat indicative of a socialized medical system; though this type of system has its own built in restraints on health care services received.

Another acid test for rights is whether the right is conditional or absolute. The conditional right, as the claim right, has certain conditions which must be met before the right can be exercised; this type of right usually contains certain limitations which may allow for the interference or voiding of the right. Obtaining and keeping a driver's license is an excellent example of this type of right.

The conditional right also tends to be very specific in its language, e.g., any person 16 years old or older who passes a written test and can prove the ability to drive an

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[121] Such financial indicators, and their effects, are illustrated in Chapter 2.

automobile by passing a driving test may receive a driver's license. The absolute right, on the other hand, usually contains some universal or general sense, with few limitations or exceptions, e.g., Every person has a right to be treated with dignity and respect.[122]

Further clarification of rights includes whether a right is positive or negative. A positive right, also referred to as an entitlement, is usually understood to mean a right to something, i.e., a right to receive something. Whereas, a negative right means a right from something, or protection from interference.[123]

A prime example is found in the case of *Roe V. Wade*, which articulates a negative right in that it prohibits the state from interfering with a woman's right to have an abortion. Child abuse laws are another example of negative rights, i.e., they are meant to protect the child from exploitation or harm. Some examples of positive rights may be found in a child's right to an education or an individual's right to due process of law, i.e., the child is entitled to receive public education and the individual is entitled to a fair trial and legal representation whether he can pay for it

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[122] Wright, 35.

[123] Ibid., 36.

or not.[124]

Whether a right is considered positive or negative will also depend on one's social and political conception of justice. The libertarian view, for example, maintains that a just society will recognize and protect individual's moral rights to such things as life, liberty, and property, but their welfare is a matter of personal responsibility. These are conceived as negative rights, and any government intervention should be only to protect the individual's rights against interference, fraud, or coercion.[125]

A socialist conception of justice holds rights of equality to be primary and positive in nature; therefore, government and collective intervention ideally serves to ensure social equality. While the idea of what constitutes social equality may vary, the grounding principle stresses the obligation of government and society to promote the welfare of its citizens, ensuring that the most important needs are met, even to the point of limiting individual liberty.[126]

In the liberal idea of justice, those individuals and

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124 Ibid.

125 Thomas A. Mappes and Jane S. Zembaty, eds., Introduction to "Social Justice and Health-Care Policy," *Biomedical Ethics*, 3d ed. (New York: McGraw-Hill, Inc., 1991), 546.

126 Ibid.

institutions which are prosperous and have more than enough are morally bound to help those in need. Identifying with the socialist, "the liberal recognizes the extent to which economic coercion in an industrial society actually limits the exercise of negative rights by those lacking economic power."[127]

Unlike the socialist, the liberal concedes the importance of enforcing some of the basic liberties associated with the idea of noninterference, e.g., freedom of speech, and is not opposed to all social and economic inequalities. In exchange, however, the liberal position does argue that the institutions which serve to protect these negative rights are also morally bound to support the positive rights which recognize and provide for the basic needs of the disadvantaged in society.[128] So from the liberal conception of justice there may exist the recognition and securing of both positive and negative rights which serve to provide for the common good. At a level more germane to the topic, the physician/ patient relationship may vividly represent a combining of positive and negative rights. The patient may choose, by virtue of the right to autonomous decision making, not to allow a certain treatment or

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[127] Ibid.

[128] Ibid.

procedure, even if the choice may be life threatening, this would be to invoke negative right.

Concerning the expression of rights in relation to the medical patient, the "Patient's Bill of Rights," revised and adopted by the American Hospital Association in 1973, includes a statement supporting a positive right in that patients have a "right to essential health care." This document requires the physician, by claim of the individual's right to self-determination, to involve the patient, based on informed consent, into the decision-making process concerning treatment, procedures, and the like. The physician's right, on the other hand, is positive in nature, having the ability to prescribe certain treatments and procedures by right of licensure and training, and having the duty to provide care and avoid harm.[129]

Often incorporated into the rights language is the claim of what is considered to be "fair," at least from the individual's perspective. Fairness, however, is a totally subjective view, often equated with a desirable outcome, and has nothing to do with the aggregate perspective. In relation to health care, fair is often perceived in terms of what is subjectively desired out of an emotionally charged situation

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129 L. W. Sumner, *The Moral Foundation of Rights* (Oxford: Clarendon Press, 1989), 2.

rather than what is actually and clinically needed. Realistically, fairness has nothing to do with the issue of rights, utilitarianism, health, or health care.

While a theoretical argument may be made for a right to health care, the reality is, a basic human or claim right to the delivery of even a decent minimum of health care does not exist. The reason being that a right to health care constitutes a claim against others for either goods or services, which in this case is the good and service received from the health care system.

Such a right requires others to actively participate in the provision of the good or service and depends primarily on the principle of beneficence rather than strictly the exercise of one's autonomy. Therefore, such a claim may conflict with the rights of others who wish not to participate in the provision and realization of such a health care system.

Establishing A Concept of Rights

Because of the potential for conflicts of interest and claims for competing rights, it is generally assumed that utilitarianism cannot support a concept of rights with moral force. Conflicting claims using the language of rights cannot be resolved in a rational way without some form of legal

endorsement and corresponding institutional arrangement.[130] We may sanction a right to something with a moral position, but it is the granting of that right by some legal and/or institutional process which validates and gives substance to that right.

As Jeremy Bentham argued, a "Right . . .is the child of law: from *real* laws come *real* rights; but from *imaginary* laws, from laws of nature, . . .come *imaginary* rights."[131] The misconception of how rights come to be legitimate also seems to come from the failure to establish a clearly defined set of principles associated with an identified right relevant to a particular sphere, system or institution. Rather, claims of a right often come from the individual's desire or assumption of having a right to that particular thing, good, or service, or merely serve as an appeal to ideal values.

As stated in the "Introduction," one important element which is seemingly overlooked by many individuals, and in most theories addressing the issue of rights, is the participant's responsibility. The tendency is to discuss and define the

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Wendy Donner, *The Liberal Self: John Stuart Mill's Moral and Political Philosophy* (New York: Cornell University Press, 1991), 174.

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Jeremy Bentham, *Anarchical Fallacies*, ed. John Browning, Vol. 2 (New York: Russell and Russell, 1962; as reproduced from the 1843 edition), 220.

concept of a right(s) without mention of the recipient's responsibility of reciprocity to the community which gives meaning and support to that particular, identified right. Given the complexities of the concepts of equality and rights, the idea of distributive justice, in this utilitarian scheme, is best defined from the framework of an identified sphere (for example, the sphere of health care, education, community services, and workplace).

Naturally, the development of such policies will not only have an affect on the individual, but the whole of society, as well. Therefore, clearly defined boundaries and consequences must be established within the particular system, institution or policy which recognizes and supports the identified right(s).

Another problem is deciding how much of a societies resources should go toward supporting the "right to" a particular good or service. In the context of this writing, the much larger question is: "How much of our available resources should go for health care?" Additional dilemmas and decisions regarding resource allocation, benefit over burden, equality, justice, rationing, and on and on, serve only to complicate the issue. But, this does not negate the possibility of establishing a right to health care services from a utilitarian position.

The Concept of Rights and Sphere-Specific Utilitarianism

One of the central arguments against utilitarianism being compatible with rights seems to revolve around the idea that while a rights-theory is person-relative, utilitarianism is person-neutral.[132] I do not agree with this argument, since the general principle of utilitarianism, concerning the individual, is that each person's happiness or good counts as only one unit. This is a much different premise than the charge of being totally person-neutral.

It is my intent to deal with this misconception and show that utilitarianism is not only compatible, but recognizes and supports rights of the individual, within the larger context of the society which makes use of the goods or services and within the identified sphere of utility. This perceived problem is further perpetuated by the "moral choice criterion"[133] of traditional utilitarianism which tries to dictate unreasonably rigid moral standards on every individual action.[134] In a sphere-specific theory of utilitarianism, recognition is given to the idea that morality is fluid and

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132 C. L. Sheng, *A New Approach to Utilitarianism: A Unified Utilitarian Theory and Its Application to Distributive Justice* (Norwell, Main: Kluwer Academic Publishers, 1991), 10.

133 Harsanyi, 60.

134 Ibid.

the end or desired utility may be achieved by different means, actions, or choices.

Of course, such a proposal is not without its problems. In the particular utility sphere of health care, if the individual's right to health care is fully recognized, the distribution of services will vary according to needs, that is, the services required by one person might well be greater than that of others.

Simply stated, a problem of distributive justice has been raised. The question then is whether the utility of the individual should be included in the aggregate utility, which leads back to the problem of the individual's rights in the sphere-specific utility equation.

Another major conflict is between the notion of a right and the obligation of supporting that right. The claim of having a right is ineffectual by itself, but has validity only in relation to the corresponding obligation as recognized by others. For an obligation which goes unrecognized by others loses none of the full force of its existence, but a right unrecognized or unsupported has little value.[135]

It makes no sense to say that rights exist without the concept of preceding obligations which validate the rights,

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135 Simone Weil, *The Need for Roots*, trans. A.F. Willis, with a Preface by T.S. Eliot (New York: Routledge, 1995), 3.

for the actual relationship between the two is as between object and subject. Case in point, a man in isolation has only a duty or obligation towards himself. In community, however, the idea of duty towards self is superseded by a two fold concept of obligations and rights. That is, the individual has rights only when recognized as obligations by others, and in turn his participation in community calls for reciprocal recognition and support.

A person alone in the universe would have only obligations toward himself, for genuine rights exist only when recognized and supported by others.[136] It may be argued that the lone individual has rights or the right to do as he pleases, but such a premise seems merely a matter of semantics with no theoretical or applicable substance. Only in relation to others can there be a genuine claim or identification of rights.

It is also the case that the ethics of utilitarianism makes us all members of the same moral community,[137] thereby creating the necessity of moral equality or humanitarian consideration. It is only out of a sense of community that rights get their force and meaning. In turn, the conferment

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136 Ibid.

137 Harsanyi, 56.

of clearly defined rights provides the individual with the recognition of entitlement to participate in the community.[138]

While it could be argued that rights exist whether fully endorsed or supported by all members of a particular group, the fact still remains that the existence of a genuine right is given meaning only by an acknowledged sense of obligation by others. Of course, an additional problem exists with the notion of obligation, for an obligation clearly undefined allows for arguments of how much or how often members of a particular community or society will be involved or support that identified right.

The view that rights and utility are incompatible seems to stem from the idea that rights are considered to have a higher value or priority than utility, except when the utility is extremely large, and only then is the utility given serious consideration. The problem with this position is that the threshold above which the utility becomes relevant is undefined and is predicated on the whimsical decisions of a few.

Another problem is that the guarantee of a right does not necessarily translate into an equal right, for such an equality is defined more by the arena or sphere to which it is

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Jay Bernstein, "Right, Revolution and Community: Marx's 'On the Jewish Question,'" *Socialism and the Limits of Liberalism*, ed., Peter Osborne (New York: Verso, 1991), 103.

related, than to the ideal concept. To unmask the ideal abstractions tends to point to the realities in which individuals live their lives. For example, the guaranteed right to vote may be equal for all who meet the stipulated criteria of age, etc., but such a right does not guarantee an equal distribution of power. Neither does the right to equal treatment before the law translate into legal equality.[139]

While such concepts may be bolstered as the moral ideal, serving as rhetoric for equality, the existence of rights is in no way diminished for the individual by the utilitarian equation. The meshing of idealism with pragmatic reality does nothing to diminish the philosophical validity or stability of such a premise, even when the consideration of social and economic constraints are factored.

In this sphere-specific utilitarian theory, the morality of rights is predicated on the idea of equality, while the ethic of responsibility relies on the concept of justice, with consideration given to the differences of need. The reality is that the ethics of rights is a manifestation of equal respect, which attempts to balance the claims of others and self, creating an ethic of responsibility and reciprocity

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139 Anne Phillips, "'So What's Wrong with the Individual?' Socialist and Feminist Debates on Equality," *Socialism and the Limits of Liberalism*, edited by Peter Osborne (New York: Verso, 1991), 142.

which rests on an awareness of and gives rise to an ethic of compassion and care.[140]

Even in an ideal state which fully supports the concept of equal rights and justice, the need or desire to exercise a particular right, by an individual, is not going to be the same for all individuals at the same time. The fact that an identified right exists and is supported by a sense of obligation by the aggregate, even in theory, seems to warrant a valid case for the argument supporting the adjudication of utilitarianism and rights.

While there may be cases which seemingly compromise or negate a particular right, or theoretical scenarios which create exceptions to ideal principles of moral choice or behavior, the fact remains that the right still exists. The exercise of a particular right not only perpetuates the idea of aggregate obligation, but creates a sense of responsibility and accountability to those who give authenticity to that right.

Even in an ideal state of existence, the needs of one individual are not going to be the same as the need by others, if the concept of individual identity is to be maintained. The wants and desires of individuals vary, unless

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140 Carol Gilligan, *In a Different Voice* (Cambridge: Harvard University Press, 1982), 164-165.

individuality is negated and all are programmed to desire the same things.

Arguments Favoring Rights and Sphere-Specific Utilitarianism

In spite of the apparent conflicts, four arguments may be made which support a theory of rights for the individual from a sphere-specific utilitarian position, and more specifically, a right to a decent minimum of health care. In such an attempt to adjudicate the issue of rights and utilitarianism, it must be remembered that ethical problems are not like those in science, that is, while scientific problems may have apparent solutions, ethical problems usually do not.[141] Regardless of the inability to provide "solutions," or the so called last word on a particular ethical question, ethical issues may be adjudicated by a society's sense of community.

It is from this supposition that the first argument is based, that is, a sphere-specific utilitarian ethic makes us all members of the same moral community. The second argument is based on the notion of "collective social protection." The third argument contends for principles of "fair opportunity"[142] balanced with obligation. The fourth argument analyzes the

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141 Hilary Putnam, "How Not to Solve Ethical Problems," The Lindley Lecture (Kansas: The University of Kansas, 1983), 4-5.

142 Beauchamp and Childress, Fourth Edition, 351.

validity of rights and the concepts of utility based on legal and institutional support and the concept of distributive justice.

Beneficence, Morality and the Greater Good

While the fact that all members of a particular society are members of the same moral community may be an apparent tautology, the congruity of a particular society's morals are not always self-evident. Therefore, the fundamental support in a sphere-specific utilitarian moral commitment to others is based on the principles of beneficence, human sympathy and a general notion of goodwill.[143]

In the sphere-specific theory of utility, the moral judgment of decisions and actions serve as a measure or representation of a society's interest based on a particular sphere. In this case, the sphere of health care distribution and the right of an individual's access, and the communities sense of obligation to provide such a good or service is the primary focus. Such a measure of utility serves as a measure or representation of human interest, and what it means for a person to have such a right.

First, it should be noted that utilitarianism in general, and sphere-specific utilitarianism in particular, "is not a

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143 Harsanyi, 56.

metaethical theory about what it *is* for a person to have a right. . ., [but serves as] a normative theory about *which* rights people have."[144] Such rights are those which have been clearly identified, defined, and incorporated into a society's general moral code, serving to benefit all it's members.[145] In this case, the right to health care[146] serves as the identified sphere of utility to be examined and adjudicated with the issue of rights.

Second, it must be acknowledged that many moral rules, principles, and virtues have exceptions. Even if a certain moral principle, rule or virtue is accepted in a society, there will be varying opinions and alternate methods of achieving the desired end or result. In other words, morality is often fluid and even adamantly held positions are found to contain exceptions.

For example, a moral position against murder has been

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144 Richard B. Brandt, *Morality, Utilitarianism, and Rights* (Cambridge: Cambridge University Press, 1992), 375.

145 Ibid.

146 The idea of a "right to health care," does not equate to a "right to health" or a "right" to unlimited health care resources when such use does nothing to help diminish a particular disease process and/or help the recipient to return to some semblance of functionality or quality of life. This concept of a "right" does equate to equal access to a decent minimum of health care and the setting of priorities in the allocation of resources, based on the principles of beneficence and fairness as justice.

historically an accepted principle. Yet, while considered usually wrong, it cannot be said that it is always wrong, for exceptions have been made through the centuries. While people may disagree about exactly what exceptions should be allowed, there must be a general agreement that exceptions do exist.

Most people would agree that it is permissible to kill in self-defense, if that is the only way to prevent someone from murdering you or your family. Others would concede that it is permissible to kill in time of war, provided that the war is "just," sanctioned by the government, and the rules of war are observed.

Some may think that capital punishment is permissible, as a way of dealing with vicious murderers. Others, hold that abortion is acceptable as an exception to the rule. Therefore, while murdering is usually considered morally wrong, it is not always considered wrong. And once this is admitted, it must be acknowledged, even theoretically, that exceptions do exist.

Given the fact that exceptions do exist in moral considerations, and according to the sphere-specific utilitarian theory, there may even exist conflicts between principles, rules, and virtues. In the case of decision-making for moral actions, and under normal conditions, the utility rather than rule is considered the ultimate criterion. In the event of dubious cases, moral judgments would be

considered on a case by case basis rather than being decided by a rigid application of established rules, principles, or virtues.

Still the task remains of determining if a sphere-specific theory of utilitarianism can serve as an adequate justification for such a claim right as access to health care. Based on the principle of beneficence, a fundamental basis of moral commitment exists to do good; in this case, to provide a good and do good by supporting the concept of a right to health care services.

Rights and the Collective Social Protection

The concept of "collective social protection" focuses on the correlation between legitimate health care needs and other needs that have conventionally been protected by various institution and governmentally supported agencies, such as, law enforcement, the fire department, public health departments, and environmental protection agencies.[147]

It is out of a sense of communal well-being that such principles and services are founded and perpetuated. While such a concept cannot pretend to provide the last word on this or any other ethical or moral issue, it does derive its force from the shared sense of what is and is not rational, and a

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147 Ibid.

commitment to the welfare of a particular community by its members, even while "'muddling through' together."[148] While the argument may be made that the provision for such services or public goods are not the obligation of the government or an institution, and that such responsibilities are nonessential and expendable, such a claim is not only morally unjustified but ludicrous as well.

Even a libertarian account of justice, which holds that such services "sacrifice basic liberties to the larger public interest,"[149] does not oppose other distribution modes of services if they are freely chosen. However, the decision to support such services are binding only to the extent that fraud or force of participation are prohibited. What is not clear, from this perspective, is if such a decision must be unanimous or merely agreed upon by the general consensus.

Another unanswered question is what becomes of such services and the distribution there of if one of the members becomes unable or unwilling to freely participate in supporting such assistance. Even in such an ideal state of individualism and "natural rights"[150] any type of infringement,

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148 Putnam, 9.

149 Beauchamp and Childress, Fourth Edition, 336.

150 Jeffrey Reiman, *Justice and Modern Moral Philosophy* (New Haven: Yale University Press, 1990), 238.

real or otherwise, would be considered grounds for appealing to some government agency, group, or legal institution, asking for correction or protection of the perceived rights violation.

Regardless of the theoretical position, the fact remains that ". . .we live in a world in which the powers of government [and institutions] are routinely called upon to enforce (as well as define)"[151] those rights and services deemed necessary for the welfare and greater good of society. While there may be disagreement in how these goods should be distributed and supported, even in theory, such needs do exist.

Even if one were to accept Robert Nozick's "entitlement theory" of justice in which government intervention is justified if (and only if) it protects the liberty and private property rights of individuals, it seems unclear how the general welfare of society is to be maintained. The position that those that have it (what ever "it" is, money, property, social position, etc.) should keep it and those that don't, suffer, seems morally unjust.

Even acts of charity, which may support the distribution of certain services and goods, serve as a potential means of

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151 Bruce A. Ackerman, *Social Justice in the Liberal State* (New Haven: Yale University Press, 1980), 19.

discrimination, by providing limited or poorer quality goods and services. Such charitable actions may also be subject to the ebb and flow of cooperativeness of those contributing to the continuance of such provisions. To argue that property and the accumulation thereof serves as entitlement to certain services and goods available also diminishes the general well-being and safety of society.

From the argument which advocates a right to health care, the libertarian position supports the idea of private health insurance which is voluntarily purchased, and promotes the idea that society is not morally obligated to provide funds which support public health care services.[152] While such a theoretical position may bolster a claim of supporting individual rights, it is blind to the "coercive effect of property on nonowners."[153]

While it could be argued that utilitarianism does not fair much better in the recognition of rights, that is, some individual rights may be violated or subjugated by the general welfare commitment, the sphere-specific utility of health care takes such seeming violations or decisions into consideration. In this sphere of utility, the individual's right to health

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[152] Beauchamp and Childress, Fourth Edition, 336.

[153] Reiman, 239.

care is not denied but does contain certain limitations or qualifications, based upon the recipients responsiveness to health care services received. That is, other measures may be deemed more appropriate than the continued use of technological and prophylactic interventions found in a hospital.

For example, the person who is in a terminal condition may be offered the services of hospice, rather than the option of continued treatment which is deemed futile and only serves to prolong the agony and dying process. While this example may seem a justifiable or even radical exception, it serves to illustrate the premise that rights are not ignored in this sphere-specific utilitarian theory, but there are conditions of responsibility in laying claim to services and resources intended for the general welfare.

From the argument for "collective social protection," any number of services or goods meant for the general well-being of a society will serve to support the sphere-specific claim of recognizing and supporting rights. Of course, none of the services will be immune to criticism or arguments which advocate a "better way" to utilize the resources. However, it still seems that a sphere-specific approach allows for a more equitable and just way of supporting rights and providing for the common good.

Take for example, the need for law enforcement; such

services are provided by local, state, and federal agencies, funded by the general public through various taxes, grants, and donations. Each citizen has a right to expect, request and/or receive the services provided by such agencies, which serve to promote the common good of society. The fire department also serves as an example of an agency which promotes the general welfare of a community.

The right of the individual to receive such specific assistance, without regard to social status or income, is based on the idea of a recognized entitlement to live and participate within the community. Even the arena of health care provision, while multi-tiered in its funding methods, recognizes the need and right of individuals to receive needed services. This stems not only from a sense of beneficence, but from the premise of a recognized need for the betterment and safety of society.

While it may be argued that such access is not a genuine right, all hospitals have posted signs which state that each person has a right to receive medical services, regardless of ability to pay. While such agencies and services may be considered a given or necessity with exceptions, not subject to the same conditions relevant to the general claim of rights, they serve as definite and well defined support for such a premise, based on the notion of rights and the greatest good.

Fair Opportunity and Individual Responsibility

From this position, rights and the notion of fair opportunity gauge the justice of social institutions by their tendency to counteract a lack of opportunity or misfortune of the individual who has no meaningful control.[154] In as much as disease, injury, or some form of disability creates seriously significant disadvantages and diminishes a persons' capacity to function properly, justice is served if societal health care resources are used to restore an individual to some semblance of health, which in turn provides a fair chance for that person to use his/her abilities.[155]

However, the obligations and sense of responsibility associated with utilization of the various public agencies and services, cited under the previous heading, are found in the pertinent conditions or rules of use. To abuse the rights by false claims or reports, and negligent or felonious actions, renders the individual liable with penalties of fines, prosecution by law, or other measures which punish such aberrant behavior. While a utilitarian theory cannot impose a moral obligation of goodwill and beneficence toward the community, it can take measures which address such antisocial

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154 Beauchamp and Childress, Fourth Edition, 352.

155 Ibid.

conduct.[156]

In terms of the concept of fairness, one of the main problems of classical utilitarianism is that it tries to dictate unreasonably rigid moral standards on each individual, which requires assessment of every action in terms of maximizing the social utility, regardless of the personal cost.[157] In a sphere-specific form of utility, the individual is required to give moral consideration not to every action, but only the action(s) relevant to the maximization of that particular sphere of utility. For example, whether an individual decides to read a book for personal enjoyment or professional enhancement is not a consideration in the utility equation.

While the principle of fairness as justice, in this sphere-specific form of utility, requires the individual to give consideration to the aggregate welfare in relation to that particular sphere, it does not demand that every personal action be scrutinized so as to maximize the social utility. For example, in the sphere of health care, the individual would give consideration to the actual "need" versus "want" for treatment.

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156 Harsanyi, 56.

157 John Rawls, *A Theory of Justice* (Cambridge: Harvard University Press, 1971), 117.

The idea that all individuals seeking medical treatment are in need is unwarranted. The fact is, there are those who abuse the system with personal wants of attention, drugs, and simply from the conditioning of a society which advocates immediate gratification and a quick fix. The belief that medicine can alleviate all the aches and pains, colds and runny noses, stress and worries is ludicrous. Such expectations have led to a general abuse of the system, and a total disregard to the notion of individual responsibility and reciprocity to the general welfare.

Even if consideration is given by the individual to the aggregate welfare, an argument could be made that the concept of fairness is neglected when focusing on the distribution of benefits and burdens, apart from the general welfare. For example, rights of society's "sickest and most vulnerable"[158] may be compromised by the inability to maximize the social utility. While such discrimination may be a concern, the concept of fairness as justice does not negate the realities of life.

Equal considerations may be given to all, but the individual's response to the good or service received must also be a factor in the equation. A right to health care does not necessarily mean receiving any and all services available,

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158 Beauchamp and Childress, Fourth Edition, 336.

regardless of the condition. Home care and palliative care may be considered just as much a right as entrance into a hospital. The fact that people are born unequal in many respects, such as, health, sex, color, intelligence and family situation, does not mean that equal consideration or treatment is neglected in the utilitarian equation.

The concept of a right is meaningless without a clear understanding of what that right entails and the responsibility it holds. In a sphere-specific form of utilitarianism, the notion of fairness associated with a particular right is clearly identified and the responsibilities associated with that right are well defined.

Legal and Institutional Support

In the history of health care development, the policies designed to address the needs of the general public has seemingly contained more political rhetoric than careful analysis. It has also been the case that general distribution of these goods has been left to the market place, with policies and beneficent considerations to be tacked on after the market has established its hold.

In addition, though advances in technological and procedural capabilities have been greatly enhanced, the medical possibilities seem to have outstripped most logical

and ethical considerations. Such a claim finds its support in the fact that many treatments and procedures are used well beyond any probability of benefit. That is, the burden far exceeds the potential for realized benefit by the recipient, and efficient use of health care resources.

While claims of beneficence may be made, the reality is that such endeavors are often more from a defensive posture, that is, fear of criticism and possible litigation by the patient's family, than any genuine potential for the patient's welfare. Other contributing factors in the equation include the psychological, emotional, and financial motivation for the physician, institution, nurses, etc., and similar considerations by the patient and patient's family.

In such cases, the concept of a "right to" these goods and services have shifted from the individual's needs to the preferences, desires, or any number of other motivating factors, by the patient, family, and/or physician. In addition, decisions to continue treatments are often made in spite of the patient's wishes, further compromising the concept of rights, not only to receive treatment, but the right to self-determination. So, clearly, the issues go beyond those dealing primarily with conflicts between individuals, adding to the questions of rights growing out of friction between society's interests and the individual's welfare.

While the clarification and endorsement of a particular right may come from recognition given by a particular group or society, such a right is given further elucidation and enforcement by laws and the institutions which support that right, in this case, a right to health care. The argument may be made that such action forces participation by those who may not wish to support such a right, thereby, violating that individual's right to freely participate (or not), or one's right to autonomous decision making.

One favorable argument for a "legal right to health care appeals to the role of governmental coordination in effecting charitable goals."[159] Such action may be viewed as coercive, but the distribution of medical resources, or any other social goods or services may be justified if it is deemed that the recipients have moral rights to those goods or services.

Another consideration is the notion of individual responsibility and reciprocity in contributing to the general welfare of society. If the beneficent goals of a society are sufficiently and morally fundamental and important, even the libertarian and egalitarian arguments against coercive transfers of social resources are challenged.[160]

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159 Beauchamp and Childress, Fourth Edition, 354.

160 Ibid.

Even the argument from a notion of autonomy does not resolve the dispute, for being recognized as autonomous does not provide a necessary condition for exercising that right. Neither does a right to autonomous decision-making negate one's social or moral responsibility to the general welfare.

It is here that reinforcement by the powers of the legal and institutional systems serve to further establish and clarify the boundaries by which a particular right is identified. While such measures may seem intrusive and serve only to complicate the issue, it is still the case that such powers are routinely called upon to clarify and enforce rights or entitlements.[161] Even if, ideally, something similar to the status quo could be maintained without such interventions, A could still ask B to justify his claim to certain entitlements that A also wants to receive.[162]

The legal and institutional support only serves to further ensure a clear understanding of a particular right and the benefits and burdens of responsibility associated with that right, in relation to the aggregate welfare. This does not mean that the individual is called upon to relinquish his/her personal needs of a particular good or service;

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161 Ackerman, 19.

162 Ibid.

rather, it does call for a distinction between need and desire. It must remembered that whatever right or entitlement is possessed "has not been gained *independently* of society but rather as a result of an *interaction with* society."[163]

While there are many considerations left unexplored, the intent of this chapter has been to address some of the major issues associated with the question of rights and a utilitarian theory. Given the complex issues in the sphere of health care alone, it is acknowledged that the considerations and arguments given barely scratch the surface in relation to rights and distributive justice. However, such a statement does not negate the validity or viability of the arguments presented or the premise that rights and a sphere-specific form of utility are compatible.

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[163] Ackerman, 330.

Chapter 6

Rights, Utility and Distributive Justice In Health Care: Learning to Live With Limits

The four arguments presented in the preceding chapter argued for the adjudication of rights in a sphere-specific theory of utilitarianism. However, the questions related to justice and the distribution of health care resources were only minimally addressed. It will be the intent of this chapter to propose a system of distributive justice which serves in conjunction with rights and responsibilities in this sphere-specific form of utilitarianism.

To live within such a framework of health care distribution will afford everyone fair opportunity to receive the benefits of health care resources available. Of course, such a system also has accountability and responsibility in the exercise of the right to such goods and services.

While a right to health care depends "on the principle of beneficence rather than that of autonomy, and. . .may conflict with the decisions of individuals who may not wish to participate in. . .[this] particular system of health care,"[164] to choose not to participate goes against all logical and rational arguments. Regardless of the type of health care system, all participate in some form or fashion, with some

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164 H. Tristram Engelhardt, *Foundations of Bioethics*, First Edition, (New York: Oxford University Press, 1986), 336.

supporting the continuance of the system at a higher rate than others.

Take for example the current system in the United States, while the claim may be that choices are available for those who can afford it, they are still paying to support those who cannot. Whether it is through taxes, higher health care premiums, or inflated health care costs (as illustrated in Chapter 2), the choice of participation and cooperation, without paying for the health care of others, is an illusion.

Even the notion of autonomy has its limits within a given society, community or group which recognizes and support particular rights. And, while the principles of beneficence and autonomy "that lie at the foundations of justice [may] spawn conflicts within any portrayal of a just allocation of health care resources,"[165] it is my contention that a sphere-specific form of utilitarianism is the most suitable theory to address such issues of distributive justice and rights, when combined with the notion of individual responsibility.

This is not to say that all questions and concerns can or will be resolved, but many of the problems of distributive justice may be addressed. Of course the question then, from a utilitarian theoretical position, is who decides how the system will work? That is, who is going to be the objective

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165 Ibid.

observer to make the decisions?

A Right to Health Care: Justice and Inequality

In moral and political theory, rights have traditionally been understood as entitlements a person may have to some service, good, or liberty.[166] Faced with significant inequalities in the distribution of health care services and resources, there is an inclination to assert that a violation of basic human rights is involved by such a denial or constraint. While any theory may present some possible options to the resolution of conflicts and rights, it is only in tangible contexts that the extent of the obligation associated with a particular right can be determined.

"Interests in justice as beneficence are sustained in part because of inequalities among persons."[167] In the sphere of health care these inequalities become even more pronounced by virtue of the natural and social lotteries. The natural lottery, or those events which occur outside of human responsibility, may bring good health to one person and poor health to another. Some individuals may be born healthy and

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166 Tom L. Beauchamp and Ruth R. Faden, "The Right to Health and the Right to Health Care," *The Journal of Medicine and Philosophy*, vol. 4, no. 2 (1979): 119.

167 Engelhardt, 339.

remain so for most of their lives, and others may be born with genetic or congenital diseases which create life-long health problems. Then there are those who by virtue of an accident or serious illness become dependent on even more of the services and goods provided by a health care system.[168]

In the social lottery, some individuals have better fortune than others, that is, some have more advantages, more money, or more influence, and others are less fortunate, have less money, no influence, or become victim of the malevolent actions of others. Regardless of the circumstances, some will have greater need for health care services and resources, some will be able to afford more services, will have more choices regarding which doctor to see and which hospital to enter and others will not.

While the notion of specific rights and obligations of beneficence may presuppose a particular moral viewpoint, the idea of need does not necessarily create a right to particular services or goods. Only by the recognition and willingness of others to meet such a need, and the validation by institutional, governmental, and even legal support, can a right be considered legitimate.

Rights in this context, then, are contingent upon a balancing of individual need and social interests or the

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168 Ibid., 339-340.

willingness to support such a claim.[169] In this attempt at social equilibrium, claims of rights are prima facie rather than absolute, that is, while a particular right may be valid, it may also be overridden by more demanding claims.[170]

For example, if a hospital is evaluating the need to implement a new program which would allow for cardiac bypasses to be performed or use the money for existing services, competing needs would be a factor in the utility equation. If such a service exits at a nearby hospital, or even in a neighboring city, duplication of services may not be warranted. The decision not to offer such a program does not negate the right of an individual to receive a needed heart bypass, it only creates a potential inconvenience of location.

Another consideration from a sphere-specific utilitarian position is the "problem of interpretation," which challenges the premise that the utility must be "'maximal' in every case,"[171] or that equal access means equal distribution.

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169 Beauchamp and Faden, 122.

170 Ibid.

171 Sheng, p. 38. While Sheng uses this phrase in terms of negative and positive duties (or rights), from a sphere-specific utility position, the notion is that while the maximal utility may not be achieved in every case, it can be realized through the maximizing of the identified sphere of utility. In this instance, the specific sphere is the provision of medical care and the utility to be realized is the greatest benefit in the overall distribution and use of

Seemingly unequal distribution does not mean a violation of or negate a clearly defined right; in this case, a right to health care services and resources. The right to receive health care will have value in varying degrees to different individuals, and the services and resources will be determined by need.

Concerning the potential claim that such a theory does not take seriously the utility maxim of "the greatest good for the greatest number," and compromises the notion of fairness and justice in distribution, health care needs cannot be satisfied in the same manner as other needs, such as those for food and shelter.

Regarding the utility maxim, there are certain conditions under which the "greatest good" is served. Immunizations for certain diseases certainly prove to be for the greater good, and the restoring of one's health may prove to be beneficial to the aggregate well-being. Another example may be the person who has need of a heart bypass; while costly, such a procedure will, ideally, allow the individual to return to a productive life, contributing to the general welfare and minimizing the need for continuous demands on health care resources.

In this context, such a proposal, based on the notion of

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health care resources for the greatest number of individuals.

genuine need, while seemingly only serving to enhance distributive inequalities or injustices has actually created a more stable and equitable system. It must be remembered that not all inequalities are the same as inequities or that what seems unfortunate is always unfair.[172]

Just by virtue of the natural lottery alone, needs for health care services will vary from person to person. Individual circumstances will also be another determining factor. Much like a triage system found in an emergency room, there will be those individuals with major trauma who take priority over others with cuts, colds, and minor injuries.

Another relevant point is that just because a particular medicine, test, or procedure may be available, it is not always the case that such treatment is warranted. Kenneth Arrow, Ph.D., and Nobel Prize laureate, has rightly pointed out that while consumers may be better educated to the ways of medicine, they are not well qualified to decide which tests, medications, or procedures they genuinely need.[173]

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[172] Engelhardt, 344.

[173] Eli Ginzberg, Ph.D., "A Cautionary Note on Market Reforms in Health Care," *JAMA*, (November 22/29, 1995), vol. 274, no. 20: 1633.

Utility, Futility, Rights and Health Care

While consideration of authentic medical need is of major importance, another equally important point is whether or not the treatment being received is or will be of benefit. Such an assessment may include the possibility of the care being a potential burden, that is, doing more harm than good or being of no significance. In such cases, while a life may be prolonged, so is the suffering, only serving to extend the dying process and expend medical resources.

Though it is essential to give consideration to the beneficial qualities of medical intervention, by determining the prognosis and value of the treatment available, it is also important to examine the appropriateness of excessive or futile treatment. If a morally realistic and just plan for health care allocation is to be maintained, it will only be with the contributions of physicians who can provide an understanding of the clinical significance and limitations of what is genuinely attainable.[174]

In medical ethics, in general, and the sphere-specific utilitarian formula specifically, the secondary set of moral principles which ideally govern the behavior of physicians and support the utility construct are beneficence, nonmaleficence,

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174 H. Tristram Engelhardt, Jr., MD, "Medical Ethics for the 21st Century, *Journal of American Cardiology*, vol. 18, no.1, (July 1991): 303.

distributive justice, and autonomy.[175] While not immutable, these four ethical principles have evolved over time providing a moral framework for making medical/ethical decisions, including those involving life-prolonging therapies.

As a learned profession, physicians have a moral role in making clear the human condition, and the limitations of resources and technology available.[176] It is through their contributions that a better understanding of the medical constraints and moral implications are possible, in the continuation or withdrawal of medical care.

In spite of the general public belief, there are particular circumstances that will make the use of medical resources a central issue in medical ethics. For example, the reality that we are subject to the constraints of finitude, i.e., human life does and will continue to have a limited duration. Another consideration is that resources for health care do have limitations. Treatment is often only partially successful, leaving some individuals with a quality of life they find unacceptable. And, while medical techonology will continue to produce new, promising, and expensive therapeutic interventions, medicine must acknowledge the conditions,

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[175] Beauchamp and Childress, Fourth Edition, 38, 120-394.

[176] Ibid.

limitations and finitude of the human condition.[177]

In light of this human condition, the concept of futility will depend upon an acceptable definition and what we believe to be the appropriate goals of medicine. It must also be acknowledged that by offering life-sustaining treatment which is genuinely futile, the physician sends a mixed message to patients and families, implying a real choice when in fact none exists.[178] It is also the case that "physicians who offer futile interventions under such circumstances are in fact deceiving their patients [and/or families] and compromising professional standards of medicine.[179] Perhaps some case studies will illustrate the way this topic is raised.[180]

Case One: Mrs. A Mrs. A is a 66-year-old woman with metastatic lung cancer. She has developed brain and bone metastasis and was hospitalized for increased shortness of

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177 Ibid., 306.

178 Stuart J. Youngner, MD, "Futility in Context," *JAMA*, vol. 264, no. 10 (September 12, 1990): 1295.

179 Nancy S. Jecker and Lawrence J. Schneiderman, "Medical Futility: The Duty Not to Treat," *Cambridge Quarterly of Healthcare Ethics*, 2 (1993): 153.

180 While these cases are fictitious, they do represent possible real case scenarios. That is, while not based on any particular or factual case or cases, the diagnosis, prognosis and probable treatments and outcomes are possible given the particular disease process.

breath and pain control. She is awake, oriented to time and place, and able to participate in treatment decisions. The primary physician and nurse have a conference with Mrs. A and her family to discuss her prognosis, the plans while she is hospitalized, and the possiblity of sending Mrs. A home with her family and beginning hospice care.

The physician explains that there is no further treatment available which will stop the progression of the cancer and the goal now is to keep Mrs. A comfortable. Mrs. A accepts the doctor's prognosis concerning her cancer and states she wishes to discuss the recommendation with her family. Her family, however, knowing that her disease is advanced, state they cannot imagine being without her. They know the end is near, but tell the doctor they want everything possible to be done, including attempts to resuscitate her should she go into cardiac or respiratory arrest.

Case Two: Mr. S Mr. S is a 56-year-old man with a history of insulin-dependent diabetes and coronary artery disease. He entered the hospital for a total knee replacement and initially did well after surgery, until suffering a respiratory arrest on the third postoperative day, possibly due to a pulmonary embolus (PE or blood clot to the lung). He was resuscitated but suffered anoxic brain damage and did not regain consciousness. He has been in the intensive care unit

for one week, but has not been weaned from the ventilator because of the anoxic damage to his brain stem.

In discussing his treatment plan with Mrs. S, the physician raises the subject of Do-Not-Resuscitate orders. He explains that Mr. S is not going to have any improvement in his neurologic status, that it is unlikely he can be weaned from the ventilator, and that he will continue to require total support, including artificial nutrition and hydration. The physician recommends that resuscitation not be done if he should arrest again, and offers the option of withdrawing other treatments.[181]

His wife seems to understand the facts about her husband's condition, but insists that "he has always been a fighter" and would want everything that could maintain his life, even if it does not restore him to his previous level of functioning. She also acknowledges that she understands he will need to be transferred to a long-term care facility at some point.

Case Three: James James is a 12-year-old boy with leukemia who has been receiving treatments for his condition over the past two years. Initially, he seemed to be

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181 In this case other treatments include the continued use of antibiotics for infections or medications which will help maintain his blood pressure, heart rate and reduce the potential for additional pulmonary emboli.

responding to the regimen, but over the past six months his admissions to the hospital have increased due to his immunosuppressed state. He has persistent pain, has developed pneumonia, and is showing signs of increased septicemia (systemic infection), along with the progression of the disease and the continuous failure to respond to treatments.

The only available treatment option is a bone marrow transplant, for which there is not a match within his family. While another donor match might be possible, the probability of finding a suitable donor is low. During the search for a donor, the increased wait decreases the likelihood of his survival while his condition continues to deteriorate and his pain level increases.

The physicians taking care of James all agree that palliative care is the only realistic and beneficent option left. In discussing this decision with the parents, they intimate that hospice care could be arranged and James could be kept comfortable at home while waiting for a possible donor match.

James' parents vehemently object to hospice care, feeling that such action only admits defeat and would lessen the continued search for a matching donor. They demand that he be kept in the hospital while waiting for the donor marrow.

Case Four: Brandy Brandy is a four-year-old girl who

was born HIV positive and has recently been diagnosed with AIDS. She has developed opportunistic infections, Kaposi's sarcoma and other symptoms related to her immunodificiency, along with pronounced wasting due to weight loss, diarrhea, and poor nutrient absorption. She is also showing signs of *Pneumo-cystis carinii pneumonia* (PCP).[182]

While in the hospital, Brandy has been receiving symptomatic treatment for the pneumonia, AZT to interrupt the HIV cycle, alpha interferon for the Kaposi's sarcoma, and pentamidine for the PCP.[183] IV fluids and nutritional supplements are given to combat her poor physical status.

The physicians, nurses, and support staff taking care of Brandy meet with her mother to discuss discontinuing further treatment, keeping Brandy comfortable, and not resuscitating her should she arrest. Her mother objects to any decrease in the current level of care, stating that "a cure might be found in the near future."

Case Five: Mr. J. Mr. J. is a 44-year-old man who has wide-spread metastatic cancer from an unknown primary site. For unknown reasons, a noxious odor emanates from every orifice in his body. His pain is controlled and he remains

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182 Kathleen Talaro and Arthur Talaro, *Foundations in Microbiology* (Dubuque: Wm. C. Brown Publishers, 1996), 790-95.

183 Ibid., 795-96.

alert and oriented. His doctor has explained that nothing further can be done to treat his cancer and suggests that palliative care be initiated.

Mr. J. asks that "everything" be done to keep him alive while he is still alert and oriented. He states that he knows he is going to die, and the odor coming from his body is sickening to everyone who enters his room, but his family and friends still come to visit him, so remaining alive has some meaning. He adds, however, that he wishes to be kept alive only as long as he is able to interact with his family and friends, and should he become comatose, he then wishes to be allowed to die.

In all five cases questions exist regarding futility and its normative implications, for example:

- Is it ethically permissible to offer care that does not benefit the patient?
- Are we ethically or morally obligated to continue the use of costly medical treatments and resources which do not benefit the patient?
- Must we continue treatments even if it means the possibility of increasing the patient's suffering?
- Must the physician(s) continue treatment(s) which he deems futile?
- Must treatment, which could benefit another patient, be given to a patient which is considered futile?

Of the five cases presented, it seems clear that the first four constitute requests for the continuation of medical care which is not medically indicated and futile. The fifth case, however, provides an example of the precarious nature of medical decision making. The patient has not requested that

he be just "kept alive" or phsiologically viable at all costs. He has made it clear that should he become comatose, he should be allowed to die.

Historically, decisions not to offer or continue providing care considered futile "were made by physicians operating under the principles of nonmaleficence and beneficence."[184] These concepts allowed physicians to do what they considered to be in the patient's best interest, including not providing or continuing care which was considered futile.[185]

However, with the heightened concern for patient autonomy, the increase in technology and potentially beneficial therapies, and even the physician's own fear of a malpractice suit for not "doing everything possible," intensive and often futile care is offered. Such actions serve not only to compromise the autonomy and moral conscience of many physicians, but promote the idea that any patient demands for treatment will be met.

To feel compelled to offer futile medicine not only exploits the ethics of many physicians but also enhances the

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184 John M. Luce, MD, FCCM, "Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists," *Critical Care Medicine*, vol. 23, no. 4 (April, 1995): 760.

185 Ibid.

public's fear of death and increases the inflated ideas about what medicine and science can achieve.[186] And, for those physicians who do offer futile interventions, for what ever reason or motivation, they "are in fact deceiving their patients and compromising professional standards of medicine."[187]

Obviously, physicians and the health care system are not blameless in this shift of patient and surrogate expectations. Also, third party insurance has helped perpetuate consumer demands, and the fee-for-service reimbursement has encouraged physicians and hospitals to disregard costs and other social considerations. An additional concern, besides a family's request or demand for continued futile treatment, is the physician who, for what ever reasons, refuses to stop treatment(s) which is not medically indicated or beneficial.

Increasingly, medical decisions and treatment demands are made by patients and their families or surrogates under the principle of autonomy. However, respect for autonomy does not empower patients or surrogates to demand that physicians prescribe treatments which are considered futile and medically

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[186] Jecker and Schneiderman: 155.

[187] Ibid., 153.

nonbeneficial or inappropriate.[188] Neither is the principle of patient autonomy an ethical absolute which functions as a trump card, serving to cancel "out other ethical values with which it may conflict."[189] Like all moral principles, autonomy "has only prima facie standing and can be overridden by competing moral considerations."[190]

Ultimately, the exercise of professional and institutional responsibility and ethical standards must address the requests and demands for inappropriate, marginally effective and futile therapies.[191] There must also be a statutory framework and institutional policies developed, supported by a social consensus and case law, which sanction only appropriate medical options, when attempts to arrest or minimize a disease process have failed.[192]

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188 Steven H. Miles, M.D., "Informed Demand for 'Non-Beneficial' Medical Treatment," Sounding Board, *The New England Journal of Medicine*, vol. 325, no. 7 (August 15, 1991): 514.

189 Nancy S. Jecker and Lawrence J. Schneiderman, "Judging Medical Futility: An Ethical Analysis of Medical Power and Responsibility," *Cambridge Quarterly of Healthcare Ethics*, vol. 4 (1995): 28.

190 Beauchamp and Childress, Fourth Edition, 126.

191 Ibid.

192 David Crippen, M.D., "Inappropriate Medical Treatment For Moribund Patients: an international consensus on futility." http://www.okstate.edu/artsci/philosophy/futility/ fcp1.htm. In the attempt to prescribe a contextual framework and

Such policies, developed within the framework of a sphere-specific utilitarianism, would establish and support the professional, institutional, and societal ethical standards. The criterion in determining the explicit values and probabilities in the use of expensive and scarce medical resources and technology would be instituted in light of the patient's diagnosis and prognosis, ability to respond to medical treatment, and the appropriateness of the medical treatment. Decisions to withdraw treatment would be made only after discussions with the patient and/or family, providing clear and precise reasons as to why no further life-prolonging care will be given.

It is also possible to create medical policies and procedures which address the "issues of use of high technology

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policies which address the issue of futility, it may simply be more effective to use other more pragmatic measures to apply the standards related to futility rather than attempting a definition. For example, the Oregon plan, discussed in Chapter 2, seeks to reflect community values by ranking various health care goals related to Medicaid (e.g., placing preventive care ahead of cosmetic surgery). Or a society may simply choose to limit the use of therapies that may be of limited value and have a likelihood of minimal success in isolated cases if the expense limits the utility for the larger population. Since rationing policies make specific the values and probabilities that futility-based arguments leave implicit, it seems preferable to develop and adopt such policies rather than use subjective futility arguments as guidelines for limiting the availability and use of expensive and scarce resources.

near the end of life."[193] By developing professional practice guidelines for limiting, withholding, or withdrawing treatment, including CPR (cardiopulmonary resuscitation), the physician is encouraged and supported in the decision to discontinue medical treatment deemed futile.[194]

Such policies and guidelines could be developed by a public commission, augmented by lay members, which made recommendations, disseminated information and allocated priorities in the care of patients near the end of life. The legislative process would then transform these coalition sentiments into public policy.[195]

However, in communicating the decision to stop treatment, the physician should not tell the patient or family that "There is nothing more we can do for you." "Instead, the physician should. . . underscore that everything possible will be done to keep the patient comfortable and to maintain the patient's dignity."[196] Such action not only respects the patient's right to be informed (when possible) but also will

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193 Lofty Basta, MD, FACC, FRCP, and Jeffrey Tauth, MD, "High Technology Near the End of Life: Setting Limits," *JACC*, vol. 28, no. 6 (November 15, 1996): 1627.

194 Ibid.

195 Ibid.

196 Jecker and Schneiderman: 30.

hopefully help patients and families begin to cope with the gravity of the situation and the inevitability of death.

While such attempts may be viewed as the usurping of individual rights and autonomous decision making, the utility of such decisions addresses the reality of the necessity to balance benefits and burdens. There is also a case to made for the ethical duty of the medical profession to omit futile therapies which are considered *prima facie* wrong. When there is no benefit to be realized, other than supporting a family's wishes, such actions compromise the intent of medicine and the welfare of society.

To attempt to deny that a situation exists, merely from the perspective of subjective and wishful thinking, does not negate the facts of a case. If anything, such a realistic approach acknowledges the authenticity of the situation, potentially supporting the individual's wishes and the well-being of society.

Such a process gives voice to all parties concerned, that is, the patient, if possible, the physician and staff, and the family or surrogate who may speak on behalf of the patient. While the physician is under no obligation to prescribe treatment deemed futile, the physician is ethically bound to inform and educate the patient and/or family of the reasons for the decision.

This determination not to continue ineffective or inappropriate treatment would also include the use of cardiopulmonary resuscitation (CPR) and the writing of a Do-Not-Resuscitate (DNR) order by the physician. While CPR is viewed as an emergency procedure to be administered on patients who experience cardiac arrest, to perform such efforts in this context of futility would only serve to give mixed messages to the patient and family.

Furthermore, studies suggest that while the use of CPR may restore cardiopulmonary function, survival of the patient until discharge from the hospital is frequently less than favorable.[197] "Of the patients who receive CPR, one third survive the resuscitation effort, and one third of these individuals, in turn, survive until discharge from the hospital."[198]

In two independent studies, of the various 26,227 cases reported, an average of only 38.75% of the patients survived 24 hours and only 15.8% of those patients survived until discharge.[199] Consideration must also be given to the

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197 The Council on Ethical and Judicial Affairs, American Medical Association, "Guidelines for the Appropriate Use of Do-No-Resuscitate Orders, *JAMA*, vol. 265, no.14 (April 10, 1991): 1868.

198 Ibid.

199 Ibid., 1868-69.

patient's physical condition, any preexisting condition, the diagnosis and prognosis, and whether the patient was in the hospital at the time of the cardiac arrest.

While it would definitely be a violation of the mandated medical ethic of beneficence to discriminate against a patient on the basis of a condition or diagnosis, for example, HIV, AIDS, or old age, it is not a breach of the ethic to refuse to treat those who are "overmastered by their diseases,"[200] realizing that in such cases medicine is impotent. Again, in such cases, it is part of the physician's duty to educate the patient and/or family, providing a basic understanding of the particular disease and the potential for success or failure in treatment.

For example, "cancer" is generally understood by the public in a nearly singular conceptual framework, when in fact there are numerous "cancers", so different from each other that some are in fact curable, while others are not. In the case where multiple and varied treatments have not proven successful in arresting the specific disease process, continued treatment only gives mixed messages and false hope. In such cases, the principle of beneficence calls for an honest, albeit painful, decision to not continue providing

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J. Chadwick and W.N. Mann, *The Medical Works of Hippocrates* (Boston: Blackwell Scientific Publications, 1990) quoted in John Luce, *Critical Care Medicine*: 760.

medical care which is futile. It is then the responsibility of the physician to make appropriate recommendations and referrals for the patient to receive hospice or palliative care at home.

Such goals and resulting actions, supported by policies, affirm the ethical intent of medicine, the moral value of the individual, and the institutional integrity in discerning the limits of medical interventions. The social utility to be achieved by such a sphere-specific theory would, in turn, allow for a medical ethic which speaks out of beneficence, temperance, justice and human finitude.

Distributive Justice and Individual Responsibility

Clearly, the issues go beyond those dealing primarily with conflicts between individuals. At stake are concerns growing out of conflicts between society's interests and an individual's interests. While the futility argument addresses and supports a major point from a utilitarian perspective, there is still the questions of competing claims for general health care services and justice in distribution.

Perhaps the issue can be made clearer by the following poignant question: To the extent that our health care system can make it possible, does the child of a manual laborer, unemployed or uninsured person have the same chance of

avoiding a significant or life-threatening illness, and if contracted, surviving and fully recovering from it as the child of a well insured individual, physician or corporate executive?[201] Evidently, given the current state of affairs in the market driven, U.S. health care system, it can and does offer a higher probability for the physician's, executive's, or fully insured person's child to avoid such an illness, or, of surviving and fully recovering from a given illness, than it offers the child of a person who is uninsured or underinsured.[202]

In arguing for a proper distributive ethic of health care, it must be realized that the current U.S. system is a market-driven, multi-tiered system which rations according to income, ability to pay, and insurance coverage. And, while the patient may be a so-called consumer, medical care in the U.S. differs greatly from the usual commodity market purchase by customers.[203]

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201 Uwe E. Reinhardt, Ph.D., "Economics," *JAMA*, vol. 275, no. 23 (June 19, 1996): 1803.

202 Ibid.

203 Kenneth Arrow, "Uncertainty and the Welfare Economics of Medical Care," *American Economic Review*, vol. 53, 1963: 941-73. Arrow further notes several distinct qualities in which medical care differs from other goods and services. First, the demand for medical care is generally unpredictable and irregular, apart from the preventive services, such as annual checkups, flu shots, childhood immunizations, etc. Second,

However, even with a universal health care system it would be impossible to afford such a system based strictly on the majority of patients' demands, physicians' personal agendas or the strongest perceived notion of rights. Such an interpretation of a utilitarian system would only perpetuate the irrational allocation of health care resources to the socially powerful, well-to-do, or the greatest number of healthy persons with the strongest preferences. For example, if just one person more than half the populace is 'healthy' then the greatest good is in fact determined by eliminating the benefit or "right to" such health care goods and services for all those who are in poor health or otherwise considered a drain on society.

It is here that the proposed sphere-specific utilitarian formula can accommodate an ethic of distributive justice which supports the notion of rights to health care. Rather than the notion of achieving the "greatest good" in general, the sphere of utility focuses on the maximum good to be achieved for those needing the services and goods in a particular sphere.

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the cost of the care that will be needed usually cannot be predicted in advance. The need for the medical care often comes suddenly, minimizing the possibility of "shopping around." Another point is that the ethics of the medical profession makes medicine unlike any other business; there is no open price competition; physicians do not advertise; and, when a physician recommends treatment, ideally he is to be completely unaffected by considerations of personal gain.

Consideration is also given to the notion that eventually all are, or will be, recipients of the needed goods and services.

In this case, the particular sphere is health care, and the theory calls for a realistic look at the diagnosis and prognosis of the patient, and the physician's assessment of the patient's ability to respond to treatment. Here, the notion of collective social protection serves as a driving force, calling for the preservation of resources for the future use of those in society whose need is also legitimate. Such a program would be a single-payer, triage based system, designed to meet the person's genuine health care needs, and treatment decisions would be "made despite society's diverse moral values."[204]

While a general consensus of moral values is not obtainable, a social process of priority setting would allow for the determination of what therapeutic and diagnostic

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Robert A. Gatter, Jr. and John C. Moskop, "From Futility to Triage," *The Journal of Medicine and Philosophy*, vol. 20, no. 2 (April 1995): 195. That is, despite the diversity of moral opinions, the sphere-specific utility moral maxim, in this case, is to achieve the most equitable distribution of health care for the greatest number, while acknowledging the individual's rights and responsibilities to such goods and services. As part of the individual's responsibility of reciprocity to the system, there would be a known implied agreement not to expect or demand continued aggressive and futile treatment. This does not mean that the patient is left without care, but that palliative/comfort care would only be available. Also, the individual would agree to be considered as a potential organ and tissue donor.

interventions will be guaranteed to all as a part of the basic health care package.[205] Such decisions must also frame an ethic for medicine that takes human mortality seriously and that can guide us through the tensions that exist between ever new, promising and expensive medical interventions and the reality of limited resources.[206]

In order to provide universal and equitable coverage, this health care system would be based on the following five elements of the Canadian health care system:[207]

(1) *accessibility,* which prohibits any direct charges for insured services, and therefore does not allow for any co-payments or deductibles.[208] For those services not considered insured, the individual would be financially responsible, with cost considerations based on preestablished co-payment fees. Such a condition supports the general utility condition of providing the greatest good for the greatest number, and, at the same time, recognizes the legitimate right of the

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205 Englehardt, "Medical Ethics for the 21st Century": 306.

206 Ibid.

207 Robert G. Evans, "Canada: The Real Issues, *Journal of Health Politics, Policy and Law,* vol. 17, no. 4 (Winter 1992): 743.

208 Raisa B. Debert, "Canadian Medicare: Can it Work in the United States? Will it Survive in Canada?, *American Journal of Law & Medicine,* vol. XIX, nos. 1&2 (1993): 79.

individual to access the health care system.[209]

(2) *comprehensiveness* provides coverage for all medically required physician and hospital services. This includes preventive care, physician office visits, and medications and diagnostic tests as an inpatient.

(3) *universality* grants coverage for all eligible residents, though emergency services are not denied to non-residents.

(4) *nonprofit administration* reduces the overhead costs which add to the expense of health care without contributing to the resources available.

(5) *portability* of benefits allows for coverage anywhere within the United States, without the worry of filing an insurance claim or having additional out-of-pocket expenses for health care services and goods obtained away from a designated health care provider.

Such a plan of distributive justice would also make it illegal for an "insurance company to sell coverage for services provided by the national health plan."[210] However, supplemental insurance would be available, at a minimal rate,

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209 Ibid.

210 Louis M. Montgomery, "Can Canadian-Style Health Care Help Us Get Canadian-Style Malpractice?," *NCMJ*, vol. 53, no. 2 (February 1992): 100.

to help cover the cost of the services not provided or paid for by the universal plan. For those who choose or cannot afford the additional coverage, minimal cost-sharing provisions would be indicated for those services not universally insured.

In an effort to perpetuate the notion of distributive justice, within this sphere-specific utility formula, a system of revenue sharing between state and federal governments would be required. While not operated by the government, there would be federal funding and established guidelines to which each state must adhere in order to receive operating revenue.[211]

There would also be the need to establish a series of local payment agencies that work within the established national guidelines.[212] In turn, each payment agency would function like a large, prepaid, group practice, all providers would agree to accept assignment, and all residents would receive a medical plan number which guarantees the right to receive health care benefits.[213]

While such access does not support or guarantee a right

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211 Ibid.

212 Debert, 79.

213 Ibid.

to any and all treatment deemed necessary by the individual, it does provide the right to reasonable and beneficent medical care. This sphere-specific form of utility takes seriously and provides a balance between rights and responsibilities for the individual and society. That is, to restrict or withdraw health care services does not sacrifice the rights of the individual for the greater good, but recognizes and acknowledges the limits of medicine, the scarcity of valuable medical resources, and human finitude.

As with any other major sphere under consideration or imposed upon the theory, the utility to be evaluated and achieved will depend upon the how the good, for that particular sphere, is defined and endorsed by the goals and policies established by a beneficent society. Accordingly, in order to support the rights of the individual, consideration is given to the individual's duty of responsibility to the well-being of society.

Chapter 7

Conclusion: The Sphere-Specific Construct Revisited

It has been the attempt of this dissertation to adjudicate utilitarianism with the issue of rights. While the process may have seemed a bit unclear in the beginning, it was necessary to give an historical setting to the current realities in health care in order to better illustrate the theoretical and applicable possibilities of such a theory.

Admittedly, there are many questions and arguments left unaddressed, but it is my contention that the general premise that utilitarianism and rights are compatible has been illustrated. That is, the greatest good to be realized in the sphere of health care is to recognize and accommodate a right to equal access of medical care in conjunction with a scheme of distributive justice. The result being the mutual sharing of benefits over burdens, whereby scarce resources are optimized, futile treatment is minimized, and the greatest need is met. Such a theoretical proposal also enhances the idea of ensuring the rights of the individual, supports the idea of "fair opportunity" and provides for the "collective social protection."[214] And, while the focus has been primarily on the sphere of health care, I still maintain that any major sphere of life can be plugged into the theory with equal

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[214] Beauchamp and Childress, Fourth Edition, p. 351.

results.

In the first chapter we examined some of the general contributing factors to the escalation in health care demands within the United States. It was noted that numerous philosophical arguments and intricate theories have been constructed in an attempt to resolve some of the substantive moral/ethical issues to which medical practice gives rise. In particular, two theorists' positions were generally alluded to, with the claim that these positions hardly meet the theoretical or practical challenge before them.

The supporting claims for this sphere-specific form of utilitarianism were presented as follows:

(1) Since health care is closely linked to economics, the rational and efficient use of resources is by necessity a primary component to be considered.

(2) Since the function of morality is to serve as a guide for ethical human conduct, and utilitarianism is a consequence based theory, the value or utility of the associated actions to health care are to achieve the greatest benefit for those needing such services. Such decision-making allows for *prima facie* obligations to become clearer and conflict resolution reduced.

(3) By virtue of the principle of reciprocity, the individual who expects and receives benefits from society

becomes obligated to promote or contribute to the society's well-being.

(4) Part of the intent of medicine is to do the most good with the health care resources available.

(5) While patient participation and self-determination in the care received are a valued part of medical intervention, such considerations do not validate the use of scarce resources when such actions are medically unwarranted and considered futile.

Though it may be theoretically desirable to ignore the economic factors associated with the sphere of medicine, such considerations are morally and ethically necessary. To aspire to provide access to the health care system for every individual and ensure quality medical treatment, regardless of ability to pay, is a pipe dream. And what is even less defensible is the illusion that health care within the United States is a guaranteed right, with minimal to no costs involved or personal responsibilities attached.

As argued, one particular advantage of utilitarianism over other theories is that the principle of utility serves as the grounding principle by which all other principles, morals, ethical positions, and virtuous actions are measured. In defining this sphere-specific utilitarian system and in an attempt to address some primary issues associated with health care, the major focus has been to adjudicate the internally

coherent ethical theory of utilitarianism with the issue of rights.

The primary intent, therefore, has been to develop a theoretical and practical model which addresses and adjudicates a theory of "rights" within a sphere-specific utilitarian system. Ideally, any significant life sphere can be plugged into the construct and provide a means whereby specific rights are endorsed and the aggregate well-being is achieved.

The general assumption is that utilitarianism cannot support the general notion of rights with moral force.[215] Such a supposition presupposes a "conflict of interest" and a "conflict of welfare" among the recipients because of the potential for perceived injustices and inequalities in benefits afforded to individuals by the system.

The claim is further made that utilitarianism is incompatible with rights, with the premise being that utility is person neutral. While utilitarianism may not be a respecter of persons, it does take rights seriously by virtue of not creating a hierarchy of individual respect. If rights are to be taken seriously, a right exists by virtue of a recognized need by the aggregate, and while all may not agree on the disbursement or enforcement of the right, the intent is

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215 Hardin, 77.

that all have claim to that particular identified right.

In the various notions of utilitarianism, it seems that "states of mind" and "perceptions of happiness or pleasure" have predominated, rather than proposing the idea that the moral impetus of utilitarianism is to define the right as just actions and motivating people to achieve them.[190] The utilitarian dictates for right action, in the sphere of health care, are supported by the principle of beneficence and the need of the patient. As to whether the person has a "right" or entitlement to this service has been the question at hand.

My contention has been that the issue of "rights" must be defined in conjunction with the idea of a particular system with established and clearly interpreted rights, rather than from the individual's purely subjective desire or claim of an assumed right. It has been reiterated throughout that one important element which is overlooked in most theories addressing the issue of rights is the participant's responsibility; the tendency is to discuss rights without mention of the recipient's obligation in relation to that particular, identified right.

Given the complexities of the concepts of equality and rights, the notion of distributive justice must be analyzed only within a particular sphere (for example, the sphere of

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190 Ibid., 3.

health care, education, community, or workplace). Naturally, the development of any supporting policy will not work strictly within the micro realm of the individual or the macro realm of society at large. Clearly defined boundaries and consequences must be established within the particular system or policy being examined.

It has been my assertion that only by utilitarian considerations, in health care or any other major sphere of life, can a clearly defined system of distributive justice be identified and a genuine right to a particular good or service be clarified at a more objective and equitable level.

It seems evident that the idea of "justice" and "fairness" in the sphere of our current system of health care is obscure, self-serving, and totally subjective for the individual and/or family. This is especially true given the fact that there is generally no accountability for demands made (i.e., "I want it because I think I need it," or "I want it because it is available"). And, in many cases, there is no sense of financial or personal responsibility for care received by the individual.

Neither does such a position give evidence of a perception of moral obligation to the well-being of society. Though the utilitarian construct may be seen as potentially coercive, the principle of utility can provide an educational foundation of moral duty and reciprocal obligation between the

individual and aggregate claims for particular goods and services.

Another valid claim for the educational process is to provide a basic understanding of genuine medical success. For example, the diagnosis of "cancer" may be understood by the general public from a nearly singular conceptual framework, when in fact there are numerous types of cancer, so different from each other that some are in fact curable, while others are not. As noted in Chapter 6, while health care consumers may be better educated to the ways of medicine, they are not genuinely qualified to decide which treatments, tests, or procedures are most needed for specific diseases.[191]

While it is true that education alone cannot establish the legitimacy of moral principles, such an endeavor can introduce the axioms and demonstrate their validity. And, while such education may not enforce a sense of duty, it does prescribe an awareness of the individual's responsibility to the needs and claims of others.

Such instructive endeavors may also be effective by virtue of the systems design. It seems, primarily, that individuals and society as a whole become accustomed to expecting what is available. If the sphere of health care is recreated with certain limitations, then the process of access

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[191] Ginsberg, 1633.

is instructional in and of itself. Such a scheme further enhances the idea of ensuring the rights of the individual and the "collective social protection," described in Chapter 5.

While such a concept may be bolstered as the ideal, serving as rhetoric for equality, the existence of rights is not diminished by the sphere-specific utilitarian equation. The meshing of idealism with pragmatic reality does nothing to diminish the philosophical validity or stability of such a premise, even when factoring in the consideration of social and economic constraints. Furthermore, the utility or the good to be achieved is realized or produced by compliance with the secondary or supporting principles established by the particular sphere, in this case, beneficence, nonmaleficence, autonomy and justice.

While the overview of the historical development of medicine in the 20th century may not have seemed immediately clear, or relevant, as stated in the introduction, the purpose was to provide insight into the ethical concerns and inequities which exist within the sphere of health care. Any theoretical construct must be established within its historical setting, in order to give a clearer understanding of the goals to be achieved.

As with any major social sphere, escalation in demands for a particular good or service and the advancement in technology creates new problems and ethical concerns

associated with equal access and distributive justice. Therefore, without a sense of the history associated with a particular sphere, the theoretical and practical implications and applications seem meaningless.

Along with a description of the current realities of health care, an examination of the positives and negatives of a liberal, sphere-specific, utilitarian system approach were given. To emphasize the dynamics of such a system, some specific case studies highlighted associated ethical concerns of futility and problems of distributive justice. As indicated, the notion of individual responsibility is a key element in this sphere-specific utilitarian theory.

A construction of the sphere-specific utilitarian theory served as the primary focus for Chapter 4. While the general notion of the "greatest good for the greatest number" serves as the primary ethical construct for utilitarianism, such a supposition is too obscure when not defined from a particular or intentional point of utility reference to be achieved. It has been my assertion, therefore, that the "greatest good" or benefit must necessarily be defined from within a particular arena, or sphere, not from some nebulous concept or subjective position about life or feelings in general.

In support of this sphere-specific utilitarian construct, economic concerns and the appeal to man's common sense were cited as two primary and pragmatic reasons for the validity of

this theoretical proposal. The idea that these two premises lend support to the adjudication of utilitarianism and rights, was also introduced.

While it is generally assumed that one of the primary problems with utilitarianism is that the individual is ignored, i.e., "the greatest benefit for the greatest number," I have argued that the individual agent should be included in the utility equation. As a member of the identified society, the individual is entitled to and automatically given equal consideration within a particular sphere.

It was also noted that while this sphere-specific theory contains a seemingly "situational ethics" approach, more akin to act utilitarianism, such action helps to identify and more clearly define the good or benefit to be achieved. This in turn sets the parameters which qualify and quantify the desired utility, clarify the established right, and determine the efficacy of decisions made and actions taken within the sphere under consideration.

In an attempt to address the adjudication of rights and utilitarianism, my assertion has been that the language of rights cannot be resolved in a rational way without some form of legal endorsement and corresponding institutional arrangement.[192] While we may sanction a right to something

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[192] Donner, 174.

with a moral position, it is only by some legal and/or institutional process that substance is given to a particular right. Jeremy Bentham's claim that a genuine right is the child of law seems to hold true, for only from "*real* laws come *real* rights."[193]

The misconception seems to be that rights come to be legitimate merely by an appeal to ideal values or the individual's desire or assumption of having a right to a particular thing, good, or service. Another problem is the failure to establish a clearly defined set of principles associated with an identified right, which is relevant only to a particular sphere, system or institution.

As reiterated throughout, one important point generally overlooked in most theories addressing the issue of rights, is the claimants' responsibility. The tendency is to discuss rights without mention of the recipient's reciprocal obligation to society in relation to that particular sphere and identified right. Given the complexities of the concepts of equality and rights, it seems apparent that the idea of distributive justice can be pursued only within an identified or specific sphere.

Furthermore, the claim of having a right is ineffectual in and of itself. Such a declaration only has validity in

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193 Bentham, 220.

relation to the corresponding sense of obligation recognized by others. That is, an obligation which goes unrecognized by others looses none of the full force of its existence, but a right unrecognized or unsupported has little value.[194]

It was further argued that the concept of a right is meaningless without a clear understanding of what an identified right entails and the responsibility it implies. In this sphere-specific form of utilitarianism, the notion of "fair opportunity," associated with a particular right, is clearly identified and the individual's responsibilities are clarified.

As stated, equal consideration may be given to all, but the individual's need to the good or service must also be a factor in the equation. Such consideration, in turn, calls for the person to give value to the notion of the "collective social protection."

It is also recognized that such an ethical construct makes us all members of the same moral community, with like considerations and responsibilities. In support of this idea of a moral commitment to others, this sphere-specific utilitarian theory further recognizes the supporting notions of human sympathy and goodwill.

To further reinforce the idea of a particular right, the

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[194] Weil, 3.

powers of the legal and institutional systems may serve to establish and clarify the boundaries by which the right is supported. While such measures may seem intrusive and coercive, it is still the case that these entities are routinely called upon to clearly define and enforce rights or entitlements.[195]

One of the great myths is that rights are acquired prior to, or independent of, social interaction. This tale is further perpetuated by the assertion that individuals have "rights" merely by the philosophical idea of a "state of nature."[196] The truth is, however, that genuine rights exist "only *after* people confront the fact of scarcity and begin to argue the normative implications."[197]

Such rights become further entrenched, within this sphere-specific form of utilitarianism, when the "normative implications" have been addressed and the pertinent system and/or legal support has been established. To some degree, such an examination of the normative implications results in actions which refute and cause a break with the myth or idea

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[195] Ackerman, 19.

[196] Ibid., 5.

[197] Ibid.

of a social contract.[198] Rather than the individual laying claim to a right by virtue of some "privileged moment of promising,"[199] the particular right is realized by an ongoing social practice incorporated into the notion of social justice.

This does not mean that the individual does not give consideration to personal needs or desires, but that value is given, by the agent, to the notion that individuality is not realized apart from society "but rather as a result of *an interaction with society.*"[200] When taken seriously, such a claim gives rational support to the sphere-specific notion of taking individual rights seriously, while maintaining the concept of achieving the greatest good associated with a particular sphere of utility.

Rights in this context, then, are contingent upon a balancing of individual need and social recognition of a particular right.[201] In order to realize social equilibrium, claims of rights are prima facie rather than absolute, that is, while a particular right may be valid, it may also be

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198 Ibid., 6.

199 Ibid.

200 Ibid., 330.

201 Beauchamp and Faden, 122.

overridden by more demanding claims of social need.

Another consideration from this sphere-specific utilitarian position is the "problem of interpretation," which challenges the notion that utility must be "'maximal' in every case,"[202] or that equal access always means equal distribution. Unequal distribution does not mean a violation or negation of a clearly defined right; in this case, a right to health care services and resources. The right to receive such goods has value in varying degrees, based on individual need and ability to respond to resources used and care received.

As indicated, such value entails consideration of the notion of futility of treatment, which raised questions concerning the following normative implications:

- Is it ethically permissible to offer care that does not benefit the patient?
- Are we ethically or morally obligated to continue the use of costly medical treatments and resources which do not benefit the patient?
- Must we continue treatments even if it means the possibility of increasing the patient's suffering?
- Must the physician(s) continue treatment(s) which he deems futile?
- Must treatment, which could benefit another patient, be given to a patient which is considered futile?

While such questions deal with the utility considerations associated with health care, any sphere under consideration

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202 Sheng, 38. While Sheng uses this phrase in terms of negative and positive duties (or rights), from a sphere-specific utility position, the notion is that maximal utility will not be achieved in every case, but realized through the maximizing of the overall sphere of utility.

will have its own unique set of questions regarding need, distributive justice and benefit over burden. Whether it be public education, law enforcement, fire protection, or a clean environment, each individual has varying needs for such services, but it is society which benefits as a whole.

Ultimately, the exercise of professional and institutional responsibility and established ethical standards must address the requests and demands for any service or good connected with an identified right.[203] There must also be institutional policies and a statutory framework, supported by a social consensus, which sanctions the identified right(s) associated with a particular sphere of utility.

As stated earlier, clearly the issues surrounding rights go beyond those dealing primarily with conflicts between individuals. At stake are concerns growing out of claims between society interests and individual interests. While the futility argument, associated with the sphere of health care, may address and support a major utilitarian premise, there is still the question of competing claims for general health care services and justice in distribution.

In this context, the notion of a right is meaningless without a clear understanding of what that right entails and the responsibility it holds. In a sphere-specific form of

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203 Beauchamp and Childress, Fourth Edition, 126.

utilitarianism, the notion of fairness associated with a particular right is clearly identified and the corresponding responsibilities are well defined. Such action only serves to provide additional support to the premise that rights are genuinely compatible within a utilitarian theory or system.

As indicated by the discussion and case studies concerning the issue of futility, primarily in Chapter 6, but mentioned throughout, there will be specific instances and necessary considerations which help clarify the boundaries or limitations associated with the distribution of particular goods and services. Even in the best of all possible worlds, unless everyone is identical, the needs of some are going to be different than the needs of others. Such variations of need do nothing to diminish the concept of a right, supported by a particular society, but do give rise to legitimate considerations concerning the individual and the reality of a particular situation.

The fact remains that the individual need not be sacrificed for the greater good. It is also true that morality is flexible, and virtuous principles, actions, and the utility, associated with a particular situation, good or service, can be realized in numerous ways and to varying degrees. Even in a pluralistic society, with diverse moral views, a sphere-specific utilitarian construct may serve to quantify and qualify the conditions associated with a

particular right. Such considerations and actions, in turn, contribute to the process of conflict resolution and decision-making within that particular utility sphere, without jeopardizing or ignoring the rights of a few for the welfare of the many.

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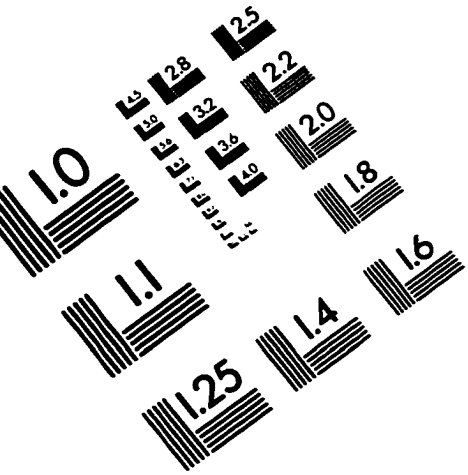

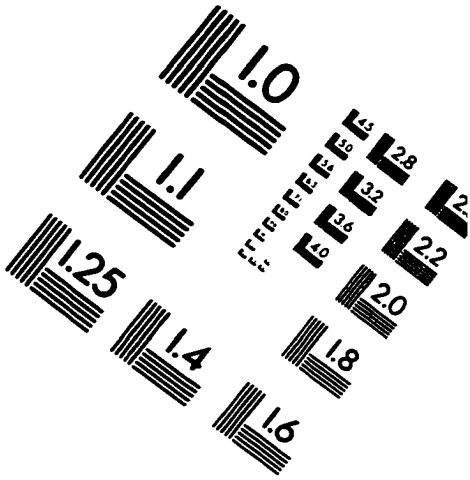

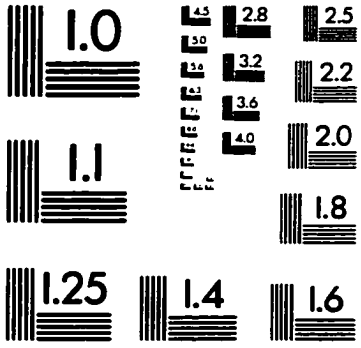

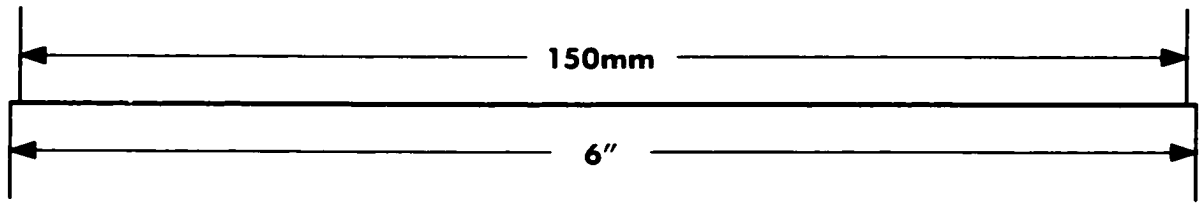

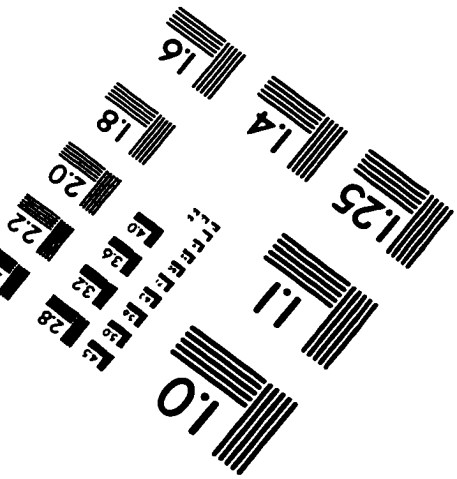

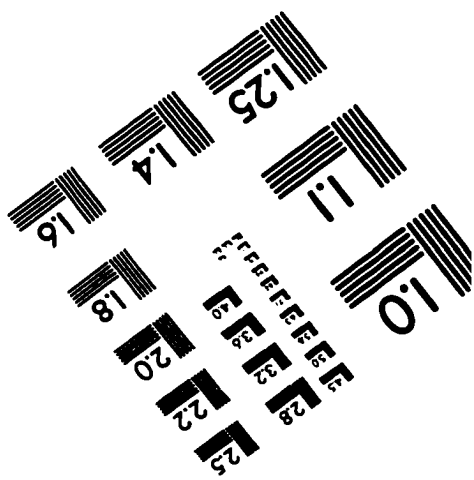

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