Beyond 'justice vs care': Can the ethic of care coordinate with the ethic of justice to support palliative care?

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BEYOND 'JUSTICE VS. CARE': CAN THE ETHIC OF CARE
COORDINATE WITH THE ETHIC OF JUSTICE
TO SUPPORT PALLIATIVE CARE?

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of

Master of Arts

in

Ethics and Policy Studies

Department of Ethics and Policy Studies
University of Nevada, Las Vegas
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ABSTRACT

For the past 20 years, there has been a growing awareness and acceptance of the palliative care concepts of Hospice. Hospice and the concept of palliative care represent a dramatic shift from the traditional medical model of physician-directed, institutional-centered health care.

What are the guiding principles of palliative care and what are their ethical underpinnings? The ethical principles of autonomy, justice and care will be explored, as well as the possibility for the abuse of palliative care under the current climate of healthcare reform.

Recommendations will be made pertaining to reform of the healthcare system, the education of healthcare professionals and safeguards against using palliative care for the sole purpose of cost-savings. Finally, there will be discussion about the benefits and burdens that might surface as a result of viewing the provision of palliative care from a combined perspective of justice and care.
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To the staff of Nathan Adelson Hospice, the patients and their families, I am greatly indebted for teaching me the meaning of caring.
CHAPTER 1

INTRODUCTION

Hospice, as defined by the National Hospice Organization provides palliative care to terminally ill patients, their families, and significant others, 24 hours a day, 7 days a week, in both home and facility-based settings. Physical, social, spiritual, and emotional care is provided during the last stages of illness, during the dying process, and during bereavement by a medically-directed interdisciplinary team consisting of patients, families, professionals, and volunteers. Hospice philosophy recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life, neither hastening nor postponing death.¹

The growth of the hospice movement is one of the most recent developments in the health care industry and has come at a time when the focus has shifted from primarily institution-based care to predominantly home-based care.² At the same time, with the acceleration of pressures on reducing health care costs and calls for reform, considerably more attention has been focused on proposals to control costs at the end of life.³ "Several studies have shown hospice care in the last year of life to be less expensive than conven-
tional care, with a greater cost advantage for home care hospices than hospital-based hospices. However, the only study that randomized patients to conventional care or hospice care found no significant differences in cost. Although it is not unanimous, the literature points to positive trends in the ability of hospice to be a cost-effective alternative for the terminally ill.

Our inability to finance the ever-increasing demand for health care services is forcing us to evaluate the principles of justice that have previously guided our society in formulating its health care policies. If the requirement of distributive justice is that people should get what they deserve, then the challenge for those working to reform health care is to determine what it is that people are entitled to. Proponents of hospice are telling us that what the terminally ill are entitled to is access to palliative care.

Health care policies have generally been established with three primary goals in mind: increasing access, reducing costs, and increasing quality. These goals are sometimes in conflict with each other and may require tradeoffs that would initiate discussions of the ethical problem: who should get what health benefits? It is within this context that this thesis will examine the problems of providing care for the terminally ill as seen from the
viewpoint of the ethics of justice as contrasted with the ethic of care.

In the midst of these discussions about what care should be available to whom and at what cost, the concept of palliative care has been gradually developing within the structure of the hospice movement. During the last twenty years, the hospice movement has been not only the voice but the heart of palliative care philosophy. Similar to Carol Gilligan's metaphor for women's way of reasoning, hospice has been a "different voice" in health care.10

Advocates of palliative care are hesitant about placing too much emphasis on the cost-saving benefits of hospice care. If the justification for palliative care is based solely on its ability to conserve health care dollars the fear is that the boundaries between palliative care and futile care will become blurred. While palliative care enhances comfort and improves the quality of the patient's life with no specific therapy being excluded from consideration, futile care places limits on what treatments will be available based on that treatment's ability to cure, ameliorate, improve or restore a quality of life that would be satisfactory to the patient.11 Palliative care explores and evaluates options in the context of the patient's values; futile care frames the decisions within the physician's medical expertise consistent with the available medical literature. Emily Friedman, a health policy analyst, fears
that futility policies will be applied unevenly and doubts whether implementation will be free of social bias, including age, gender, and income.\textsuperscript{12}

Palliative care is not about achieving "efficient or cost-effective dying."\textsuperscript{13} It is about the ethical responsibility of our society to care for the dying when the inevitable limits have been reached. "What hospice care itself acknowledges is the fundamental relatedness and mutual obligation of human social membership."\textsuperscript{14}

In an effort to support my premise that society has an ethical responsibility to provide palliative care for the terminally ill, it became evident to me that the ethic of care, as developed initially by Carol Gilligan and later expanded upon by Nel Noddings, provided the substance for my argument. These two women were the initial pioneers. However, there have been a small, but steady succession of psychologists, philosophers, and ethicists who have continued to refine the concept. Some have begun speaking the language of care when discussing care for the dying. The most comprehensive approach to the ethic of care and public policy was recently written by Joan C. Tronto. Where Gilligan and Noddings were very firm in their beliefs that the ethic of care was primarily a feminist ethic and could stand alone to support our moral behaviors, Tronto believes that it is not just a feminist ethic. It is a perfect complement
to round out the shortcomings of a viewpoint based on a formal concept of justice.

Dr. David J. Roy, in his presentation, "Is Palliative Care a Matter of Justice?" defines a formal concept of justice as one in which all beings of a given category should be treated alike. The dilemma then becomes: (1) who are the beings that belong in the same category and (2) what is the treatment that they should be given? Dr. Roy proposes that "there is no current theory of justice that can answer these questions." Furthermore, he proposes that what is needed is a radically different concept of justice. I would suggest that rather than developing a new concept of justice, a complement of justice and care can be used to support palliative care.

There is support in the literature to substantiate providing palliative care as an ethically sound way to provide health care for one who is dying. By promoting the ethic of care along with the principles of justice, individuals and society in general can be shown the need and see the benefit of caring for the terminally ill.

I propose that the only way to ensure that palliative care is a readily available option for all terminally ill, regardless of whether they are enrolled in a health care plan or not, is to make the provision of palliative care a matter of public policy. "Only when the needs of the dying receive a reasonable priority in political, economic, and
medical discussions will the financing needed to deliver hospice services to all in need be assured." The fact of the matter is that in almost all instances the dying will receive medical care whether it be provided in their home or in a facility, and those who have no health care coverage are generally treated in an acute care facility which is the most cost intensive point of service. The only question that remains is whether the care that the dying receive will be provided by a caring community sensitive to their needs with an emphasis on symptom control, or will it be an "allocation of medical care according to an individual's perceived utility or relative worth to society?"

It is imperative that the progress that has already been made by those in the hospice movement over the last twenty years be the foundation for the development of this policy. A precedent has already been set by the establishment of the Hospice Medicare Benefit in 1983. Palliative care is a benefit available to all who are insured under Medicare. It is now time to extend that same benefit to all terminally ill persons.

Chapter 2 will provide a history of the hospice movement with a thorough discussion of palliative care. Based on the three desired outcomes of a successful health care policy (increased access, decreased costs, and increased quality), several recommendations will be made for develop-
ing public policy that includes the provision of palliative care for the terminally ill.

After a brief discussion of autonomy and justice, chapter 3 will take an in-depth look at the ethic of care as developed by Noddings and Gilligan. Finally, the possibility of combining justice and care in order to support the provision of palliative care as public policy will be explored.
ENDNOTES


5. V. Mor and D. Kidder "Cost Savings in Hospice: Final Results of the National Hospice Study." Health Services Reserve 1985; 20: 407-422.


12. Ibid.

13. Margaret P. Battin, "Dying in 559 beds: Efficiency, 'best buys,' and the ethics of standardization in national

15. David J. Roy, Pal, Dr. Theol., "Is Palliative Care A Matter of Justice?", audiotape of presentation at The 5th Annual "To Comfort Always" Conference, Milwaukee, December, 1994, audiocassette. (Dr. Roy never references the ethic of care in his presentation. Therefore, it is unclear whether he thinks it is not valid or whether he is unaware of it.)

16. Berry and Lynn, JAMA, 222.

CHAPTER 2
PALLIATIVE CARE AS PUBLIC POLICY

Although palliative care is truly an "old art of medicine"\(^1\), it is one that is now taking on significant importance as the hospice "movement" comes of age. Hospice is gaining recognition and acceptance as a provider of specialized care for the terminally ill. With a focus on improving the quality of care extended to terminally ill patients while controlling the cost, hospice has achieved two of the three desired outcomes of health care policy. The third component is increasing access. In most instances these goals have proven to be conflicting. However, there is evidence suggesting that a change in public policy promoting palliative care as the treatment of choice for the terminally ill would enable hospice to achieve all three goals of a successful health care policy.

As a background to the discussion of the ethics of justice vs. care in the hospice movement, this chapter shall examine the "coming of age" of the discipline of palliative care and the evolution of the hospice program of care, the development of its philosophies and standards, conflicts that surround the delivery of palliative care and the criticisms that have been leveled against it. Additionally,
policy issues will be explored and recommendations will be proposed. For the purpose of this discussion, hospice care and palliative care will be used interchangeably as the hospice philosophy espouses the provision of palliative care services and this interchange of terms is an accepted practice in the literature.

**The Coming of Age of Palliative Care**

The concept of palliative care has most recently evolved in three countries: Great Britain, Canada, and the United States. Great Britain was the trailblazer by incorporating hospice benefits into their national health plan and developing the first specialty training programs in palliative medicine for physicians.

Approximately 25 years ago, Dame Cicely Saunders opened St. Christopher's Hospice outside of London. It was born from a mission of providing palliative care services to the terminally ill in a homelike setting, a vision that combined scientific medicine and nursing with a belief that terminal care was part of a continuum of treatment, not a sudden "soft option" (e.g. an excuse for failure on the part of the medical profession.)

Dr. Saunders began her hospice work as a volunteer nurse at St. Luke's Hospital (formerly known as St. Luke's Home for the Dying Poor). In order to look at the pain (not just the physical pain, but the emotional and spiritual pain) of terminal illness, she completed medical school and
began as the first full-time doctor at St. Joseph's Hospice. Dr. Saunders, together with the Sisters of St. Joseph, began to develop what she called an appropriate way of caring for the dying. Saunders emphasized the need for effective control of symptoms (particularly pain), care of the patient and family as a unit, an interdisciplinary approach to care, the use of volunteers, a continuum of care across all treatment settings (home, inpatient, other residential), and follow-up of the family members after the death of the patient.

The Canadian model of hospice differs from the British, functioning more like the American model, because it "takes hospice to the patient rather than the patient to the hospice". Although there are several prominent Canadian physicians who are strong advocates of palliative care, the number of palliative care programs has leveled off and may even be decreasing. However, Canada has the distinction of developing the first hospital-based hospice in North America, the palliative care unit at the Royal Victoria Hospital in Montreal.

The fact that hospice care in the U.S. is primarily home-based, while in England the focus is more facility-based with some adjunctive home care services, is the primary difference between the two countries. There are far more similarities than differences. The hospice movement began in this country as a grass roots effort run primarily by
volunteers. The best known established effort to adapt the British model of hospice to American health care is the Branford Hospice at New Haven, Connecticut which opened in the late 1970's. In 1983, after conducting demonstration projects throughout the U. S., Medicare began offering a hospice benefit to Medicare Part A beneficiaries. Hospice has experienced tremendous growth since that time, from 516 hospices in 1983 to over 2000 today, and several authors are now reporting that hospice has become an accepted part of the health care system.5

**Hospice Philosophy and Standards of Care**

The guiding principles of hospice care, initially emphasized by Dr. Saunders, became the foundation of Medicare's Hospice Benefit and the Standards of Care as outlined by the National Hospice Organization. A significant issue that the hospice movement has struggled with is the establishment of a universally accepted definition of what constitutes palliative care. If ever the concept is to be an accepted component of a public policy on health care, it is imperative that there be acceptance of a single definition. A definition of palliative care was drafted by the Standards Committee of the National Hospice Organization (NHO), the first national trade organization representing the hospice industry, in order to have a "gold standard" by which hospice programs could measure their decisions about
what was appropriate hospice care. Palliative care, as defined by NHO is:

treatment that enhances comfort, and improves the quality of the patient's life. No specific therapy is excluded from consideration. The test of palliative treatment lies in the agreement by the patient, the physician, the primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, easing of pain, and enhancement of quality of life. The decision to intervene with an active palliative treatment is based on the treatment's ability to meet the stated goals rather than its effect on the underlying disease. Each patient's needs must continue to be assessed and all treatment options explored and evaluated in the context of the patient's values and symptoms.6

In short, hospice care is about choice, with the emphasis on controlling symptoms and improving the overall quality of life, rather than on the reversal of the basic disease process.

The hospice emphasis on palliative care, rather than prolonging life, means that many disorders are not treated as in other care settings. "Anemia, infections, and anorexia, for example, are not treated with transfusions, antibiotic therapy, or mechanical feeding and hydration."7 The focus is on easing the discomfort caused by symptoms of the disease process.

Hospice has the distinguishing characteristic of an interdisciplinary team approach to care. "The team attempts to draw together and coordinate the planning and work of all persons who have contact with the terminally ill in each specific case."8 Indeed, this concept is so germane to hospice, it is one of the Conditions of Participation required
for a hospice to be certified for reimbursement by Medicare.
The basic hospice team consists of the patient's attending
physician and hospice medical director, nurses, medical
social workers, chaplains, other therapy providers (physi-
cal, occupational and nutritional), counsellors, and volun-
teers. In addition, the patient and other family members
are also considered team members. This multidisciplinary
approach is one of the cornerstones of hospice care.
Hospice administrative boards are meant to be multi-
disciplinary as well and strive to move in two parallel
directions.

On the one hand to preserve the autonomy, integrity,
and flexibility of the hospice team within the health-
care establishment; and, on the other hand, to make
sure that there is adequate representation from hospi-
tal administration, influential physicians and nurses,
and to ensure that the program will have the support of
the medical community.9

If the objectives of hospice are to be achieved, it is
imperative that teamwork exists at both levels: administra-
tive and direct patient care.

**Factors Influencing the Development of Hospice**

It has been said that hospice has grown from the dis-
satisfaction of some health care providers with the manage-
ment of terminal illnesses in the traditional, acute care
medical model. It is curious to note that those involved in
hospice care are predominantly female. The question arises,
was the emergence of hospice influenced by the fact that the
medical establishment was male-dominated? Advances in medi-
cal technology were now allowing physicians to prolong life beyond what was ever believed possible, and patients were not being given a choice to forego life-saving or life-prolonging therapies in lieu of having symptoms controlled adequately and preparing for their eventual deaths. One of the primary contributors to patient satisfaction with hospice care is the direct involvement of the patient in the decision-making (self-determination). In light of the historically paternalistic approach of the medical profession, this may be one of the reasons patients are not routinely informed by their physicians that hospice care is an alternative.

Even more significant is that "modern medicine brought with it a stance toward death that is ambivalent about its necessity and inevitability." In the frenzy to save a life at any cost, "[T]he whole apparatus of modern hospital care seems designed to create a nonperson of the 'terminal' patient and to sequester him as a slightly indecent failure of modern technology." Since hospice was in direct conflict with what was common medical practice, it is understandable that it was not readily accepted as mainstream medical care. At least one author believes that hospice is still not at that level of acceptance. "The movement is at a crossroads; the future challenge is to become ingrained in mainstream medicine where terminal care is an automatic part
of a physician's training, and all hospitals and long-term institutes offer hospice programs."

Not to be overlooked is the prevailing attitude of the general public regarding illness and death. Generally speaking, death is not a socially acceptable topic of conversation. No longer is death seen as the necessary and inevitable end point of life. Philip Aries, French historian, has contrasted the concept of a "tame" death that was "tolerable and familiar, affirmative of the bonds of community and social solidarity, expected with certainty and accepted without crippling fear" with the "wild" death of technological medicine which began to occur in the late 19th century "marked by undue fear and uncertainty, by the presence of medical powers not quite within our mastery, by a course of decline that may leave us isolated and degraded." Advances in medical technology have mislead us into thinking we have a ultimate control over our own mortality.

Criticisms of Hospice

There is a minimal amount of information in the literature that offers criticism of hospice or palliative care. What was found can be summarized into three categories: elitism, disrespect for life, and futile care.

A brief, summary of opposing viewpoints was found in an article, "Criticisms of Hospice" by Holly Fleischman in which she cites two primary criticisms of hospice care.
First, hospice caters to an elite class, "particularly cancer patients from the white, middle, and upper classes, who have supportive families." While it is true that in its formative years hospices served cancer patients almost exclusively, this was not a result of elitist activity. It was more a result of limits of the medical profession and their ability to predict disease outcome with some degree of certainty. Because of the somewhat predictable life expectancy of cancer patients, oncologists were the primary supporters of the hospice movement. Hence, the primary diagnosis cared for in a hospice program was cancer. It is only within the last five to seven years that medicine has been able to give a more accurate prognosis for other illnesses and have recognized the value of hospice care for these patients as well. Currently, in most hospice programs, approximately 75% of the patients have cancer as their diagnosis. The other 25% is comprised of patients with cardiac, respiratory and immunological diseases (this includes AIDS).

The second criticism is that rather than affirming life, hospice may actually hasten death by not utilizing life-support equipment. Furthermore, the hospice program may be "so emotionally or financially attractive that patients are induced to forego aggressive and curative treatment options."
In answer to these criticisms it is important to reinforce hospice's goal to affirm life, "providing the dying every opportunity to live as full a life as possible and to enjoy as much freedom and control as they are able." By not utilizing life-support equipment, hospice is not injuring the patient nor hastening death, but allowing death to occur naturally as a cause of the particular terminal illness.

With its holistic approach to caring for the patient and family, hospice is meant to be "emotionally attractive" to patients. Currently, this is the only type of care that provides this much needed support for the dying. In addressing the criticism of financial attractiveness, I would say that the burden should not be placed on hospice to change. Caution should be exercised in the development of health care policy so that hospice is not promoted as a justification for care-as-conservation of resources. This, in fact, would have the potential of inducing patients to forego other treatment options.

The second reference offering criticism of hospice care is found in The Hospice Movement by Cathy Siebold. Again, hospice was criticized for inhibiting a patient's fight for life. The fear is that "if the natural death philosophy (meaning that death is a natural human experience) comes to dominate medical practice, for example, the individual who wants to use every conceivable medical technology to prolong
his or her life regardless of cost or efficacy becomes the odd person out." 16

This is a legitimate fear and has recently become a topic for discussion in questions surrounding futile care policies. Futile care is defined as "any clinical circumstance in which physicians and their consultants, consistent with the available medical literature, conclude that further treatment (except comfort care--palliative care) cannot, within a reasonable possibility, cure, ameliorate, improve or restore a quality of life that would be satisfactory to the patient." 17 The advancement of hospice philosophy is not what is driving the establishment of futile care policies. Futile care policies are driven by a need to control costs and the hope that if there are defined rules that everyone has theoretically agreed to, patients' rights will be protected.

Another criticism of hospice care that is not readily found in the literature is the fact that some programs limit access to care by requiring patients to have a caregiver in order to receive hospice services. Since hospice is primarily a home care program, it is understandable that a caregiver in the home is desirable. It is extremely difficult to provide services to a terminally ill patient in a home when there is no one physically present to assist the patient. However, it is also not legitimate to deny services to those without caregivers. This is truly a
dilemma for hospice providers and for all who are concerned about providing quality care for the terminally ill.

Public Policy Issues

The public debate about palliative care focuses on the issues of choice, cost, outcome and the balance between quality and cost. It is incumbent upon the hospice industry to provide the information needed by consumers and policymakers to make decisions that will serve the needs of society.

Choice

Although the issue of choice was addressed in a previous section in more detail, it is important to reiterate that patients have the right to be able to make informed choices about the type of treatment they desire. The key concept is "informed". In order for one to make a decision about treatment options one must have information that is clear and understandable. One needs to know about the consequences of each decision. For example, if one chooses to have radiation and chemotherapy as treatment for a particular type of cancer, it is imperative to have knowledge of not only the side effects but of the success rates with such treatment. One also needs to know that 'no treatment' is an option. The patient should know that this option exists at every step of the decision-making process, and
that if no treatment is the option, palliative care is available.

It has been said that one of the reasons patients choose treatment, even when there is a minimal success rate, is fear of being abandoned by the health care system. The symbolic message conveyed by offering curative treatment only is that patients can only feel truly cared for when the most modern invasive technologies are applied. If palliative care is readily available and offered as an option, that fear can be eased.

**Cost of Care**

Given the ever-increasing cost of health care in this country, it is necessary to evaluate the current financial impact of palliative care and what the ramifications would be of increasing availability. Aiken and Marx, in their writing about hospice and public policy, discuss the unanticipated consequences of modifying payment for health services and the policy debate regarding the provision of hospice services. The authors believe that the debate centers around devising methods of payment that will make needed services accessible without costly duplication of services or exploitation of the dying by proprietary interests.\(^\text{10}\)

Although studies of hospice care have demonstrated the cost savings that can be achieved by substituting palliative care in the home or a hospice facility for aggressive, cure-
oriented hospital care, some analysts remain worried about encouraging the growth of a new health care institution that may add to the public's expense at a time when we are faced with reducing present commitments for basic health services for the poor and the elderly.19

The majority of data gathered about the cost-effectiveness of hospice care revolves around the provision of care as outlined by the Hospice Medicare Benefit (HMB). The Hospice Medicare Benefit was the precursor of managed care and has become a model for providing a comprehensive program of care for the terminally ill in a cost-effective manner. Since the first funded demonstration project in the early 1980's, it was recognized that the provision of hospice care as outlined by Medicare was a cost-effective way to care for those dying of a terminal illness. "A major rationale for hospice reimbursement by Medicare and other insurance programs is the premise that hospice care, by substituting home care services for hospital inpatient care, is less expensive than conventional care."20 Several studies have shown that more than 20% of Medicare expenditures are for terminally ill patients who are not part of a hospice program, with the majority of these expenses occurring in the final month of life.

By contrast, it has been demonstrated that hospice care provides the greatest savings in the final 1-2 months of life. One of the largest studies ever conducted was the
Medicare Hospice Benefit Program Evaluation. It found that when a patient was on a hospice program from 30-59 days, a freestanding hospice saves $1.59 for every $1.00 spent by Medicare for Part A services. A study conducted in 1991 by Nathan Adelson Hospice, Las Vegas, Nevada showed a minimum of 40% cost savings over traditional methods of caring for the terminally ill patient.

The "Benefit" became available in 1983 as part of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982. One of the ways in which the HMB achieves cost savings is in its per diem method of reimbursement. The agency caring for the terminally ill patient receives a preset amount of reimbursement on a daily basis. The rate of reimbursement differs only according to treatment setting (i.e. home or inpatient). The only cost for the patient is a 5% copayment for drugs. In return, the hospice provides for all the needs of this patient that pertain to the terminal illness. For example, the hospice provides all nursing services, counselling, medications, supplies and medical equipment. This system of reimbursement allows the hospice team, which includes the patient and family, to control how and where care is delivered and makes the hospice accountable for monitoring the cost of care.

Although the Hospice Medicare Benefit has been proven to be cost effective, other third party payors have been less enthusiastic about providing comprehensive hospice
services as a covered benefit. Due to the proliferation of mandated benefits, many are required to offer a hospice benefit, but very few offer one that is comparable to that of Medicare. The benefit offered in the private sector usually limits the type and frequency of services as directed by a representative of the insurance company. Often services are unbundled and parcellled out in a "Fee for Service" manner similar to the way traditional home health care is provided. This drastically reduces the efficiency gained by the package of multidisciplinary services as outlined by the Hospice Conditions of Participation required for Medicare certification. When this occurs the cost saving benefits that could be achieved are lost.

Another difference in the provision of hospice benefits by third party payors is the imposition of an unrealistic "cap" or maximum limit on the amount of benefits available. This can be as low as $2000. With the average cost of hospice home care being about $75 per day and hospice inpatient care about $350 per day, a $2000 benefit would provide for approximately 25 days of care at home or 6 days in a hospice facility. Remembering the statistic that the greatest expenditure for Medicare patients occurs in the final month of life and that savings from hospice care are highest during the last 1 - 2 months of life points out the disparity in providing a benefit that limits services at the exact time when they can be most cost effective. A limitation of
this kind encourages patients to utilize less efficient, more costly forms of care (i.e. hospital emergency rooms, home health agencies and acute inpatient care).

Although the reasons for resistance to providing reasonable reimbursement for hospice services among most private insurance companies is not quite clear, there are several possibilities. (1) There seems to be a lack of awareness about the advantages of palliative care on the part of the day-to-day decision makers. (2) The demand for services by beneficiaries of private insurance companies is low. Private insurers generally provide coverage for a young, healthy, working population and typically this group does not give a lot of thought to the possible need for hospice care.

**Outcome**

Hospice is about making possible what Weisman calls "appropriate death." An "appropriate" death is "one that is as pain free as possible, permitting an individual a measure of control and decision-making power that is both possible and desirable, given the patient's health, value system, and needs." Weisman outlines four conditions that must exist in order for death to be appropriate: awareness, acceptance, propriety and timeliness. Awareness is about more than just knowing one has a terminal illness. It is about "open awareness" which implies an atmosphere that encourages
communication and the sharing of ideas, feelings, and expectations.

Acceptance of one's death is about an open confrontation with whatever problems may arise during the dying process. Propriety implies dying in a way that does not conflict with others' expectations (i.e. having tended to one's affairs, being as independent as one's situation allows, and being able to withdraw from others when one chooses.) Timeliness reflects the individual's sense of the "right" or proper time to die. This usually is contingent upon completing any "unfinished business."

The hospice benefit encourages involvement as early as six months before death in order to allow the team to assist the patient and family in achieving an "appropriate death" by working through the many anticipatory grief issues that occur. Currently the national average length of stay on a hospice program is only 59 days. This is far less than what many consider to be adequate to allow for achieving an "appropriate death."

Quality vs Economy

"The primary debate about hospice focuses on whether terminally ill people and their families can be better cared for, in terms of comfort and quality of life, if care is provided in their homes or in special institutions as opposed to conventional inpatient institutional medical care." Perceptions of well-being and feelings of discom-
fort are the two major components of quality of life according to a comparative study done by Yates, McKeegney and Kun at the Vermont Regional Cancer Center. Perceptions of well-being relate to independence in self-care, desire for food, and overall assessment of condition. Discomfort is evaluated by pain, inability to sleep, and other uncomfortable symptoms.

The National Hospice Study followed 1754 terminal cancer patients in 40 hospice programs and 14 conventional care settings during the period 1981-83 and found that quality of life was similar for patients in hospice and conventional care.\textsuperscript{25} However, a secondary analysis of the data found that the quality of death (the last three days of life) was significantly better for those in hospice.\textsuperscript{26} The criteria identified by patients as being important was freedom from pain and being able to stay at home. In addition, most hospice programs survey surviving family members to determine levels of family satisfaction with hospice care. Anecdotal evidence suggests an overall satisfaction rate of approximately 95%. In the past, this data has not been compiled on a nationwide level. However, in 1994, NHO implemented a universal survey tool to measure satisfaction and will publish the results.

Studies done by W. L. Freeman as an audit of hospital care for terminal cancer patients reveal a strikingly different outcome. "Less-than-optimal" treatment was given
for pain to 92 percent of the patients, 91 percent for nausea and vomiting, 100 percent for breathing difficulties and 93 percent for pulmonary secretions. In another assessment of pain control, Foley states that "physical pain occurs in from 60 to 90% of advanced cancer patients but is inadequately controlled in about 25%." According to Aiken and Marx, in order to justify changing reimbursement patterns two questions must be answered:

1. Is the impact of hospice care on the quality of life of the terminally ill and their families as good or better than conventional arrangements (i.e. acute hospital care)? and,
2. If the quality of life is the same or better, would there be a major change in the cost to insurers?

The results of studies quoted in previous sections make it clear that hospice has made a tremendous impact on the quality of life of the terminally ill and their families. One could make the assumption, given Freeman's horrifying statistics, that any level of hospice care would result in better care than what is currently available. However, hospice care delivered in its entirety, with all the component services, provides the best possible solution.

The response to Aiken and Marx's second question is the subject of ongoing debate. The argument has been made that just by making a benefit easily accessible and promoting its value, the number of people utilizing the benefit will
increase, hence the cost of providing the care will automatically increase. However, in the case of providing a specialized type of care to those dying of a terminal illness, the argument is not valid for two reasons.

First, the number of people who are dying will not increase solely on the basis of availability of a benefit. Although it is true that as the population increases there is a natural rise in the number of deaths, that is a different argument.

Second, for the most part, the terminally ill are receiving care in some form. More than likely this care is being provided in a more costly, less palatable manner (i.e. frequent visits to emergency rooms, reoccurring hospitalizations that probably include the requisite x-rays and lab tests). Another concern is that some of the care is being provided by non-profit health care organizations. This in turn places a financial burden on the community supporting the non-profit. It is legitimate to suggest that if one allocated all the money being spent to care for the terminally ill in non-palliative driven settings to providing palliative care, there would not be an increase in cost. Perhaps there would even be a reduction. I would agree with Aiken and Marx's premise that if quality of life is the same, there would be no reason to change reimbursement patterns. However, if it is improved, as it is with hospice care, do we not have a moral obligation to attempt to mobi-
lize financial resources in order to provide a higher quality of care?

**Policy Recommendations**

The discussion in this chapter has focused on the benefits of providing palliative care as the treatment of choice for the terminally ill. The primary issues have been how to increase access to care and maintain a high level of quality without escalating the overall costs.

Reviewing the philosophies and standards of the hospice industry emphasizes the commitment of the National Hospice Organization to providing its members the leadership and direction needed to offer a consistent level of high quality services. The conflicts surrounding the implementation of hospice services have been discussed and the criticisms of palliative care have been enumerated.

Based on the three desired outcomes of a successful health care policy (increased access, decreased costs, increased quality), I am making the following recommendations:

**Increased Access**

In order to increase access to palliative care, hospice services must be available for all who are dying of a terminal illness. This requires a change at several levels. First, at the federal level, the Hospice Medicare Benefit should be preserved and used as a model for other hospice benefit programs. Second, at the state level, public
assistance programs (i.e. Medicaid, Medical, etc.) or state health care plans, should include hospice care as one of the available benefits. Third, all other third party payers should offer a hospice benefit that is comparable to that of Medicare. Fourth, at the community level, a community based, not-for-profit hospice should be developed and supported through donations in order to provide hospice care for those who are not included in the other categories.

Education is the second component of increasing access. Making a hospice benefit available is insufficient; consumers of health care and providers (primarily physicians and nurses) must be educated about the availability and benefits of hospice care. It is incumbent upon hospice programs to work within their local communities to facilitate discussions about death and dying as well as treatment choices for the terminally ill. No one is better equipped to do this than hospice providers.

Developing curricula for health care providers that emphasize patient autonomy and teach concepts of death and dying, and offer specialty training in palliative medicine is the second tier of the educational component. One author suggests a curriculum for physicians in terminal care that would include instruction in pain and symptom management, provision of care in various settings (i.e. home, hospital, hospice, nursing home), communication skills, psychosocial issues, team interaction, and bioethical issues. At the
very least, these classes should be available as electives. Teaching physicians how to save lives as well as how to recognize when a life cannot be saved will require a great deal of revamping of current medical school curricula. Even more problematic may be providing a framework in which physicians can learn to acknowledge that they must work as partners with other members of the health care team and that the patient is also a partner with a voice that must be acknowledged.

**Decreased Costs**

Hospice has remained a cost-effective way of caring for the dying. With the goal of hospice being to keep people in the familiarity and comfort of their own or a family member's home, the number of days spent in acute care settings by the terminally ill has decreased with the use of hospice services. Persons not enrolled in hospice spent 23 of their last days in the hospital, while patients enrolled in hospice spend only eight days in acute care settings.\(^{30}\) Since acute care (i.e. hospitals) is the most expensive treatment setting (approximately $1,756 per day), admitting patients to hospice programs (approximately $90 per day for home care and $350 for inpatient care), can decrease the costs for this specific population.\(^{31}\)

The Hospice Medicare Benefit, with its per diem method of reimbursement, has demonstrated that the cost of care can be decreased by providing a holistic approach to the deliv-
ery of services. I would recommend that the per diem reimbursement be maintained and that services model the Hospice Medicare Benefit in order to maintain maximum efficiency and benefit.

**Increased Quality**

In order for us, as a nation, to discuss a change in policy, it is imperative that everyone be speaking the same language using universally accepted definitions and terms. The National Hospice Organization's definitions of palliative care and hospice philosophy should be adopted as the language to be used when speaking of palliative care. NHO's membership has spent several years crafting these tools for exactly this purpose.

Medicare's guidelines for hospice have been in effect since 1986 and have undergone only one revision. For nearly ten years they have been providing hospices with standards by which to judge the quality of their programs. They are well-accepted in the hospice community and have proven to be beneficial in maintaining quality care. Adopting the Medicare Conditions of Participation in conjunction with the NHO's Standards of Care as benchmarks will provide a uniform method for measuring and maintaining the quality of care being provided to the terminally ill.

It will be important to implement safeguards to protect the rights of the terminally ill to ensure that palliative care is not used as a justification for care-as-conservation
of resources. Since euthanasia and futile care policies are being debated more often than ever before, the motivations for providing palliative care--making possible a "good death"--must be constantly reiterated, supported and safeguarded to ensure that palliative care is not used as a justification for care-as-conservation of resources. I would urge us to supplement the limited terms of the euthanasia and futile care debates with a discussion of an ethic of care as a way to promote humane, compassionate care for the dying.

I propose that if palliative care, as it is currently defined by the experts (hospice providers), is made available to all terminally ill persons, it will be the treatment of choice for most and will not place an undue burden on our health care system.
ENDNOTES


15. Ibid.


19. Ibid., 251.


21. Information provided by the National Hospice Association.


24. Aikens and Martita in Hospice Programs and Public Policy, 251.


31. Ibid. Source: Hospital data are from Social Security Bulletin, Annual Statistical Supplemental 1993; Hospice information is from HCFA (Health Care Finance Administration), Bureau of Policy Development, September, 1994.
CHAPTER 3
AUTONOMY, JUSTICE AND CARE

An ethic of care has a long-standing and prominent place in the history of medicine, summarized nicely by the 15th century French adage, "to cure sometimes, to relieve often, to comfort always." Nursing literature has articulated an ethic of care as a commitment to protecting and enhancing the patient's dignity, going beyond good intentions or simple kindness and including psychologic, philosophic or religious, and physical components, taking into consideration the patient's social context and specific goals (Fry 1988; Gadow 1985; Watson 1985).

After a brief discussion of patient autonomy, this chapter will offer an in-depth look at the ethic of care, examining its modern-day origin, progression toward acceptance, and some of the criticisms of it. In order to accomplish this, the works of Carol Gilligan and Nel Noddings will be explored in depth with Joan C. Tronto's writings concerning moral boundaries offering additional support. The question of whether an ethic of care can singularly support the provision of palliative care as public policy or whether it requires a combination of justice and care will also be explored.
Autonomy

Personal autonomy has been defined as "the right [of a person] to bodily integrity, to control his or her own body, and to define his or her own existence." In the case of the terminally ill, this entitlement protects a person's right to refuse unwanted medical treatment. "Patients have a right to know their condition, to choose or reject the treatment regimen, to choose or reject attempts to prolong their life, and to decide the disposal of their remains." With the acceptance of palliative care within the structure of organized medicine, control can be given back to the terminally ill. With the advent of the Patient Self-Determination Act (PSDA) of 1990, people have an opportunity to make such decisions prior to entering the health care system.

As explained later in this chapter, a central characteristic of caring is the sharing of mutual respect for the autonomy of both members of the caring relationship. In the case of palliative care that would be patients and the health care professionals. An additional advantage of this caring relationship with the terminally ill is that "the process of dying can be a period of moral development for both the patient and the professional. By appropriately caring for patients, members of the team simultaneously can develop their moral awareness, their character and professional maturity."
An Ethic of Care

Ethics is defined as the philosophical study of morality (actual beliefs and practices that we turn to when we must decide what we ought to do). The principles of ethics guide us through moral quandaries utilizing moral reasoning. Karl Wellman has defined moral reasoning as "a process by which one attempts to identify, organize, analyze and justify human acts in order to determine what is the right thing to do in a given situation." Many ethical discussions originate from the Greek framework of ethical theory with a dominant "...focus on virtue and right reason as central concepts for the moral evaluation of agents and actions."

It is Noddings' assessment that ethics has been discussed largely in the language of the father: in principles and propositions, in terms such as justification, fairness, justice. In proposing her ethic of care, Noddings argues that human caring and the memory of caring and being cared for form the foundation of ethical response. And, typically, it is in the language of the mother that these responses are vocalized.

Some (Noddings 1984; Gilligan 1982; Baier 1987; Blum 1987; Ruddick 1989; Walker 1989) who advocate the recognition of an ethic of care claim that there is a distinct difference in the way moral reasoning generally occurs in males and females, and that the ethic of care is reflective
of what has traditionally been categorized as a "feminine" method of reasoning. In this context, "feminine" reflects the search for women's unique voice that advocates nurturance, care, compassion and networks of communication. It is important to note that this discussion is not meant to imply that there is no place for men in this ethical concept. There is, however, the implication that what Kohlberg saw as the traditional method of masculine moral reasoning, based on an ethic of justice, stressing rules and rights, is in direct contrast to the ethic of care.

The beginnings of those ideas of a 'female ethic', 'feminine' nature, and specifically female forms of virtue which have formed the essential background to a great deal of feminist thinking about ethics can be traced back to the eighteenth century. It was during this time that industrializing cities saw the emergence of questions about femininity and female consciousness arising from the changes in women's social situations. "A subordinate but virtuous and idealized wife and mother, whose specifically female virtues both defined and underpinned the private sphere of domestic life, came to dominate a great deal of eighteenth and nineteenth century thought." Since these first inferences to an ethic of care there has been a progression not only in how to think about it, but also as to what place, if any, it has in the hierarchy of moral theories.
In a short time, philosophical writers have taken the ethic of care from a feminine theory to a feminist theory to a holistic ethic\(^1\) to "an adequate theory of how we might make human societies more moral."\(^4\)

For Noddings, when individuals (male or female) adopt an ethic of care, they base their judgements and actions on their relationships with and responsibilities to other individuals. If one subscribes to the idea that a point of morality is to establish a world in which we remain in relation to one another, caring is taken to be the very foundation of the ethical. This concept "of care as an ethical orientation and its contrast to the patriarchal preference for individual rights and justice has powerful impact on many fields...and has garnered an enthusiastic international following."\(^5\)

**Gilligan vs. Kohlberg**

The first discussions of an ethic of care were the result of Carol Gilligan's work wherein she described what she calls the "different voice" of women. She challenged Lawrence Kohlberg's work on moral reasoning and launched an important debate about the gender boundary implicit in Kohlberg's theory.\(^6\)

His goal was to explain the development of moral reasoning by posing hypothetical moral dilemmas to his subjects, initially young boys at a preparatory school and later, young girls at a private academy. "His work has been
viewed as the definitive account of moral development and it has had a large influence on psychologists, educators, and political philosophers such as Jurgen Habermas and John Rawls." (Kohlberg's theory of moral development is alluded to in Rawls's *A Theory of Justice*.)

An individual's response to various moral scenarios expresses, according to Kohlberg, the level of moral development of that person. The classic example of a moral dilemma, cited in most discussions of Kohlberg, is known as the Heinz dilemma. Heinz lives in a faraway country with his wife who is sick. The pharmacist in his town has a drug that can make his wife well; without the drug she will die. Heinz cannot afford the drug, and the pharmacist refuses to give it to him unless he can pay for it. The dilemma: should Heinz steal the drug?

Kohlberg devised this dilemma as one in a series in order to measure moral development in adolescents by presenting a conflict between moral norms and exploring the logic in their ability to resolve such dilemmas. "Kohlberg believes that there are definitive stages of moral development and, moreover, that there is a measure of congruence between it [moral development] and psychological development with regard to cognitive skills."

Kohlberg established six stages, two stages in each level, to categorize moral development. The stages in the pre-conventional level are, (1)"heteronomous morality," the
amoral stage of avoiding punishment, and (2) "individualistic, instrumental morality," where one acts and expects a similar response. Stages three and four, (3) "interpersonally normative morality," the "good boy" stage, and (4) "social system morality," expands the audience to whom one's moral judgements are oriented. The range extends from people who are the closest to you to abiding by the rules and judgements of others as extended to the entire community.  

The third level, labeled post-conventional and principled, includes stage five, the stage of prior rights and social contract, and stage six, "morality of universalizable, reversible, and prescriptive general ethical principles." At stage five, one is concerned that "laws and duties to society be based upon the ideal of the greatest good for the greatest number." As a rational creature, "one is obligated to abide by the precepts, which embrace life and liberty, to which one had otherwise agreed." This is seen as a utilitarian moral theory. If one has developed to the ultimate level of stage six, it is accepted that "there are universal ethical principles that all should follow, and which take priority over all legal and other institutional obligations." The person is no longer ruled by self-interest, the opinion of others, or the force of legal convention, but by self-legislated and self-imposed universal principles such as those of justice, reciprocity and respect for the dignity of human beings as intrinsically
valuable persons. Stage six is based on a deontological theory of morality. According to Kohlberg, very few people reach the post-conventional stages; the estimate is approximately five per cent.

Although Kohlberg's study involved many pre-adolescent students, the results of his interviews with two eleven year olds (one boy and one girl) are most frequently used as typical examples of how this theory is applied. Given the Heinz dilemma, the young boy decides that the husband should steal the medication, seeing it as a conflict between the values of property and life. This decision is considered to be conventional (a mixture of stages three and four) for the boy's age and cognitive development. Kohlberg feels that "his ability to bring deductive logic to bear on the solution of moral dilemmas, to differentiate morality from law, and to see how laws can be considered to have mistakes, points toward the principled conception of justice that Kohlberg equates with moral maturity."  

The young girl's response is quite different. She does not believe that the drug should be stolen; neither does she think the wife should be allowed to die. She contends that there should be discussion between the husband and pharmacist and thinks that another solution could be worked out. Perhaps the husband could pay for the drug over a period of time. Her solution lies in a further examination of the relationships involved: wife to husband, husband to
wife, pharmacist to community. In light of Kohlberg's stages, the girl is scored at a full level lower than the boy is. "Scored as a mixture of stages two and three, her responses seem to reveal a feeling of powerlessness in the world, an inability to think systematically about the concepts of morality or law, a reluctance to challenge authority or to examine the logic of received moral truths." Kohlberg found her reliance on relationships and her belief in communication as the mode through which to resolve moral dilemmas a sign of dependence, vulnerability and naivety. She is thought to be in the pre-conventional stage.

It is from this point that Gilligan begins to develop her theory of a "different voice." Gilligan sees the girl's response as a demonstration of "awareness of the connection between people that gives rise to a recognition of responsibility for one another, a perception of the need for response;" a sense of community. Seen in this light, the girl's understanding of morality as arising from the recognition of relationship, her belief in communication as the mode of conflict resolution, and her conviction that the solution to the dilemma will follow from its compelling representation seem far from naive or cognitively immature." Rather, these insights seem to reflect the way women, either instinctively or by virtue of conditioning, make moral decisions and are central to an ethic of care.
Gilligan believes that the difference in logic used by the young girl and the boy stems from the way they interpret the question. The young boy considers whether or not the person should act in the proposed dilemma while the young girl interprets "how" one should act. Furthermore, Gilligan's work attempts to substantiate her claim that when one studies the moral development of women, a process emerges that is quite different from Kohlberg's six stages. Namely, "the moral problem arises from conflicting responsibilities rather than from competing rights and requires for its resolution a mode of thinking that is contextual and narrative rather than formal and abstract."27 This concept of morality, as concerned with the activity of care, centers moral development around the understanding of responsibility and relationships, just as the concept of morality as fairness ties moral development to the understanding of rights and rules. "Traditionally, many psychologists and philosophers have reasoned from an androcentric point of view, seeing women's moral inferiority where they should have seen women's moral difference."28

Gilligan's account of women's moral development has three stages that are traversed, with the third assuming moral maturity. At level one, the self is the sole object of a woman's concern. In level two, she moves to an overemphasis on others. Finally, level three is a proper emphasis on self in relation to others. "A woman attains moral
maturity when she stops opposing her needs in favor of others, simultaneously recognizing the falseness of this polarity and the truth of her and others' interconnectedness. "

A work by Joan C. Tronto, Moral Boundaries, critically examines the works of both Kohlberg and Gilligan. Her criticism of Kohlberg is that his theory of moral development is hierarchical in its stages based on the fact that "an individual's progress through successive stages of moral development requires that his or her sense of moral reciprocity deepens. Reciprocity deepens through the ability of an individual to assume different roles. Thus, moral development, though a cognitive process, is dependent upon certain kinds of social stimulation in order to occur." 

Although Tronto does not support Kohlberg's assumptions, she also takes exception to Gilligan's premise of a different voice being feminine, an alternative way to conceive of morality. She sees it as an account of partial privilege that only reinforces the existing moral boundaries and deemphasizes the need for change in our concept of gender roles. "Women presumed to speak in a different moral voice are both partially privileged yet ultimately excluded from the loftiest type of moral thinking." Designating a different voice as a woman's morality only supports the notion that men and women have different moral capacities. Because of the assumption that those who are in power are at
a higher level of moral development and, therefore, morally
dprivileged, women advocating speaking in a "different"
moral voice inadvertently place themselves in the disadvan-
taged category since they are generally not the ones in the
privileged positions. Putting oneself in this position pro-
vides no incentive for promoting an ethic of care.

Tronto believes that there is equal necessity for both
care and justice orientations for a full and proper morali-
ty; "women need not be the bearers of a women's morality;
but in order for all people, men and women alike, to be
fully human, it is necessary that all possess both the
orientations of justice and Gilligan's ethic of care."32

Nel Noddings: Approach to Caring

Just two years after the publication of Gilligan's
work, Nel Noddings, an Associate Professor of Education at
Stanford University, published her book, Caring, A Feminist
Approach to Ethics and Moral Education. Her intent was to
produce an essay in practical ethics from the feminine view,
rooted as it is in relation and identifying joy as a basic
human affect. "Joy" is described as a feeling, rather than
an emotion, and is considered a reflective mode of con-
sciousness. It is the recognition of and longing for relat-
edness that form the foundation of this ethic, and the joy
that accompanies fulfillment of our caring enhances our
commitment to the ethical ideal that sustains us as the
'one-caring'. In the caring relationship, both parties con-
tribute: the 'one-caring' and the 'cared-for'. In order for the relation to be described as caring, one's caring must be completed in the other. The natural caring which is described as "the human condition that we, consciously or unconsciously, perceive as good" provides the motivation of ethical caring. The perceived "good" is the condition toward which we strive, "and it is our longing for caring--to be in the special relation--that provides the motivation for us to be moral." Noddings says "relation will be taken as ontologically basic and the caring relation as basically ethical." She recognizes human encounter and affective response as basic facts of human existence. We want to be moral in order to remain in the caring relation and to enhance the ideal of ourselves as 'one-caring.'

Although Noddings presents caring from what she refers to as the "feminine" view ("feminine in the deep classical sense--rooted in receptivity, relatedness and responsiveness, in the way that some believe women reason morally")

34, this is not to say that all women will accept it or that men will reject it. What she is saying is that men and women can and must learn how to care if they are to become moral beings. This concept is supported by Rosemarie Tong when she says "an ethic of care can be communicated just as effectively as an ethic of rules and principles."
The 'One-caring'

Caring involves, for the 'one-caring', a "feeling with" the other. This is seen as having two distinctive features: engrossment and motivational displacement. Engrossment is characterized as a receptive mode of consciousness characterized by absorption and sensory concentration in which "we receive what is there as nearly as possible without [self] elevation or assessment." Engrossment is not restricted to only the emotional. "There is a characteristic and appropriate mode in caring." This appropriate mode of consciousness is a switch "from an assimilatory mode to a receptive-intuitive mode which allows us to receive the object, to put ourselves quietly in its presence." This is clearly different from the "analytic-objective mode in which we impose structure on the world." Motivational displacement means that we apprehend the other's reality so that, "when we see the other's reality as a possibility for me, we must act to eliminate the intolerable, to reduce the pain, to feel the need to actualize the dream."37

Functioning as the 'one-caring' requires more than feeling. A motivational shift is needed. One does not relinquish herself, but allows her energy to be at the service of the one for whom she is caring. It is a shift to the receptive or relational mode. Noddings believes the receptive mode is at the heart of human existence, with existence defined in the existential sense of living with
heightened awareness to include awareness of and commitment to what we are doing and what we are living. As the 'one-caring,' one receives the other into herself and sees and feels with the other, becoming a duality. However, "I am not caused to see or feel— that is, to exhibit certain behavioral signs interpreted as seeing and feeling—for I am committed to the receptivity that permits me to see and to feel in this way."\textsuperscript{38} The 'one-caring' sees the best self in the 'cared-for' and works with her to actualize that self.

Undoubtedly, at times, the 'one-caring' will shift out of this mode in a response to converting what we have received from the other into a problem, something to be solved. At this point, we move away from the cared-for in an attempt to objectively analyze, study and interpret the data of the cared-for's reality. These "turning points", as Noddings refers to them, are entirely appropriate as long as we recognize the shift. She describes it as keeping our objective thinking tied to a relational stake at the heart of caring. When we fail to do this, we lose ourselves as one-caring focusing on the problem rather than the person.

**Concentric Circles of Caring**

According to Noddings, those who are 'one-caring' find themselves at the center of a concentric circle of caring. It begins with caring for oneself and expands to those we may never actually know. For those who are in the inner circle, we care because we love them. They are usually
family or close friends. As we move outward, there are those for whom we have personal regard, such as neighbors and colleagues. The "guidelines" for these relationships are a reflection of "someone's sense of relatedness institutionalized in our culture."\textsuperscript{39}

Beyond this group are those one has not yet encountered. They may be linked to the inner circle by such means as spouses of children. One must be prepared to care for these people. "Chains of caring are established, some linking unknown individuals to those already anchored in the inner circles and some forming whole new circles of potential caring. I am prepared to care through recognition of these chains."\textsuperscript{40}

Noddings discusses the dilemma of the stranger who is not bonded through the chains of caring. How are we supposed to respond? Her answer is to remain receptive. "In an important sense, the stranger has an enormous claim on me, because I do not know where he fits, what requests he has a formal right to make, or what personal needs he will pass on to me." Aware of one's limitations, there may be a fear of a request that cannot be met without hardship.

Is it appropriate to establish caring chains with trust, rather than love, as the affective link? Noddings believes it is. For example, one may not be able to personally be present for the health care needs of those in the community, but one can respond to an appeal for public sup-
port for an allocation of dollars for improvements in the
provision of health care by someone in whom one trusts. In
Tronto's discussion of caring, she makes a distinction
between "caring about" and "taking care of". This will be
given more attention later on.

The 'Cared-for'

What is the responsibility, if any, of the 'cared-for'
in the relationship? Noddings would say the 'cared-for'
responds to the presence of the 'one-caring' with caring
being completed in all relationships through the apprehen-
son of caring by the 'cared-for'. "The attitude that is
perceived by the 'cared-for' as caring is generated by ef-
forts of the 'one-caring' at inclusion and confirmation." When this attitude is missed, the one who is the recipient
of care-taking feels like an object.

The concept of reciprocity surfaces again in the dis-
cussion of the 'cared-for'. As previously mentioned, in
order for caring to be actualized, there must be recognition
on the part of the 'cared for'. This does not mean that the
'cared-for' must also care for the 'one-caring'. Although
it is true that mutual caring can occur, that is not what is
meant by reciprocity.

Referring to the concept of engrossment, a receptive
mode of consciousness helps describe reciprocity. It occurs
when the 'cared-for' acknowledges and responds to the par-
ticular form of engrossment in the 'one-caring'. In order
to "behave ethically in the potential caring relation, the 'cared-for' must turn freely toward his own projects, pursue them vigorously, and share his accounts of them spontaneously." Additionally, by sharing aspirations, appraisals and accomplishments, the 'one-caring' has a fuller knowledge of what the 'cared-for' is striving toward and more readily supports these efforts. "The motivational displacement of caring occurs naturally, supported by any responsiveness of the 'cared-for.' The 'one-caring' for a fully participating 'cared-for' is sustained and invigorated and her caring is unlikely to deteriorate to cares and burdens."

The freedom, creativity and spontaneous disclosure of the 'cared-for' that manifests itself under the nurturing of the 'one-caring' completes the relationship. Even when one cares, if the 'cared-for' does not feel it or believe it, Noddings claims that the relationship cannot be characterized as caring. This points out a limit of caring.

The Ethical Self

Noddings believes that the ethical self is an active relation between one's actual self and a vision of one's ideal self as 'one-caring' and 'cared-for.' One's ideal self, as 'one-caring,' comes about as a result of the goodness that is felt when one accepts and affirms the internal "I must". The "I must" is described as the natural imperative that arises "directly and prior to consideration of
what it is that I might do" as I receive the other. "This vision of what I might be is the genuine product of caring." In other words, it is the moral imperative. This goodness, according to Noddings, is an assessment of the state of natural caring, some degree of which each of us has been dependent upon for our continued existence.

My caring for others and their caring for me enables me to care for myself. This allows me to "receive the vision of what I might be, enabling the 'I must' to arise with respect to the ethical self." My acceptance and affirmation of this caring for self will commit me to strive toward the other in spite of feelings of doubt, aversion or apathy. Summoning a concern for the ethical self is what prompts the "I must" in situations where it would not arise naturally. If I did not care for my physical well-being, I would not be able to appreciate the efforts of those who care for me. Noddings suggests that the answer to the question, "why should I behave morally?" is because I am or want to be a moral person. She believes that the interest in moral behavior arises out of our natural impulse to care.

Moral Boundaries

A more recent look at the ethic of care by Joan Tronto takes the concept one step further. Tronto sees the ethic of care as more than a discussion of "women's morality". This way of thinking leads some to believe that it is not part of the realm of moral choice, but merely a discussion
of values that are traditionally associated with women. These values are described as attentiveness, responsibility, nurturance, compassion, and meeting others' needs. It is Tronto's position that these values are traditionally excluded from public consideration and "tied to the 'naturalness' of women's caring, that is either instinctive, or deeply social or cultural behavior." In order to include an ethic of care in our definition of a good society, it will be imperative to move these values from our private lives into a political context. It is upon this premise that I suggest that the ethic of care can provide the support needed to establish a policy of access to and endorsement for palliative care.

It is Tronto's belief that care is a universal aspect of human life; "it is not universal with regard to any specific needs, but all humans have needs that others must help them meet. Several scholars have argued that what we care about defines who we are as people and as unique individuals." Tronto sees the ongoing process of caring divided into four phases: 'caring about', 'taking care of', 'care-giving', and 'care-receiving'. Within these four phases are four ethical elements: attentiveness, responsibility, competence, and responsiveness.

'Caring about' is noting that a need exists and making an assessment that this need should be met. It is highly individual and usually culturally shaped. For example,
hospice relies heavily on the use of volunteers. They are considered a core service and are a requirement for Medicare certification. Upon hearing a public service announcement requesting volunteers, one person may acknowledge that this is a legitimate need. Another may comment about what a waste it would be to spend time with someone who is dying, preferring instead to spend time with a youth organization because he could see the results of his efforts.

In order to be able to care about the needs of others, one must be attentive, accepting the fact that others matter. Tronto believes that our society has an unparalleled ability to "know" about others due to the proliferation and availability of information; and yet, the temptation is increasingly to shut others out and focus only on our own needs.

'Taking care of' is the next step and involves assuming responsibility and determining how to respond. One does not necessarily need to assume personal responsibility. It is more recognizing that some action can be taken. 'Taking care' of generally involves an agency that bears the responsibility. Tronto views responsibility as both central and problematic requiring constant reevaluation. Responsibility is not to be confused with obligation. Obligations generally arise from promises we have made or formal/legal bonds; responsibility comes from implicit cultural practices.

"Ultimately, responsibility to care might rest on a number
of factors; something we did or did not do has contributed to the needs for care, and so we must care.\textsuperscript{47} Responsibility can also have different meanings depending on one's gender roles. For example, traditionally women have had the responsibility for care-giving.

When extending this idea of responsibility vs. obligation to a physician's role in the care of the terminally ill, it may illuminate a physician's dilemma in choosing between advocating continuation of curative forms of treatment or palliative care. Perhaps the ability to recommend palliative care hinges on whether the physician sees her role as one of responsibility rather than one of obligation. Undoubtedly, the physician feels a sense of responsibility for the patient's well-being. However, if the physician has a sense of obligation, feeling that there is an imminent commitment to do everything in her power to prevent the death of a patient, she may find it unethical to suggest palliative care. This could be construed as a breach of faith between the physician and patient.

In her argument for the inclusion of care as a political and philosophical notion, Tronto is suggesting "that we are better served by focusing on a flexible notion of responsibility than we are by continuing to use obligation as the basis for understanding what people should do for each other."\textsuperscript{48} This suggests that performing out of obligation provides one with less opportunities for flexibility in
decision making. However, caring encompasses responsibilities that go beyond obligation. This flexible notion would give a physician a kind of "permission" to offer palliative care and recognize that this demonstrates responsible behavior that is concerned with a patient's well-being.

'Care-giving' is about the personal responsibility to directly meet the needs for care. It involves physical work, and for this reason, providing money for care is not considered to be care-giving; rather, it is taking care. This distinction is crucial to her argument. It has been our history to relegate those with care-giver status to a position of lesser value and, at the same time, to perceive the allocation of money, either private donations or public funds as a form of care-giving. Tronto believes that the fact "that we quickly equate in the United States the provision of money with the satisfaction of needs points to the undervaluing of care-giving in our society." This differs from Noddings' 'one-caring' in that Noddings' classification encompasses both 'taking care of' and 'care-giving.' The contribution of money or other resources to providing care does not, in Noddings' opinion, diminish the value of the effort.

Tronto argues that a paradigm shift is necessary. We must move from accepting care as necessary, but delegating it to others of a particular gender or social class, to a premise that holds care as a process by which life is sus-
tained and therefore placed at the center of our moral and political universe. In other words, instead of placing the responsibility for caring on others who are generally considered to be of a lower social status, each of us must accept responsibility for being 'care-givers.'

Competence in care-giving is seen as a moral notion. If one intends to provide care, accepts the responsibility for it, but does not provide good care, Tronto would say the need for care is not met. The only exception would be if the resources were not available to the caregiver. For example, a spouse who is himself debilitated may not be able to provide competent care for his ill partner. This situation begs the question, should the community (in this context, community means through the provision of public funds) take responsibility for care-giving and could this be accomplished within the current budget constraints. In the recent attempts to provide universal access to health care, one of the primary deterrents was the ability to finance this care.

The issue of how competency is determined can be very controversial. Who will set the standards? Should it be done through peer review, government oversight, community oversight, or a combination of all of these? Currently, entities such as state medical and nursing boards set the standards for practitioners and federal agencies such as
Health Care Finance Administration set certification guidelines based on standards of care.

In Tronto's final phase of caring, 'care-receiving', it is recognized that the object of care will respond to the care it receives. Tronto is concerned that if the evaluation of the care received is not examined from the perspective of the recipient, how care-givers choose to meet the perceived needs may cause new problems. Responsiveness, considering the other's position as that person expresses it, is the moral element that prevents this potential problem. This issue is of particular concern when dealing with providing pain medication for palliation. Far too often a physician or nurse will take the position that a patient does not really need his pain medication based on the care-givers perception of pain and/or beliefs about addiction. Hospice has taken on the additional responsibility of educating professionals and lay people about the need to treat a patient's pain or other uncomfortable symptoms as the patient desires. This may even mean providing no relief if that is the patient's preference.

By its very nature, care deals with conditions of vulnerability and inequality. This is the position in which the 'care-receiver' finds herself. Tronto contends, "[T]he moral precept of responsiveness requires that we remain alert to the possibilities for abuse that arise with vulnerability." Being at the end of one's life as a result of a
terminal illness epitomizes vulnerability. The potential for abuse is readily apparent. This is frequently an issue in the decision making process of the terminally ill when faced with the choice of continuing therapy or electing palliative care. It has been reported that patients are concerned about disappointing their physicians who have been working very hard to control the progression of the disease. Patients have said that there is a sense, on their part, that if they do not continue to engage in curative treatment, they are not putting forth all of their effort. By selecting palliative care they perceive themselves as "giving up" and fear their physicians will do the same.

There are many other examples of the vulnerability felt by one who is dying, such as the conflict of wanting to maintain control over the daily events of one's life and accepting the fact that the eventuality of death cannot be controlled.

**Moral Dilemmas in Caring**

Tronto recognizes that there are moral dilemmas that are specific to the universality of an ethic of care. She outlines these as difficulty in assessing needs, parochialism, sublimated needs of care-givers, detached care, otherness, paternalism and privileged irresponsibility.

Since the needs for care are infinite and the resources, both personal and public, are finite, there will always be moral dilemmas. Tronto argues that the problem of deter-
mining which needs should be met requires a theory of justice to determine the degree of urgency of the needs. However, Rawls' theory of distributive justice, according to Tronto, requires that one view the assessment of needs from the perspective of 'caring about' and 'taking care of'. In other words, not as one who will provide care but from the detached perspective of recognizing that a need exists and determining how the need should be responded to. The harm in this perspective is that the 'care-givers' and perhaps even more importantly, the 'care-receivers', are excluded from the process of prioritizing the needs. To illustrate this point, let us remember how decisions about health care are made in the context of a health maintenance organization (HMO). A "gatekeeper" system is used. Patients who are insured by an HMO are first seen by the lowest level of professional in the physician hierarchy, the physician's assistant (P.A.). The P.A. determines whether or not the patient requires the skill of a physician. If so, this physician will be a general practitioner who will then decide whether or not to refer to a specialist. The system encourages care to be provided at the least costly level possible. The HMO created this system from the detached perspective of recognizing that a need existed and determined how it should be responded to. Neither physicians (care-givers) nor patients (care-receivers) participated.
In a revision of this system, physicians may be asked to contribute but patients probably will not. 'Care-receivers' as participants in decision making are generally devalued because they are considered to be the needy. They need the help of all of the others. Tronto recommends, "[A]ny concept of needs must account for the concrete nature of needs and how they are met through care, and must also contain some way to make judgments about the worthiness of competing needs".

The issues of parochialism and sublimated needs of caregivers are at opposite ends of the moral dilemma spectrum. On one hand, the concern for parochialism arises from the fact that care requires more than an abstract involvement. It is not enough to 'care about' and 'take care of'. However, the requirement to be a 'care-giver' and 'care-receiver' can lead one to be so narrowly focused that one loses the ability to address more global concerns. For example, if I am caring for someone who is dying, I will be so consumed in my caring that I will have no concern for those who may be dying without someone to care for them. Tronto suggests that it is reasonable to expect some form of partiality, particularly during times of intense care-giving.

On the other hand, when providing care, there is often a struggle between the needs of the care-giver and the needs to be met. A considerable level of anger can accumulate on
both sides. The care-giver often must sublimate her needs for the one for whom she is caring. This can result not only in subverting the process of care, but ultimately could result in denying or withholding care. From the 'care-receiver's' perspective, there is often a resentment at having to depend upon another for care. Tronto believes that since the ethic of care acknowledges this dilemma as a potentially serious moral problem, it is more likely to be able to solve these types of problems than other ethical perspectives.

This dilemma is seen very frequently in the hospice setting. Generally, patients become part of a hospice program of care after a lengthy illness. There may have been a reversal of roles (i.e. the wife, who has been the care-giver in the family, is now the care-receiver.) The roles of the care-giver and care-receiver have been firmly established and both parties have been feeling the emotions previously described. Because hospice philosophy encompasses treating the patient (care-receiver) and family (care-givers) as a unit, it is well equipped to deal with these very real issues. Providing patients and family members with support and counseling to assist them in resolving such issues is a part of the delivery of hospice services. There are minimal resources within the traditional medical model for these types of services due to costs. However, in hospice, within the daily rate of reimbursement,
these services are not only readily available, but are encouraged and provided at no extra cost.

Another dilemma with care is the perception of "others" who are recipients of detached care. Taking a global perspective, it is not possible to provide care to all for whom one might feel some responsibility. Therefore, individuals often take care of much more than they give of direct care. As those who are being taken care of become more distant, it is easier to relegate them to the status of being "those other people" for whom we are not required to be responsible. Presumably, the theory of reciprocity should assist us by allowing us to put oneself into the "other's" situation. However, Tronto asserts that since we are not able to comprehend all the dimensions of the other's position, the more likely result is that there will be an incomplete understanding rather than a morally sensitive response. An example of this would be someone who is heterosexual attempting to put oneself in the position of a homosexual dying from AIDS. That person may be sympathetic to the situation, but probably cannot put himself into the other's situation. Tronto turns to Aristotle for support in this area. Aristotle's philosophy about an ultimate good for the sake of which all other goods are pursued, suggests this standard: "since the task of care is to maintain, continue, and repair the world so that we can live in it as well as possible, we should do what will best achieve this end." If we can
relegate caring to the position of being an ultimate good, we can then acknowledge the fact that all people will be either in the position of being a 'care-giver' or 'care-receiver'. By recognizing this inevitability, we can then move to accept that by virtue of our position (care-giver or care-receiver) a kind of inequality will emerge. Tronto suggests "that a moral theory that can recognize and identify these issues is preferable to a moral theory that, because it presumes all people are equal, is unable even to recognize them." ²

The issue of paternalism is very closely related to the inequality issue. "Caring does not occur between two equal and autonomous actors. There is a dependency relationship of one upon another." ³² The risk is that the perception of the needs of the 'care-receivers' will become more definitive than the actual needs. Caring must "go beyond good intentions or simple kindness and...take into consideration the patient's social context and specific goals." ³³ There is a danger that those who receive care will lose their autonomy and their sense of independence.

Privileged responsibility takes the problem of paternalism one step further. If one accepts that the caring needs of some groups are met more completely than others and is concerned that this pattern follows the distribution of power in society, one can see the danger in privileged responsibility. There seems to be nothing to inhibit the
relatively powerful (most likely the 'care-givers'), from defining their needs as more important than those of the care-receivers. And, by looking only at whether or not their needs are being met as a measure of their caring responsibilities, they will have no reason to examine the situation from any other perspective. Tronto points out that in the context of the American ideology of individualism, universal morality is not an automatic solution to this problem.

The founders of hospice recognized this risk and developed a philosophy to safeguard against it. The hospice guidelines issued by Medicare and the National Hospice Organization explicitly include the patient and the family as members of the Interdisciplinary Group in order to prevent them from being excluded in the decision-making process. However, there is often a difference between the ideal situation and reality. The fact that physicians, nurses and other of the "helping" professions are also part of the Interdisciplinary Group makes the potential for detached care, otherness and paternalism very real. The fact that these issues are identified in an ethic of care as moral questions that must be acknowledged and dealt with allows one to feel hopeful. If one supports care as the foundation of the provision of palliative care, it provides reassurance that a system of checks and balances will be in place to safeguard against abuse.
Every moral theory has its problematic areas. Often the debate about an ethic of care is whether or not it is compatible with other theories of moral reasoning. Tronto suggests that if one only looks at the different metaethical perspectives of, for example, care and justice, "any attempts to make the two compatible are viewed as philosophically unsophisticated."\textsuperscript{55} However, if we combine the principle that care is necessary with the particular practices of providing care in a given situation, compatibility can be achieved.

\textbf{JUSTICE}

"The distributive logic of the practice of medicine seems to be this: that care should be proportionate to illness and not to wealth."\textsuperscript{56} However, in reality, care is not always proportionate to illness, and very often it is dependent upon the physician's perspective and the patient's insurance benefits or lack thereof.

If one accepts the theory of justice as "belonging to the domain of obligation rather than to the domain of charity and as being concerned with giving people what they deserve or should rightfully possess,"\textsuperscript{57} one can begin to understand the inability of justice to support the provision of palliative care. When decisions are made from a position of justice as fairness, we can suppose that the decision-makers come from "a position wherein they are cooperating on terms to which they would agree if they were free and equal
persons whose relations with respect to one another were fair. They could all view their arrangements as meeting the stipulations which they would acknowledge in an initial situation that embodies widely accepted and reasonable constraints on the choice of principles.\textsuperscript{58} Theoretically, this provides the basis for public acceptance.

Rawls determined that justice as fairness consists of two parts: (1) an interpretation of the initial situation and of the problem of choice that it poses, and (2) a set of principles which would be agreed to. This has come to be known as the contract theory.\textsuperscript{59} A key principle so chosen would be: "All social primary goods--liberty and opportunity, income and wealth, and the bases of self-respect--are to be distributed equally unless an unequal distribution of any or all of these goods is to the advantage of the least favored."\textsuperscript{60} Rawls has built his theory of justice on the foundation of Kant's theory. Decisions are made from the "original position" behind a "veil of ignorance." Rawls believes "we can say that when persons act on these principles they are acting in accordance with principles that they would choose as rational and independent persons in an original position of equality."\textsuperscript{61}

Gilligan's objection to this theory is that "morality is not grounded in universal, abstract principles but in the daily experiences and moral problems of real people in their everyday lives."\textsuperscript{62} In her disagreement Gilligan focused on
the question "how might what has to be done in this situa-
tion best preserve and nurture the human relationships
involved?" Susan Okin offers support to Gilligan's per-
spective. Okin believes that Rawls' theory is flawed by
believing that those in the original position should assume
that people are mutually disinterested rather than mutually
engaged. Many believe that we have lost our ability to
make morally sound decisions about whose needs we will meet
and that care must be practiced congruently with justice in
order for our moral ideals to be put into action. This
would still allow decisions to be made from an original
position of equality, but it would include the reality of
mutual engagement. Tronto believes that in order to ad-
dress the problems with care that she and others have iden-
tified a concept of justice is required along with a demo-
cratic and open opportunity for discussion, and more equal
access to power.

Palliative care has not received full support from the
standpoint of public policy because we have not yet dis-
cussed what dying people deserve. By reframing the issue,
using an ethic of care to discuss how the terminally ill and
their caregivers are mutually engaged with those who are
healthy, palliative care becomes not only a viable option,
but a desirable one. Because of our tendency to be a death-
denying society, we have ignored the fact that people need a
special kind of care in their dying. That special kind of care exists in hospice.
ENDNOTES


4. Ibid.


12. Ibid.

13. Rita C. Manning describes the ethic of care as holistic because it recognizes that we are embedded in connections of care and that our self-identity is, in large part, a function of our role in these complex interconnections, thereby seeing ourselves as part of a larger whole and inseparable from this whole in Speaking from the Heart: A Feminist Perspective on Ethics, (Lanham, Maryland: Rowman & Littlefield, 1992), 84.


16. In 1993, Carol Gilligan's *In a Different Voice* was republished with a new preface by the author. In the preface, Gilligan discusses some of the work that has been done during the past 20 years that has resulted in "an active and lively and often contentious discussion about women's voices, about difference..." According to Gilligan, responses to her work are divided into two steps: "listening to women and hearing something new, a different way of speaking, and then hearing how quickly this difference gets assimilated into old categories of thinking so that it loses its novelty and its message." At the close of the preface, Gilligan states that she has not revised her book because it has become a part of a process--"the ongoing historical process of changing the voice of the world by bringing women's voices into the open, thus starting a new conversation."


21. Ibid., p.67.

24. Ibid., 30.
25. Ibid.
26. Ibid.
27. Ibid., 33.
29. Ibid., 87.
31. Ibid., 62.
32. Ibid., 86.
34. Ibid., 2.
37. Ibid., 14.
38. Ibid., 30.
39. Ibid., 46.
40. Ibid., 47.
41. Ibid., 67.
42. Ibid., 75.
43. Ibid., 72.
44. Ibid., 82.
46. Ibid., 106.
47. Ibid., 132.
48. Ibid., 133.
49. Ibid., 107.
50. Ibid., 135.
51. Ibid., 145.
52. Ibid., 147.
55. Ibid., 148.
59. Ibid.
60. Ibid., 141.
61. Ibid., 142.
63. Ibid., 78.
CHAPTER 4
PALLIATIVE CARE, JUSTICE, AND THE ETHIC OF CARE

CONCLUSIONS

Hospice is a philosophy of care designed to provide physical, emotional and spiritual support for people at the end of life. The goal is to allow the dying process to unfold with a minimum of discomfort and the maintenance of dignity and quality of life. Over 210,000 persons at the end of life and their families receive care annually by the nearly 2,000 hospice programs in the United States.¹

Since the median age of hospice patients is 65 years, the majority of hospice care is provided under the provisions of the hospice Medicare Benefit. However, hospice care comprises a very small percentage of the total dollars spent on health care. For example, payments made for the hospice Medicare benefit were less than 1% of total benefit payments in 1994.² Although this group is small by comparison to the entire population, their needs are great. Hospice care is based on the premise that as a society, we have an ethical responsibility to care for the dying and this responsibility is grounded in the fundamental relatedness and mutual obligation of human social membership. It is impera-
tive for the continued moral development of our society that we do not ignore the needs of the dying.

Providing health care benefits has traditionally been based on a Rawlsian principle of distributive justice, attempting to provide opportunities for equality of well-being. A requirement of distributive justice is that people get what they deserve. The problem is determining what it is that they deserve. In a formal concept of justice, all beings of a given category should be treated alike. But, who are the beings that belong in the same category and what is the treatment that they should be given? I suggest that all who are dying of a terminal illness belong in the same category and the treatment they should be given is palliative care. It is a just society's responsibility to make this care available.

Robert Veatch discusses a "slice of time" perspective on justice. This means viewing the provision of just care for the terminally ill from the perspective of those who are currently in that position rather than from the vantage point of all of society projecting that someday they may have a terminal illness. "...an independent theory of justice will give planners at least prima facie reasons for committing substantial resources to the terminally ill."

In a discussion of the future of palliative care, Abyad states his belief that conflicts between physicians, patients, families and institutions will continue to increase
in the face of limited resources. He suggests several models upon which to rely:

(1) The autonomy model holds the patient's right to self-determination as supreme.

(2) The paternalism model allows the physician to guide and/or limit the available choices.

(3) The patient-provider collaboration aims for joint decision making.

(4) The beneficence model which requires the physician to act in the patient's best interest.4

Choices two and four point to the past. This is how our system has been operating and is in direct conflict with both an ethic of care and the philosophy of hospice care. Choices one and three are more compatible.

In her later writings, Nel Noddings has explained that her description of caring was meant to be "a phenomenologic­al analysis of how we are when we care and are cared for."5 She believes that we all must learn to care as a way of being in the world. The benefits of Noddings' perspective of care as a way of being in the world is the potentially profound impact this concept would make on relationships between those who are dying and those who are caring for them.

Health care professionals and an Ethic of Care

Edmund Peligrino's four components of caring (care as compassion, doing for others, caring for medical problems,
and taking care) provide the guidelines for the role of physicians in providing palliative care. "Instead of a relationship of curing between physician and patient, a relation of caring is needed to express the nature of the obligation between physician and patient." The fact that there is an obligation is supported by the principles of justice. The ultimate obligation is to achieve "patient good" and Pelligrino uses caring to accomplish this.

Nurses comprise the largest portion of health care providers in the United States and they have already articulated caring as an important value. At least one author believes that the nursing actions of touching and truth-telling demonstrate a form of existential caring. "To touch the patient is to affirm the patient as a person rather than an object and to communicate the value of caring as the basis for nursing actions." Truth-telling assists the patient in assessing subjective and objective realities in illness and to make choices based on the unique meaning of the illness experience.

Justice and Care

According to Michael Walzer, most philosophers' deepest assumption is "that there is one, and only one, distributive system that philosophy can rightly encompass." However, both Gilligan and Tronto argue that there is equal necessity for both justice and care orientations for a full and proper morality. Several other authors (Card 1990, Okin 1989,
Tronto 1993) have suggested that a combination of justice and care must take place in order to achieve an "adequate" ethic.

A major concern in combining justice with care in the support of palliative care is the tendency, when discussing justice, to posit one greatest good that is not the primary one for all people. Tronto believes that care will be the balancing force that will cause us to think about which needs are met and how, about the distribution of care, and about the its adequacy. We must be cautious not to mandate palliative care as the only alternative for everyone with a terminal illness. Instead, palliative care must be available as an option for all.

**Palliative Care as Public Policy**

The recommendations for how to change existing policies in order to create a climate for palliative care were outlined in Chapter 2. They were positioned within the framework of the three primary goals of health care reform (increased access, decreased costs, increased quality). What was not addressed was Tronto's concept of care and political theory. She believes that only if we understand care as a political idea will we be able to change its status and the status of those who do caring work in our culture. Tronto advocates expanding our moral boundaries to include caring, in the ethical sense, into our political vision. She suggests that "the practice of care describes
the qualities necessary for democratic citizens to live together well in a pluralistic society, and that only in a just, pluralistic, democratic society can care flourish." An ethic of care relies on a political commitment to value caring and to reshape institutions to reflect this commitment. I would suggest that this commitment would be valuable in reshaping public policy on palliative care.

Using an ethic of care to support providing palliative care affords our society a significant opportunity. That is, to profoundly impact the final relationship of one's life (as we know it), that between the dying and those who are caring for them. In light of the fact that we have become a society that shuns our dying, viewing them as failures of our health care system, this opens the door for a major shift in perspective.

2. Health Care Finance Administration, Office of the Actuary, unpublished information used for FY94 Board of Trustees Report.


7. Ibid., 89.

8. Ibid., 92.


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