



March 1988

## The Bioethics of Chronic Illness

Arthur L. Caplan

*University of Pennsylvania*, [caplan@mail.med.upenn.edu](mailto:caplan@mail.med.upenn.edu)

Bruce Jennings

*The Hastings Center*

Daniel Callahan

*The Hastings Center*

Follow this and additional works at: [https://repository.upenn.edu/bioethics\\_papers](https://repository.upenn.edu/bioethics_papers)

---

### Recommended Citation

Caplan, A. L., Jennings, B., & Callahan, D. (1988). The Bioethics of Chronic Illness. Retrieved from [https://repository.upenn.edu/bioethics\\_papers/37](https://repository.upenn.edu/bioethics_papers/37)

© The Hastings Center 1988. Reprinted with permission. This article originally appeared in *The Hastings Center Report, Special Supplement: Ethical Challenges of Chronic Illness*, Volume 18, Issue 1, March 1988, pages 1-16.  
Publisher URL: <http://thehastingscenter.org>

This paper is posted at ScholarlyCommons. [https://repository.upenn.edu/bioethics\\_papers/37](https://repository.upenn.edu/bioethics_papers/37)  
For more information, please contact [repository@pobox.upenn.edu](mailto:repository@pobox.upenn.edu).

---

## The Bioethics of Chronic Illness

### Abstract

There is a specter haunting the American health care system. It is the prospect of widespread chronic illness and disability in an aging society. With it comes a daunting challenge to our health care delivery system, social welfare services, families, and communities. And it presents an equally difficult challenge to millions of us as individuals. For prolonged, slowly debilitating chronic illnesses will most likely be our companions in the twilight of our lives.

At present, it is unclear whether the American health care and social service systems are prepared to cope with the challenges, both financial and ethical, that chronic illness poses to our society. Innovative policy ideas are needed, as are continuing research, extended and better coordinated social service programs, and educational programs that will equip health care providers to meet the special needs of persons with chronic illnesses.

### Comments

© The Hastings Center 1988. Reprinted with permission. This article originally appeared in *The Hastings Center Report, Special Supplement: Ethical Challenges of Chronic Illness*, Volume 18, Issue 1, March 1988, pages 1-16.

Publisher URL: <http://thehastingscenter.org>



## Special Supplement: Ethical Challenges of Chronic Illness

Bruce Jennings; Daniel Callahan; Arthur L. Caplan

*The Hastings Center Report*, Vol. 18, No. 1. (Feb. - Mar., 1988), pp. 1-16.

Stable URL:

<http://links.jstor.org/sici?sici=0093-0334%28198802%2F03%2918%3A1%3C1%3ASSECO%3E2.0.CO%3B2-L>

*The Hastings Center Report* is currently published by The Hastings Center.

---

Your use of the JSTOR archive indicates your acceptance of JSTOR's Terms and Conditions of Use, available at <http://www.jstor.org/about/terms.html>. JSTOR's Terms and Conditions of Use provides, in part, that unless you have obtained prior permission, you may not download an entire issue of a journal or multiple copies of articles, and you may use content in the JSTOR archive only for your personal, non-commercial use.

Please contact the publisher regarding any further use of this work. Publisher contact information may be obtained at <http://www.jstor.org/journals/hastings.html>.

Each copy of any part of a JSTOR transmission must contain the same copyright notice that appears on the screen or printed page of such transmission.

---

The JSTOR Archive is a trusted digital repository providing for long-term preservation and access to leading academic journals and scholarly literature from around the world. The Archive is supported by libraries, scholarly societies, publishers, and foundations. It is an initiative of JSTOR, a not-for-profit organization with a mission to help the scholarly community take advantage of advances in technology. For more information regarding JSTOR, please contact [support@jstor.org](mailto:support@jstor.org).

## Introduction

---

# Ethical Challenges of Chronic Illness

by Bruce Jennings,  
Daniel Callahan,  
and Arthur L. Caplan

A Hastings Center Report  
Special Supplement February/March 1988

---

This Special Supplement was derived from The Hastings Center project on Ethics and Chronic Illness, which was supported by a grant from the Henry Luce Foundation. The Special Supplement was edited by Courtney S. Campbell. Contents copyright 1988 by The Hastings Center. All rights reserved.

*There is a specter haunting the American health care system. It is the prospect of widespread chronic illness and disability in an aging society. With it comes a daunting challenge to our health care delivery system, social welfare services, families, and communities. And it presents an equally difficult challenge to millions of us as individuals. For prolonged, slowly debilitating chronic illnesses will most likely be our companions in the twilight of our lives.*

*At present, it is unclear whether the American health care and social service systems are prepared to cope with the challenges, both financial and ethical, that chronic illness poses to our society. Innovative policy ideas are needed, as are continuing research, extended and better coordinated social service programs, and educational programs that will equip health care providers to meet the special needs of persons with chronic illnesses.*

*The ethical dimensions of chronic illness and chronic care have been relatively neglected topics in the overall field of bioethics. Chronic care is a tedious, grinding labor of Sisyphus. It lacks the visibility and fascination of the high tech dramas played out in acute care settings. But the practical ethical dilemmas raised by chronic care are no less important than those in acute care, and the special characteristics of chronic illness make it an ideal domain in which to explore some new ethical and philosophical approaches. Chronic illness is not only a social issue that must be addressed, it is also a poignant and perplexing facet of the human condition where fresh insight can be sought. Meeting the needs of those with chronic illness, and treating them with justice and dignity as full-fledged members of the moral community, will tax our common energies, the public purse, and our moral imagination.*

*In 1984 The Hastings Center began a three-year project on Ethics and Chronic Illness with support from the Henry Luce Foundation. The project was premised on the hypothesis that the special nature of chronic care and the distinctive experience of chronic illness may lead to a transformation in many pervasive assumptions about the ethics and goals of medicine. The individualistic perspective behind much of the moral discourse of bioethics and social policy does not fare well in application to chronic illness and chronic care. Concepts such as patients' rights, autonomy, and best interests need to be revised in this context. In its confrontation with chronic illness, medicine's*

own understanding of its goals and mission must also be redefined. Intensive, high technology treatment oriented toward cure and full restoration of function, which has provided the dominant orientation for much of medicine in recent years, is usually inappropriate to the needs and problems of the chronically ill. A medical care system that lacks a sense of purpose beyond these goals will find itself increasingly uncertain and inept in the face of the demands placed upon it by chronic care.

The report offered here grows out of the overall work of the Ethics and Chronic Illness Project. Chronic illness is an exceedingly broad subject, and it has been more difficult than we imagined to capture a glimpse of the rich new agenda for bioethics that chronic illness provides. We hope nonetheless to have outlined some of that agenda in a way that will stimulate others to refine and pursue it further.

We are most grateful for the expert advice, guidance, and support we received from the members of the project research group, and others who took part in several meetings held during the past three years. Most of the project group members have prepared their own papers and studies on various topics touched upon in the following pages. These studies comprise an already substantial body of original work in the ethics of chronic illness, and we have drawn heavily upon them. An edited book containing these papers is currently being prepared for publication. It will serve as a companion volume to this Special Supplement, and will be useful to those who wish to pursue in more depth some of the points we have raised.

We would like to thank the Henry Luce Foundation for providing the financial support that made our project and this Special Supplement possible.

**Bruce Jennings**  
**Daniel Callahan**  
**Arthur L. Caplan**

#### Project Participants

**Daniel Callahan**, Director, The Hastings Center  
**Arthur L. Caplan**, Center for Biomedical Ethics, University of Minnesota

**Alexander M. Capron**, The Law Center, University of Southern California

**Christine Cassel**, Department of Medicine, University of Chicago

**Eric J. Cassell**, Clinical Professor of Public Health, Cornell University Medical College

**Larry R. Churchill**, School of Medicine, University of North Carolina

**Cynthia B. Cohen**, Department of Philosophy, Villanova University

**Peter Conrad**, Department of Sociology, Brandeis University

**Charles M. Culver**, Department of Psychiatry, Dartmouth Medical School

**Jessica G. Davis**, Division of Genetics, North Shore University Hospital, Manhasset, NY

**Anne Donchin**, Department of Philosophy, Indiana University—Indianapolis, IN

**Strachan Donnelley**, Director of Education, The Hastings Center

**Alan R. Fleischman**, Department of Pediatrics, Albert Einstein College of Medicine and Montefiore Medical Center

**Daniel M. Fox**, Health Sciences Center, State University of New York—Stony Brook

**Willard Gaylin**, President, The Hastings Center

**Janet Haas**, Moss Rehabilitation Hospital, Philadelphia, PA

**Ruth S. Hanft**, Department of Health Services Administration, George Washington University

**Bruce Jennings**, Associate for Policy Studies, The Hastings Center

**Joanne Lynn**, Division of Geriatric Medicine, George Washington University

**Kathleen Nolan**, Associate for Medicine, The Hastings Center

**Grace Riddell**, Division of Geriatric Medicine, George Washington University

**Irving Kenneth Zola**, Department of Sociology, Brandeis University

Other participants in project meetings included: **Margaret Calvano**, National Multiple Sclerosis Society; **Karen Dunn**, U.C.L.A. Medical Center; **Robert Enteen**, National Multiple Sclerosis Society; **Harry Frankfort**, Yale University; **Miriam Green**, Post-Graduate Center for Mental Health; **Mary Jane Hickey**, Henry Luce Foundation; **Gerald Klerman**, Massachusetts General Hospital; **Mary LaBrecque**, V.A. Hospital, White River Junction, VT; **Michael Lockwood**, Oxford University; **John Macca**, Dobbs Ferry Hospital, Dobbs Ferry, NY; **Frances Mason**, The Arthritis Foundation; **Joseph Ouslander**, V.A. Medical Center, Sepulveda, CA; **Mark Seigler**, University of Chicago; **Ellen Simpson**, University of California—San Francisco; **Ruth Stein**, Jacobi Hospital; **Anselm Strauss**, University of California—San Francisco.

Severe chronic illness is a domineering, unremitting presence in the lives of millions of Americans. Its onset, at whatever age, forces a revision of many hopes and expectations. When it first appears, chronic illness may seem like an unwelcome intruder, but eventually it becomes a part of oneself, still unwelcome, with which one must learn to live as best one can. In the years ahead chronic illness will enter the lives of more and more people—children and young adults who survive conditions once fatal in the first few months or years of life, and those over sixty-five who survive or avoid the acute illnesses of middle age. This will present an inescapable, possibly overwhelming problem for the American health care system. How we respond to chronic illness will be a litmus test for the character of American society.

Comprehending chronic illness requires an appreciation of the multifaceted ways in which it affects the individual, the web of familial and social relationships surrounding each chronically ill person, and the overall system of health care and social welfare services. Underlying organic dysfunction—chronic *disease*—is only one aspect of the total reality of chronic *illness*. The disease afflicts brains and bodies, the illness affects persons, and with them families and communities. Moreover, medical care is only one, and not always the most important, aspect of the social support and provision persons with chronic illness need in order to cope with the manifestations of their disease, manage the tasks of daily living, and maintain their independence and sense of self-worth.

However, recognizing the multifaceted psychological, social, and ethical, as well as medical reality of chronic illness is only the first step. We still lack an adequate understanding of the meaning and ethical implications of chronic illness in the lives of individuals, families, and the broader society; and we lack as well a serviceable vocabulary of concepts and categories with which to address its meaning and implications. Above all, we lack a guiding vision of how a just and good society should accommodate the special needs of its chronically ill members, care for them, and support them in their quest to live meaningful, satisfying lives with—and in spite of—their chronic illness. At a time when a comprehensive public discussion of how to meet the present and future challenges posed by chronic illness is sorely needed, this lack of a guiding moral vision is a serious problem.

The purpose of this report is to stimulate a broader discussion of the distinctive ethical issues posed by chronic illness, and to outline an agenda for future bioethical investigation in this area. Concomitantly, our aim is to articulate at least the rudiments of

a guiding moral vision that comes from both learning *about* chronic illness and learning *from* it. A guiding moral vision is needed to focus the efforts of individual caregivers, families, support groups, advocacy organizations, and local communities. It is needed to make the growing presence of chronic illness in our midst an occasion for strengthening the ties of mutual respect, benevolence, and caring between young and old, sick and well, in families and communities. Finally, on the national stage, a new moral perspective can help to inform a broad public consensus about the appropriate goals of chronic care and to give direction to public policies.

### A Challenge for Bioethics

---

Preventing or curing chronic illness is certainly better than living with it, both for the individual and for society as a whole. It is tempting to assimilate chronic illness to the currently prevailing outlook of acute care medicine, seeing it as yet one more frontier for science and technology to conquer and to cure. As desirable as primary prevention and cure may be in the abstract, however, an exclusive emphasis on such objectives overlooks the full dimensions of the problem. Over time it may indeed be possible to limit the incidence of some chronic diseases and to ameliorate their effects. With an aging population though, it is virtually certain that the prevalence of chronic illness will increase dramatically between now and the middle of the next century, as the postwar baby boom becomes the “elderly boom” beginning in 2010.

Medicine’s historic response to infectious disease and acute, self-limiting diseases of short duration does not offer an adequate way of understanding or responding to the personal, social, and ethical challenges posed by chronic illness and disability. What is needed, instead, is a different conception of the proper ends of medicine in the face of chronic illness, and beyond that, a better understanding of the human and social meaning of chronic illness.

The task of bioethics includes clarification of such issues. However, much of the moral discourse of contemporary bioethics is oriented by problems in acute care, and thus may overlook the distinctive issues raised by chronic illness and chronic care. There are two principal reasons for this. First, bioethics has been centered upon—and has helped to construct—an individualistic moral perspective in which the promotion of individual autonomy and the protection of individual interests are the paramount ethical goals. Second, while this emphasis on autonomy has overthrown some of the paternalistic attitudes traditionally associated with the so-called medical model, it has not fundamen-

tally altered the medical model's basic understanding of the nature of illness and the goals of care. This individualistic perspective and this continued attachment to the underlying assumptions of the medical model comprise what we shall refer to as the "autonomy paradigm" in bioethics.

Our thesis is that the autonomy paradigm is inadequate for chronic care, and that the development of a new bioethics of chronic illness is needed. It should begin with a recognition of the challenges chronic illness poses to many widespread value assumptions and institutionalized practices within and outside the health care system. Three challenges in particular merit special attention:

- Chronic illness poses a challenge to our understanding of the ends of medicine, the nature of the physician-patient relationship, and the ethical principles and standards governing health care decisionmaking.

- Chronic illness challenges the normal moral boundaries of caring, and conventional expectations about the caregiving duties of the family in relation to the social welfare obligations of the state.

- Chronic illness challenges our understanding of social justice and community, as these ideals are reflected in society's response to different kinds of health care and social service needs.

## Definitions

---

Chronic illness may be defined as a condition that lasts for a substantial period of time or has sequelae that are debilitating for a long period of time. It is also commonly defined as a condition that interferes with daily functioning for more than three months in a year, causes hospitalization for thirty days or more per year, or (at time of diagnosis) is likely to do either of these.

Defined generally in these ways, chronic illness includes a very broad spectrum of diseases that differ significantly from one another in their underlying causes, modes of treatment, symptoms, and effects on a person's life and activity. Some prevalent chronic conditions are life-threatening, such as heart disease, cancer, and stroke; others, such as arthritis, gout, epilepsy, and chronic sinusitis, are not. Some, like insulin dependent diabetes, cystic fibrosis, and muscular dystrophy are marked by early onset; others are primarily diseases of old age, like Alzheimer's disease, arteriosclerosis, emphysema, and osteoporosis. Conditions such as spina bifida, multiple sclerosis, Parkinson's disease, and Alzheimer's disease, have a devastating effect on one's life, while conditions such as hypertension, asthma, and ulcers can be controlled without undue disruption in normal activities. Overall, chronic

diseases vary greatly in their developmental course—some conditions improve over time, some stabilize, and others are progressively degenerating and debilitating. Moreover, within specific disease categories individuals vary tremendously in the severity of their impairment and in their ability to manage their illness.

In this report, we shall explore the ethical and social meaning of severe chronic illness amid the kaleidoscopic diversity of chronic illnesses. We intend to identify the common human needs and experiences that emerge in the encounter with severe chronic illness, and to examine generic ethical problems present in a range of different conditions. This task requires a more specific and unified focus than the broader definitions mentioned above permit. Accordingly, we will concentrate primarily on *organically based, severe chronic conditions that lead to significant loss of function or disability and generally have a slowly but progressively debilitating course.*

The group of illnesses distinguished by this emphasis on duration, severity, and progressive debilitation is still quite large, but share many common characteristics. They involve the greatest personal hardships and the heaviest financial costs for medical care. Aside from chronic mental illness, which would require a separate study and another report to address adequately, these are the conditions most in need of fresh ethical analysis and new policy strategies. Though these illnesses can be medically managed and their development slowed (a process sometimes referred to as "secondary prevention"), they cannot be "cured" in the sense of being physiologically arrested or fully compensated for. Typically, the long-term course of such conditions can be foreseen, but the pace and daily manifestation of symptoms in individual patients is highly variable and uncertain. Finally, many if not all of the severe chronic conditions we will be concerned with are accompanied by intermittent acute episodes and other treatable problems. Thus most of the care and management of severe chronic conditions takes place outside the hospital setting, but persons with these conditions will have an abnormally high number of hospital days, physician visits, and restricted activity days per year; and they will require some assistance with the activities of daily living and eventually a substantial amount of nursing and custodial care, either in an institutional setting or in the community.

## Elderly Boom, Chronic Care Avalanche

---

At least since the 1930s, chronic illness has been perceived as the principal health care challenge of

our time. The challenge has not diminished in the last fifty years. Chronic care for all who need it in an aging society will place enormous demands on an already exceedingly costly health care system. Now and in the future it may be said that virtually everyone will suffer from a chronic illness at some time during their lives. But in the vast majority of cases the illness will not be severe enough to alter drastically the person's normal activities or to require excessive utilization of health care services.

A useful focus on the problems created by severe chronic illness can be gained through data on morbidity and limitation of daily activities contained in the National Health Interview Survey (NHIS) begun in 1957. In the late 1960s questions concerning the prevalence of specific chronic diseases were added to the survey. NHIS and similar data show trends indicating a general pattern of decreasing mortality and rising morbidity for middle-aged and older people since 1957, with particularly marked changes occurring in the 1970s.

In 1984 approximately 24 percent of those reporting chronic illness also reported moderate or major limitations in their activities. The current prevalence of severe chronic illness in the population as a whole is difficult to gauge. Moderate estimates place the figure at approximately thirty million people. Moreover, both the incidence and the prevalence of all types of chronic illness are positively correlated with increasing age, and rise to particularly high levels in the population over sixty-five. Of those aged sixty-five to sixty-nine in 1984, 31.8 percent had a limitation in a major activity and 16.9 percent were unable to carry on a major activity. For the elderly population the leading chronic health problems are arthritis (36 percent of men; 50 percent of women), hearing impairments (33 percent and 25 percent), hypertension (32 percent and 43 percent), heart disease (26 percent and 28 percent), and chronic sinusitis (14 percent and 17 percent).

While the increase in the prevalence of chronic illness during the past twenty years has been troublesome enough, the truly staggering problems still lie ahead. The demographics of an aging population virtually ensure a chronic care avalanche. The institutional and financial implications of this for the health care system are enormous. In addition, the prospects for competition among age groups for limited public benefits and scarce economic resources are sobering.

In 1900 4.1 percent of the U.S. population (3.1 million people) were over sixty-five. By 1984 that number had grown to 28 million people or 11.9 percent of the population, and proportionally the largest areas of increase were among the "old old"

(seventy-five to eighty-four) and the "very old" (eighty-five and above). Moreover, people over seventy-five will become an increasingly significant factor in our society as their numbers increase both in absolute terms and as a percentage of the total population. The baby boom cohort is now an upwardly moving bulge in the pyramid-shaped graph of age distribution in the United States. The aging of the baby boomers, together with slowly rising birth rates and more rapidly declining mortality rates at all ages, will transform this triangle into a rectangle by the middle of the next century.

The effect of these demographic changes upon the health care system will depend largely upon the age of onset of severe chronic diseases and disabilities affecting the elderly. Some analysts believe that future lifestyle changes and more effective medical prevention and treatment will make the average age of onset increase more quickly than life expectancy, thereby producing a "compression of morbidity" in which the duration of chronic illnesses before death will be less than it is now. This relatively optimistic scenario rests on shaky epidemiological grounds, as well as expectations of widespread changes in health related behavior, something which is notoriously difficult to predict or control. At any rate, the hope of making chronic illness less chronic is a very risky assumption upon which to base future health policy planning. For the moment, it seems wiser to be guided by less optimistic scenarios, and to anticipate nearly threefold increases in the number of physician visits, hospital admissions, and nursing home placements that the elderly will require between now and 2040.

### **Policy Challenges**

---

The past record of policy regarding chronic care does not suggest that our political and policy processes are well equipped to meet the challenges that lie ahead. During the last two decades some progress has been made in providing needed financial assistance and services for the chronically ill. But individual patients, families, and private charitable organizations still bear a heavy share of the financial and in-kind costs of chronic care, while publicly funded health care entitlement programs and social welfare safety nets remain fragmented and uneven in their coverage. In 1984 the Congressional Budget Office estimated that Medicare enrollees paid on average more than \$1,000 annually in out-of-pocket medical expenses (for deductibles, cost-sharing, and noninstitutional care, such as prescription drugs, not covered by Medicare). When nursing home care is accounted for, the average annual out-of-pocket expense rises to \$1,705.



Moreover, the burdens of chronic illness still fall most heavily on the low income elderly, the medically indigent and uninsured, the working poor, women, and minority groups. Data gathered in 1977 reveal that poor and near poor elderly persons with severe chronic conditions (those living at home with annual health care bills over \$2,500) had to devote a large share of their household income to out-of-pocket expenses. Those eligible for both Medicare and Medicaid had to spend 10 percent of their income; for those relying on Medicare alone the figure rose to a staggering 53 percent. In the 1980s and beyond, the future needs of the chronically ill are on a direct collision course with the goal of health care cost containment and a general dismantling of welfare state services.

In fact there is not now, and never has been, a public policy strategy designed to address chronic illness as such. By and large, chronic illness has been responded to in an indirect fashion, as it is associated with other categorical factors such as age, poverty, or work related disability. The traditional lack of a comprehensive chronic illness policy is perhaps related to the fact that political advocacy groups have organized around specific diseases. Each chronic disease has its own subcommunity of medical and scientific experts, its own network of treatment centers, advocacy groups, celebrity spokespersons and fundraisers, and its special champions in Congress. Unfortunately, instead of finding common cause in the generic needs of the chronically ill, these groups are more often busy competing against one another for scarce research, health care, and social welfare dollars.

This state of affairs is understandable enough. It reflects the long-standing pattern of interest group pluralism and the ideology of government-as-the-last-resort that characterize the American political system. It also indicates that chronic illnesses are highly diverse in their physiological causes, treatments, prognoses, and effects. Their victims often have little in common politically, economically, or culturally aside from age and the experience of disease itself. This results in a "disease of the month" health policy sweepstakes; its winners are those conditions afflicting very large numbers of citizens (cancer), genetic diseases affecting a well defined or powerful ethnic constituency (sickle cell anemia and cystic fibrosis), and conditions that are medically "interesting" and lend themselves to something akin to cure in terms of the acute care medical model (chronic heart, liver, and kidney disease).

This is one reason why we believe it is important to focus more attention on the common, generic problems and effects of chronic illness, and on the shared needs of the chronically ill population as

a whole. As a prelude to a new politics of chronic health policy, this focus on the generic aspects of the chronic illness experience can provide a more sharply defined, coherent sense of the ethical issues that are distinctive to chronic illness, but do not simply arise in the treatment of a specific disease or disability. Medically, persons with arthritis, diabetes, multiple sclerosis, cystic fibrosis, and Alzheimer's disease may have little or nothing in common. But ethically, socially, and in the end politically too, their common interests and needs may be much more significant than their differences.

### **The Experience of Chronic Illness**

---

For the individual perhaps the most salient general feature of chronic illness is the transformation it causes in the texture of personal and social life. The person with chronic illness is thrust into unfamiliar and often inhospitable worlds—frequent hospital stays and encounters with highly complex, impersonal, and often frightening modes of acute medical treatment; prolonged and inconvenient regimens of medication, special exercise, and restricted diet; a continuing round of bureaucratic hassles with a disjointed system of medical and social service professionals and agencies; the daily prospect of sometimes disabling pain; the perpetual uncertainty that comes from the intermittent flair-ups of debilitating symptoms and the occasional onslaught of an acute, life-threatening episode.

Chronic illness also threatens the integrity of more familiar aspects of a person's life. It punctuates one's life with frequent periods of restricted activity, immobility, and unwanted dependency on others. It often interferes with the ability to work, which threatens the person's basic livelihood and economic security, to say nothing of more ambitious career plans. Chronic illness and disability are often stigmatizing; intolerance, fear, and misunderstanding, at one extreme, and well meaning but humiliating and patronizing sympathy at the other often greet the chronically ill in their everyday social lives. Lost friendships, withdrawal and isolation, and an emotionally draining struggle to sustain dignity and self-respect are often the consequence.

Cutting even more deeply into the person's life, chronic illness also transforms intimate and family relationships, placing new burdens on both the person who needs special care and family caregivers whose own lives and hopes must often be drastically revised to accommodate such needs.

#### *Chronic Illness and the Self*

Finally, it is important to understand the ways in which chronic illness can shape or transform the

person's self-identity. The impact of chronic illness on a person's self-image and sense of meaning and purpose in life can be either beneficial or detrimental, and in many cases it is both. The ordeal of chronic illness can be experienced as an enabling experience, one that sharpens the person's appreciation of remaining powers and abilities, quickens sensibilities and talents that had been dormant, and brings out a depth and strength of character previously untapped and unrealized. Alternatively, along with social stigma and isolation, chronic illness can leave the individual bereft of purpose and deeply alienated from the condition of his or her own body and the truncated future possibilities of life.

Above all, the relationship between chronic illness and self-identity is a dynamic one. It is affected by many variables, including current symptoms of the disease, the reactions of family, friends, and caregivers, and the various strategies individuals use to sustain themselves. As sociologist Kathy Charmaz observes: "Realizing a preferred identity and possessing a valued self is a constant struggle for those with serious illnesses.... Illness forces people to experiment, adapt, and reorganize in order to maintain control over themselves and their lives. In this sense chronically ill people are innovators."

Chronic illness raises exceedingly complex philosophical questions about the nature of the self and the continuity—or discontinuity—of self-identity over time amid changes in organic capacity, social circumstances, and in the ability to actively shape and direct one's life. Is the self an entity that stands above and apart from the body and the social persona so that even drastic changes in body or persona leave the essential identity of the self unchanged? Or, at the other extreme, is the self so constituted by the organic condition of the body and external social perceptions, that in the face of progressively debilitating and disabling chronic disease it may be said to have no essential stability at all?

While an adequate position on the relation between a concept of self and the impact of chronic illness is difficult to formulate, reflection on such issues is important because of their relevance for ethical and policy questions. Philosophical assumptions about the nature of the self stand behind most of the central ethical principles we use to direct the ends and procedures of health care, and also inform the goals we set in fashioning social policy and in designing the structure of the health and social service delivery system. Without understanding how the self is affected by the experience of living with—and in spite of—chronic illness, we will not be able to say with any specificity how the basic principles

of respect for persons, patient autonomy, and the duty to promote wellbeing should apply to chronic care, nor how to specify the needs, rights, and interests of persons with chronic illness. We will lack a framework for adequately addressing how the chronically ill should be served by policies of health care financing, the design of institutional arrangements for medical and social services delivery, and the allocation of scarce resources.

In contemporary society, chronic illness is a dark thread woven through the fabric of our lives; virtually everyone who lives a normal life span will undergo some type of chronic illness, and virtually everyone will be related to, love, work with, and care for someone who is chronically ill. Chronic illness thus has a significance that is at once uniquely personal and universally human. It creates special needs and vulnerabilities that set individuals and families apart, and it also creates a common bond among us in the reminder it provides of the inescapable fragility of the human condition. It generates conflict, but also the possibility of concord.

Chronic illness calls for a particularly careful and sensitive kind of moral reflection. We must somehow acknowledge the distinctive needs and interests of the chronically ill, without thereby treating them like a special class or cutting them off from common membership in our moral community. We must provide needed health care services without turning the chronically ill into a dependent, institutionalized clientele of the health care professions. We must support families and voluntary communities that provide assistance with the activities of daily living and supplement these efforts with publicly funded programs. But we must do so without eroding the special sense of familial obligation that is still powerful in our society despite changing lifestyles and family patterns, and without transforming personal care into an impersonal commodity that is merely bought and sold. Our social policies must be guided by ideals of justice and compassion and a due sense of the public entitlements that the chronically ill should possess as a matter of right, while at the same time setting reasonable limits on the claims persons with chronic illness can make.

A full discussion of these objectives, and the policies for attaining them, is well beyond our capacity in this essay. As a starting point for further research and discussion, though, we believe it is useful to begin with currently prevailing ethical frameworks in three domains—the professional ethics of medicine, the ethics of family relationships, and notions of social justice that inform public policy. We will explore the implications of chronic illness in each of these contexts.

## Toward a Bioethics of Chronic Illness

---

Chronic medical care has a number of distinctive characteristics. Most chronic care does not involve complex diagnostic procedures or invasive interventions and monitoring under direct supervision of a physician in a hospital setting, but rather long-term drug and rehabilitative therapies that must largely be carried out by patients themselves, with only periodic monitoring and adjustments by professionals. The compliance and involvement of patients are crucial to the efficacy of most forms of chronic care. When these factors are affected by the patient's home environment and family support, as is typically the case, the family also becomes integral to the care.

For the physician this raises delicate ethical questions concerning issues of privacy, confidentiality, and patient autonomy. How much should family members be told about the diagnosis and prognosis of a chronic illness, and when? If family members must have direct involvement in the implementation of a treatment regimen, do they have a right to be involved in deciding among alternative possible treatment plans? Where should the line be drawn between justifiable paternalism and unacceptable manipulation and coercion when physicians and family members attempt to modify the behavior of a noncompliant patient?

### *The Autonomy Paradigm*

During the past two decades a systematic conceptual framework for understanding the ethical dimensions of medical decisionmaking has been gradually constructed and relied upon by those involved in the study of bioethics. Although a considerable gap still exists between bioethical theory and actual medical practice, the importance of the bioethics movement should not be underestimated. Drawing on expertise within the health care professions, as well as work in philosophy, theology, law, and the social sciences, bioethics offers an influential view of what medicine is and should be—what human values it can and should serve, what legal and public policy frameworks should govern it, and what institutional forms it should take.

Three interrelated notions form the conceptual infrastructure of most contemporary bioethics and constitute what we shall call the "autonomy paradigm." The first component of the autonomy paradigm is a particular interpretation of the meaning of illness and the goal of medicine: illness is seen as an alien threat to the self, and the goal is to defend and restore the self by curing or compensating for the illness. This notion is often referred to as "the medical model" of illness.

The second component of the autonomy paradigm is a particular understanding of the role of the patient and the nature of the physician-patient relationship. According to this view, which is often called the "contractual model" of medical care, the patient is a rational, self-interested subject who, threatened by illness, voluntarily enters into a contractual agreement with a physician (or other health care provider) and temporarily submits himself or herself to medical authority in order to combat the illness.

A decidedly individualistic conception of the person is the third component of the autonomy paradigm. In this view, self-identity, autonomy, and interests are conceptually prior to and independent of the encounter with illness and the experience of participation in the caregiving process. This individualistic conception of the person is the linchpin that connects the medical model, the contractual model, and the commitment in mainstream bioethics to promoting the autonomy and best interests (wellbeing) of the patient.

Although it is not often conceptualized in precisely this form, we believe that the autonomy paradigm underlies most public discussions of health care, and is an intellectual force to be reckoned with. It has become "institutionalized" in health care delivery through the influence of court rulings, government regulations, and organizational policies in hospitals and other health care facilities. Equally important, it has become the predominant framework for reflection about how we should respond morally to future health care needs and how future public policies that will enable the health care system to meet those needs should be devised.

Does this paradigm provide a serviceable framework for understanding the ethical dimensions of chronic illness? We argue that it does not. As one's attention shifts from acute care and medicine's attack on curable disease to chronic care and medicine's contribution to the quality of life lived with chronic illness, the medical model and the contractual model require substantial revision. Above all, chronic illness provides a context in which the shortcomings and limitations of an individualistic conception of the person become particularly apparent.

### *Disease as the Enemy*

It is generally recognized that serious acute illness poses a threat to the individual, and morally requires others to assist the individual in counteracting that threat. In instances of life-threatening emergencies, and in most cases of acute care medicine even when the condition is not immediately life-threatening, the person's needs, the proper actions for the physician

to take in response to those needs, and the scope of the moral rights and responsibilities of the parties involved are all reasonably clear. By and large with acute illness—pneumococcal pneumonia is a good example—the source of the threat can be singled out and identified—the invading organism, the disease process, the biochemical malfunction. In acute care establishing the correct diagnosis is more than half the battle, for it is on that basis that the remaining course of treatment usually proceeds.

Having identified the threat, it is also easy to identify what is threatened—life, health, a level of “normal” functioning that can be restored to the *status quo ante*. Moreover, the threat is viewed as evil because life, health, and function are intrinsic values or primary human goods; they are the foundation for the pursuit of all our other ends. Finally, physicians know how to respond to the threat—the range of appropriate medical treatments is determined by the current state of medical knowledge, and perhaps there will be one specific intervention, a “magic bullet,” that will eliminate the threat once and for all.

The central theme of the medical model is thus the idea of illness as a threat that suddenly intrudes upon a preexisting condition of health and wellbeing. This perspective supports the military metaphors commonplace in our cultural ideology of medicine. Disease is the enemy within. The patient and physician enter an “alliance” in which the technical “armamentarium” of medicine is used to defend the patient and to attack the invader. Restoration of the status of the person prior to the illness—cure—is the objective sought in the campaign.

Seeing the illness as a threatening intruder serves to externalize and objectify it, and makes the illness a thing, extrinsic and foreign to the person even though it is inside the body. Illness represents a temporary unfreedom imposed upon the person by an alien source, a heteronomy that thwarts self-determination and the pursuit of life’s “normal” goals. Similarly, illness undermines wellbeing because wellbeing is taken to be, as the term implies, a state of being well without—not in spite of—illness; a state of being for which illness is an Other.

#### *The Patient Role and the Medical Contract*

Individuals confronted with acute illness generally define their needs and interests in the same way that the medical model defines them, thereby collaborating with their physicians in a common endeavor to cure the disease and to restore health and function. Acutely ill persons submit themselves to medical authority as “patients,” a role that is often taken to imply passivity, but in fact might better be described as one of active cooperation and

compliance. In the context of acute care, the patient role is warranted. Even though it places one under external authority, it can be justified on grounds of prudence: it furthers the person’s own goals, it is a temporary, self-limiting status and the person regards the acute illness as an extrinsic threat to his or her being rather than as a constitutive feature of it.

In recent years an emphasis on truth-telling, informed consent, and a generally more active role by patients (or their designated surrogates) in the process of medical decision-making—all in the name of individual self-determination or autonomy—has tended to set aside benevolent paternalism and professional expertise as the basis for physician authority. In their place, bioethics has substituted the notion of rational, voluntary consent to medical care and medical authority. This development of a normative framework for medicine is remarkably akin to the classical liberal contractarian account of political authority and obligation. Bioethics has, in essence, imported liberal individualism into the health care arena. Under the autonomy paradigm, therefore, the provider-patient relationship is viewed as contractual in nature. It is the social contract of the liberal polity writ small—a structure of reciprocal rights and obligations voluntarily entered into by both parties in order to achieve goals together that neither party acting alone could achieve.

This framework, while holding potentially significant practical implications, has probably been more influential in challenging a certain paternalistic and authoritarian *style* of medical practice than in challenging the basic medical model and patient role notions. Medical authority based upon rational (“competent”) patient consent is still medical authority. A patient-centered ethic of autonomy may be empowering and rights-enhancing for the individual, but it remains a perspective focused on the role of patient, and makes certain unanalyzed assumptions about the relationship between that role and the other roles in a person’s life. Adding respect for patient autonomy to the promotion of patient wellbeing (beneficence) as a principled obligation of health care providers still leaves the cure of disease and the restoration of function as the central ends of medicine, in so far as these goals provide the rationale for the decision of autonomous agents to enter into the role of patient in the first place. Moreover, the moral injunctions of the Hippocratic tradition—use medical knowledge and skills only for the benefit of the patient (beneficence) and do no harm (nonmaleficence)—can readily be accommodated to the newer moral emphasis on individual autonomy so long as “benefit” and “harm” are interpreted broadly enough to encompass the

patient's own values, beliefs, and conceptions of the good, as well as his or her bodily needs.

In short, the autonomy paradigm has both solidified a strongly individualistic, patient-centered orientation in medicine, and preserved the basic assumptions about the ends of medicine that inform the medical model and the contractual model in the context of acute care. The acute care "bias" of mainstream bioethics is thus not simply a function of the fact that most work in bioethics has concentrated on cases and problems arising in institution-based acute care settings. That bias, which has served bioethics well and has been quite appropriate in many discussions, is deeply embedded in the conceptual structure of the autonomy paradigm.

### How Is Chronic Care Different?

---

Earlier we noted a number of factors that make chronic care different from acute care—the reduced emphasis on diagnostic investigation, comparatively less understanding of the etiology and biologic pathways of the disease process, the variability and uncertainty of clinical symptoms, the lack of constant medical supervision and the reliance on the patient and family members to carry out long-term drug and rehabilitative therapies, and the manifest lack of magic bullets to cure the illness. These factors suggest some obvious ways in which the acute care medical model fails to describe—or to guide—chronic care.

With chronic conditions, by and large, illness cannot be conceptualized as an alien presence within the person, or as an aberrant situation that marks a temporary, reversible departure from the person's "normal" state. Chronic care must proceed from the recognition that chronic illness is a component of the person's overall state of being. Depending upon the specific chronic disease, medical therapy offers a variety of different effects, ranging from remission or slowing the progress of the disease to artificially compensating for impairments and managing symptoms. These therapies share an objective to help people accommodate themselves to the chronic illness, which cannot be vanquished or eliminated. The overall goal of chronic care is to mitigate the limitations that chronic illness inevitably brings with it in a person's life, and to control the damage that the illness might otherwise do. More specific, clinically defined goals such as rehabilitation, pain relief, and the control of symptoms through drug therapy, diet, and exercise, are consonant with this end.

In the face of chronic illness the paramount good that medicine should serve is not precisely health—

at least not ideal health, which is a chimera in any case—but rather the wholeness and the integrity of the self. Persons with chronic illness really have no choice but to try to integrate their illness constructively into their daily lives and sense of self-identity. The desideratum is to stay intact—to make the necessary adjustments with as little loss of purpose, coherence, and meaning in life as possible. Indeed, they may be able to replace former plans and aspirations with even more fulfilling new ones. Living with chronic illness is thus a process of negotiation. As sociologist Anselm Strauss points out, such a process involves many kinds of hard work—the work of controlling a sometimes irascible body, the work of managing one's biography or self-identity, the work of orchestrating the presentation of self in everyday life.

Whereas acute care aims to restore one's freedom from illness, the goal of chronic care is to sustain meaning in life lived with—and in spite of—illness. Diplomacy is perhaps a better metaphor than warfare for this kind of care. Medicine's role in chronic care is to facilitate the process of negotiation.

Many people experience a period of anger and denial when their chronic illness is first diagnosed or its symptoms first appear. It is terribly difficult and unsettling to recognize chronic illness as something to negotiate with rather than as an invader to be defeated. But over time most people find that separating themselves from their illness is not a viable or satisfying response to their condition; they must work through the phase of denial to a more constructive kind of reconciliation, without moving to the opposite extreme of defeatism and undue dependency.

Part of the task of medical care and counseling is to assist persons with chronic illness as they ride this emotional roller coaster. At one stage of psychological adjustment to their illness it is not uncommon for persons with chronic illness to become extremely passive and dependent upon their health care providers, or other caregivers. On the other hand, the long duration of chronic illness and many years of experience with a particular form of medical therapy make chronically ill persons much more knowledgeable about their condition than acute care patients tend to be, or even some of the physicians they see.

Chronic illness tends to foster a wide variety of styles and stages of being a patient. No single model of the patient role can capture the diversity and dynamism of chronic care adequately. It elicits an equally diverse set of relationships with physicians. In this setting, the rationalistic *quid pro quo* of the contractual model seems thin and unrealistic.

## Embodied Autonomy

---

These considerations suggest new ways of thinking about the role of being a patient, the nature of the physician-patient relationship, and the ethical values, especially individual autonomy, that should inform that relationship.

The traditional paternalistic model of care cast *the person as patient* into a largely passive and obedient role. More recently the autonomy paradigm has emphasized respect for *the patient as a person*, a more equal and active partner in the process of medical decisionmaking and health care. But the person or self in the autonomy paradigm is taken to be an entity separate from and independent of the illness, with preestablished interests that are also independent of the illness. As a practical matter, individuals with chronic illness are rarely, if ever, "patients" in either of these senses.

The contractual model of the physician-patient relationship is based, as we have seen, on the idea that the principal goal of patients is to protect their interests—to protect them from the illness that threatens them and to protect them from the illegitimate or paternalistic exercise of medical authority. According to this account, a person's interests are fixed, stable over time and set prior to the person's encounter with illness. However, even if this notion of interests may fit the situation of acute care (we would question whether it does), it is exceedingly problematic in the realm of chronic illness.

Interests may be defined subjectively as conditions of existence that the person finds valuable and wants to obtain. Alternatively, interests may be defined objectively as those conditions of existence that do in fact enhance the person's good and wellbeing. Chronic illness transforms interests in either sense; subjectively by altering the person's sense of self, and his or her possibilities and limitations, and objectively by altering the conditions necessary for wellbeing and human flourishing. The primary obligation of chronic care medicine, then, is not to protect the person's interests in the sense of keeping them from being affected by illness—that is impossible—but rather to assist the person in keeping the transformative power of illness under control, to integrate new subjective interests (wants) and new objective interests (needs) into a coherent and satisfying life.

The issue of compliance with a prescribed course of treatment, for example, a drug or dietary regimen, illustrates this. Compliance with a treatment program to which informed consent has been given is clearly one of the patient's duties according to the contractual model. In the abstract, rationalistic world where this model is most at home, compliance is

obviously in the patient's best interest, to the extent that persistent noncompliance is taken as *prima facie* evidence of the patient's lack of decisionmaking capacity, and a symptom of denial or maladjustment.

This interpretation may be correct in many cases, but as a generalized account it has serious blind spots and overlooks a much more complex drama often played out in chronic care. Persons with chronic illness must manage their illness socially and psychologically as well as medically; they must strive to prevent the illness from overwhelming their sense of efficacy and the control they, like all of us, wish to exercise over their lives and activities. Interactions with health care providers are one scene in this drama of self-assertion and control. Noncompliance—or better, patient-determined compliance—with medical orders is one negotiating strategy that persons with chronic illness use to achieve their social and psychological objectives, even at the expense of optimal attainment of their medical goals.

If, as we have argued, chronic care is more about negotiating with illness than about combatting disease, then the duties of the physician must also be rethought in this broader context. Respect for patient autonomy does not dictate a straightforward course of action when the physician is faced with a noncompliant patient in chronic care. Physicians should be more sensitive to the meaning and purpose of such behavior, but it does not follow from this that they simply have a duty to acquiesce in this particular style and patient strategy. Acquiescence is not necessarily respectful of autonomy, and attempts to modify the patient's behavior do not necessarily reflect a presumptuous, disrespectful kind of paternalism. Managing the illness in a self-affirming way is—or should be—the common goal of the physician and the chronically ill person. The question for caregivers, then, is whether they can help the patient design some other, less medically harmful, coping strategy that will achieve the same psychic ends as well as or better than noncompliance.

The dynamic and transformational aspects of chronic illness necessitate modifying conventional bioethical interpretations of autonomy and the physician's duty to respect or enhance autonomy. The importance we have ascribed in chronic care to sustaining an intact, well-integrated self who is in control of, not controlled by, the illness, derives in a certain sense from the value of autonomy. Thus it is not the notion of autonomy per se that we find inadequate. The problem lies rather in the peculiarly individualistic interpretation often given to the concept of autonomy, in which autonomy means freedom from external limits or constraints.

In this perspective, the autonomous self is a disembodied self; it is independent of and prior to its social milieu and its bodily condition.

This individualistic interpretation of autonomy is a philosophical fiction—an ideal of selfhood—rather than a notion rooted in our lived experience. Still, it might be argued that this interpretation is useful as a heuristic conception that points us in the right direction morally.

However, when this conception of autonomy is applied to chronic care as a guiding ethical principle, its shortcomings, even as a heuristic notion, become apparent. Individualistic autonomy builds protective fences between the self and others; chronic care must restore the fabric of community and a web of mutual support and interdependency, beginning with the cooperative—not contractual—ties between patients and providers. Individualistic autonomy sets up a logical opposition between freedom and constraint, and between respecting a person and helping that person grow beyond the limits of his or her present self-understanding.

In chronic care freedom and constraint, respect and guidance intertwine and become symbiotic. Protecting the patient's rights and interests is no less important in chronic care than it is in acute care, but it is essential to build trust and to avoid a climate of adversarialism. Chronic care is on its most solid ethical footing—and is therapeutically most effective—when both those receiving and those giving care recognize their common purpose, and when they both have the flexibility to move toward a deeper understanding of how best to preserve the integrity of the person in the face of chronic illness. Physicians and patients must both learn from and teach each other in the process of chronic care. There is time enough for this, and on an out-patient basis it should be possible to maintain the necessary continuity.

Autonomy is not some a priori property of persons abstractly conceived. It is an achievement of selves who are socially embedded and physically embodied. This is perhaps the single greatest lesson to be learned from chronic illness. Autonomy is something that grows out of the physician-patient relationship, not something that presides over it. And not out of this relationship only, but out of all aspects of life lived with—and in spite of—chronic illness and all facets of chronic care.

### **The Limits of Family Obligations**

---

Ties of kinship, marriage, and sustained intimacy create special psychological and moral bonds in our lives. Families, a term virtually impossible to define precisely in American society at present, are

composed of these ties and bonds, and so constitute a distinctive social space, a space where rules and expectations apply that are somewhat different from those in impersonal, public places and in transactions among strangers.

Family life, and especially the moral obligations that family members have toward one another, is challenged by severe chronic illness in two ways: first by the burdens imposed on families by chronic care; and second by virtue of the fact that severe chronic illness in a family can pose a crisis for our traditional moral expectations concerning family life.

Families now provide a principal source of social support and daily assistance for persons with severe debilitating chronic illness. Many of these people are homebound much of the time, and reside in the same household with one or more family members. Even those who live alone often have family members nearby who visit regularly to assist with cleaning, shopping, cooking, and other tasks that the chronically ill person is not able to perform unaided. In some instances the costs of such care, including financial expenses as well as time and emotional stress, can become overwhelming to the caregiver, and place a threatening strain on the family itself.

Clearly, the chronically ill person, no matter how difficult or demanding, is not to blame for a situation like this. The burdens an illness imposes on the ill person and the family caregivers alike are artifacts of the social and cultural context in which they live. In the United States the burdens of chronic care on families are increased by the lack of public services and community facilities. These facilities could substitute for some aspects of family care and could promote a greater opportunity for independent living by the chronically ill. However, this lack of social support does not completely account for the dilemmas and burdens families experience in chronic care. Dilemmas also arise from the moral expectations family caregivers quite properly impose upon themselves, and the cultural ideal of what it means to be a good person in a family role—a good spouse, a good parent, a good son or daughter.

Chronic illness forces us to consider how strongly we want to continue to adhere to these expectations and ideals, despite the very real costs and hardships they sometimes create when put into practice. Would our social morality be worse off if we lessened or abandoned them? Should we, in the name of individual autonomy both for the chronically ill and for family members, move toward replacing family-based care with such innovations as group homes, programs to encourage independent living, professionalized home care services, and greater access to long-term care institutions for those needing only

unskilled nursing and "custodial" care? Should we as a society come to see chronic care as exclusively a public responsibility, and remove this function from the private lives of families altogether?

The tempting and obvious response to these questions is, can't we have it both ways? As a practical matter, families will continue to play a key, but not exclusive role in the provision of chronic care. The political struggle for expanded benefits and better public financing for long-term care (both home and institutional) will continue, and voluntary community based services will continue to plug some gaps in public assistance and provide some respite and alternatives for weary family caregivers. But it is and will be an uneasy solution, with plenty of guilt and caprice to go around.

It remains to be seen whether our society will be able to move toward a system that responds to the complex needs of both families and individuals. Earlier we noted the historical absence of any coordinated public policy on chronic illness, and nowhere is the lack of such a policy more apparent than in the ambivalent attitudes displayed concerning the role of families in chronic care.

In the health care system, for example, confusing signals and conflicting trends abound. On the one hand, there is a trend toward deinstitutionalizing chronically ill patients who require sophisticated and even intensive forms of medical and nursing care. Severely disabled babies who were rescued from life-threatening complications by neonatal intensive care immediately after birth fall into this category, as do children who are chronically ventilator dependent or who require total parenteral nutrition. A new generation of medical technology has made these developments possible. They are also promoted by cost-containment considerations and by prevailing medical opinion that such children receive better care and are more likely to do well at home.

A similar trend that places the responsibilities of care in the hands of family members is a spillover from institutional interaction between the hospital and the nursing home industries. Prospective payment systems give hospitals an incentive to discharge patients more quickly, and as a result nursing home beds are now occupied by more gravely and acutely ill residents than ever before. Nursing homes, in turn, are beginning to have their own financial incentives to give priority to skilled nursing rather than "custodial care," in a quest to obtain the highest levels of state Medicaid reimbursement. Unless new kinds of step-down residential care facilities are created, families in the future may not be able to turn to institutional care as a safety-valve option when the pressures of chronic care mount.

At the same time, countervailing trends signal a decreasing reliance on family members in the provision of chronic care. In recent years more generous federal and state reimbursement for the cost of paid home care has stimulated the growth of the home health care industry, which has a sizable for-profit sector. This represents a major step toward the commercialization of services that family members—especially women—have traditionally performed on an altruistic basis.

In addition, the private insurance industry is beginning to develop individual and group policies covering the costs of paid home care and long term institutional care. In the wake of the recent extension of Medicare coverage for long hospital stays, some support is also growing for a federally financed long term care entitlement program. Many questions about the adequacy and scope of these initiatives remain to be answered, but it does appear that insurance coverage for chronic illness and long term care is an idea whose time has finally come in the United States. Assuming that this coverage is truly comprehensive and widely available, it will make persons with chronic illness less dependent on their families.

Finally, in the largely individualistic ethos of our society the self-denying and self-sacrificing caregiver does not receive much validation or moral support. Self-denial is viewed as a destructive characteristic—a pathological trap that family caregivers for the chronically ill often fall into—rather than as a praiseworthy virtue.

These trends and attitudes reveal a considerable uncertainty about the proper role of the family in chronic care. Traditional values persist and family members often have no choice other than to assume these responsibilities; but at the same time families are increasingly demanding new options, which the government and the marketplace are slowly beginning to provide.

We believe there is a clear and compelling need to provide more professional and community support to families caring for chronically ill members. These supports include publicly financed home care services with appropriate quality assurance and licensure mechanisms, respite care programs, so-called adult day care programs, counseling services, educational programs and support groups, and the like. No family can be expected to shoulder the entire responsibility of chronic care alone, and the considerable inequities that now exist in access to supporting care services should be eliminated as these services are developed and extended in the future.

The question, as we see it, is not whether public and community services should be provided to



supplement family care, but what goals these family assistance programs should serve and what moral aspects of family relationships we want to preserve and strengthen as we publicly assist families with their caregiving responsibilities. For the danger is that assistance with responsibilities may subtly be transformed into denial of responsibilities.

This danger can be avoided by creatively integrating family caregivers into coordinated networks of health care and social services, so that they won't feel either that they have abandoned chronically ill relatives, or that they must face the seemingly unending task of care alone. Such coordination represents a mixed public and private system that would both protect families from being overwhelmed and preserve the high moral expectations we have traditionally affirmed about the special obligations family membership confers. Such a system might better serve the needs of persons with chronic illness as well, because it is not clear that paid professional care can be a full substitute for family care that grows out of love and a special sense of moral commitment.

### **Justice and Community**

---

The growing prevalence of chronic illness will necessarily lead to an extension of long term care and social service programs. Both acute and chronic illness in an aging society will lay claim to a substantial portion of our national resources, probably more than the eleven percent of GNP now devoted to health care expenditures. It is equally clear, however, that this expansion cannot be unlimited. Health care and social services will always have to be balanced with other pressing social needs like education, environmental protection, capital investment to improve industrial competitiveness, national defense, housing, and transportation. This, in turn, will create the need to set priorities within the health care sector, as is done now, but perhaps more explicitly on the basis of clear principles of justice and equity.

Setting limits and priorities in health care takes two forms. First, priorities are established among persons or classes of persons by granting them differential access to health care. Second, priorities are set by the allocation of resources—funds for research and capital expenditures, manpower, third party reimbursements—among various kinds of health care services. The first influences who will receive care; the second affects the kind of care those who gain access to the system are most likely to find available.

Throughout this essay we have emphasized the differences between acute and chronic care. When

the issue of access to health care is raised, however, we believe there is no principled basis for differentiating between those who are acutely ill and those with chronic conditions. Various accounts may be given of what justice requires as a basis for distributing access to health care. Some theories claim that the provision of just and equitable access is a human right. Others maintain that it is a societal obligation growing out of the needs and special vulnerability of those who are sick. Still others hold that equitable access is required by a sense of communal solidarity and mutual respect. None of these theoretical accounts of justice provides any reason to believe that the rights, needs, or dignity of the chronically ill have less moral weight than those of the acutely ill. Of course, justice does not require that individuals should receive any and all health care they might conceivably want. Equitable access does not mean unlimited access, either for acute or chronic care. But when policies are made that have the effect of rationing health care, they should not discriminate against persons with chronic illness.

If principles of justice call for equity of access without regard to the chronicity of the health care need, however, they do not directly answer the question of what equitable access should be access to. Here the problems posed by acute care and chronic care do begin to diverge. In the first place, the scope as well as the duration of chronic care is broader than acute care. It involves not only medical treatment and professional medical and nursing services, but also a wide range of social, educational, counseling, and rehabilitative services. Proper coordination among these various components of chronic care—as well as attention to related issues such as housing, transportation, and employment opportunities—is as important as access to these services per se. Even when adequate services are in place and are open to chronically ill persons who would benefit from them, these services are often scattered, hard to identify, and inconvenient to use.

Moreover, the pattern of internal priorities within the health care system as a whole affects the type of care and services made available to chronic patients. In the United States today those priorities are decidedly skewed in favor of acute care interventions and technologically complex modes of diagnosis and treatment. The massive investments we have made and are making in these areas of medicine have certainly created a system well designed to respond to the acute episodes and life-threatening crises that punctuate the course of some chronic illnesses, and one with a powerful capacity to extend the length of life.

However, our system does not give adequate attention to the distinctive goals of chronic care that

we have identified in this essay. Existing policies of health care financing, and priorities in medical education and research give short shrift to the quality of life goals of chronic care—negotiating with and through an illness, and sustaining integrity and intactness in the face of unavoidably disruptive symptoms and limitations. In order to meet the ethical challenges chronic illness poses to our health care system, it is not sufficient simply to seek prevention and cures for chronic diseases, nor to extend the duration of life lived with chronic illness via impressive acute interventions—as vital as these objectives are. Chronic care medicine must also create within itself a holistic, supportive environment where persons with chronic illness can construct their own lives in a meaningful way. Beyond this, chronic care medicine must be part of a broader effort to create that type of environment in society as a whole.

Achieving equitable access to health care, setting reasonable limits to an otherwise insatiable and quixotic quest for perfect health, and reorienting our priorities in accordance with a revised understanding of the ends of medicine—these are among the principal challenges of social justice in an aging society marked by widespread chronic illness. And they touch not justice only, but also our vision of public purpose and our sense of community.

Chronic illness is a reminder of the universal frailty and uncertainty of the human condition. The presence of chronic illness in our midst is a moral challenge not simply because it threatens the interests or, as one philosopher has put it, the “normal opportunity range” of those who are chronically ill at any given time, but rather because it forces us to confront the question of how a good society should accommodate the expectable—but always unexpected—misfortunes that occur in everyone’s life. The provision of care and social support for persons with chronic illness by temporarily well and able-bodied citizens reflects an acknowledgement of the links that join the sick and the well, the young and the old in a community of common humanness and vulnerability.

As we move toward new public policies in response to chronic illness, rights-based conceptions of social justice and individualistic conceptions of interests and autonomy should be tempered by a communitarian perspective such as this.

Past experience with other health and social welfare policies in the United States indicates how difficult it will be to achieve this moral perspective. All too often when claims of special need have been publicly recognized and addressed, the ensuing programs have served to stigmatize the recipients of public assistance, to increase their dependency

on professional service providers and bureaucratic institutions, or to identify them in the public mind as “special interests” that overburden government finances.

Perpetually at risk of having benefits reduced or of paternalistic interference by professionals who determine eligibility or control access to services, recipients (or advocacy groups representing them) have responded by reasserting their rights. This is an understandable and perhaps unavoidable response in American political culture. But it nonetheless has the unhappy effect of pitting those with special needs against the broader society. It also perpetuates a situation in which different groups seeking special assistance must each make their claims seem more compelling than others in order to compete for limited public resources.

It would be naive to expect that the development of new and expanded programs of chronic care will not be accompanied by the usual civic discourse of individual rights and the normal pluralistic politics of interest group competition. However, a thoughtful appreciation of the meaning of chronic illness as a human experience may at least serve to supplement, if not replace, this individualistic perspective of competing, mutually exclusive rights and interests.

Setting priorities and making trade-offs among conflicting claims are vital aspects of public policy, to be sure. Analyzing problems in this way is not objectionable in and of itself. The danger arises when this is all we think about and talk about, for then civic discourse tends to lose sight of equally important communal goals of public policy—the cultivation of solidarity, reciprocity, and mutual aid; the identification of public goods; the nurturing of common endeavor. Chronic illness doggedly insists that we attend to these goals.

### Selected References

#### Books

Daniel Callahan, *Setting Limits: Medical Goals in an Aging Society* (New York: Simon and Schuster, 1987).

Arthur L. Caplan, et al., eds. *Concepts of Health and Disease* (Reading, MA: Addison-Wesley, 1981).

Larry M. Churchill, *Rationing Health Care in America* (Notre Dame, IN: University of Notre Dame Press, 1987).

Norman Daniels, *Just Health Care* (New York: Cambridge University Press, 1985).

Myron G. Eisenberg, LaFaye C. Sutkin, and Mary A. Jansen, eds., *Chronic Illness and Disability Through the Life-Span* (New York: Springer Publishing Co., 1984).

Ray Fitzpatrick, John Hinton, Stanton Newman, Graham Scambler, and James Thompson, *The Experience of Illness* (New York: Tavistock, 1984).

Nicholas Hobbs and James M. Perrin, eds., *Issues in the Care of Children with Chronic Illness* (San Francisco: Jossey-Bass, 1985).

Nicholas Hobbs, James M. Perrin, and Henry T. Ireys,

*Chronically Ill Children and Their Families* (San Francisco: Jossey-Bass, 1985).

Toba Schwaber Kerson, *Understanding Chronic Illness* (New York: The Free Press, 1985).

David Locker, *Disability and Disadvantage: The Consequences of Chronic Illness* (New York: Tavistock, 1984).

Cheri Register, *Living with Chronic Illness: Days of Patience and Passion* (New York: The Free Press, 1987).

Julius A. Roth and Peter Conrad, eds., *Research in the Sociology of Health Care*, vol. 6, The Experience and Management of Chronic Illness, (Greenwich, CT: JAI Press, 1987).

Joseph W. Schneider and Peter Conrad, *Having Epilepsy: The Experience and Control of Illness* (Philadelphia: Temple University Press, 1983).

Anselm L. Strauss, et al., *Chronic Illness and the Quality of Life*, 2nd ed. (St. Louis: C.V. Mosby Company, 1984).

U.S. Congress, Office of Technology Assessment, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*, OTA-BA-323 (Washington, DC: Government Printing Office, 1987).

\_\_\_\_\_, *Technology and Aging in America*, OTA-BA-264 (Washington, DC: Government Printing Office, 1985).

U.S. Department of Health and Human Services, Task Force on Long-Term Care Health Policies, *Report to Congress and the Secretary* (Washington, DC: Government Printing Office, 1987).

S.H. Zarit, N.K. Orr, and J.M. Zarit, *Hidden Victims of Alzheimer's Disease: Families under Stress* (New York: Pantheon Books, 1982).

Irving Kenneth Zola, *Missing Pieces: A Chronicle of Living with a Disability* (Philadelphia: Temple University Press, 1982).

#### Articles

Jerome L. Avorn, "Medicine, Health, and the Geriatric Transformation," *Daedalus* 115:1 (Winter 1986), 211-26.

Kathy Charmaz, "Loss of Self: A Fundamental Form of Suffering in the Chronically Ill," *Sociology of Health and Illness* 5 (1983), 168-95.

\_\_\_\_\_, "The Social Construction of Self-Pity in the Chronically Ill," in Norman Denzin, ed., *Studies in Symbolic Interaction*, vol. 3 (Greenwich, CT: JAI Press, 1980), 123-44.

\_\_\_\_\_, "Struggle for a Self: Identity Levels of the Chronically Ill," in Julius A. Roth and Peter Conrad, eds., *Research in the Sociology of Health Care*, vol. 6 (Greenwich, CT: JAI Press, 1987), 283-321.

Peter Conrad, "The Noncompliant Patient in Search of Autonomy," *Hastings Center Report* 17:4 (August/September 1987), 15-17.

Juliet Corbin and Anselm L. Strauss, "Accompaniments of Chronic Illness: Changes in Body, Self, Biography, and Biographical Time," in *Research in the Sociology of Health Care*, vol. 6, 249-82.

\_\_\_\_\_, "Managing Chronic Illness at Home," *Qualitative Sociology* 8 (1985), 224-47.

Karen Davis, "Aging and the Health-Care System: Economic and Structural Issues," *Daedalus* 115:1 (Winter 1986), 227-46.

James Fries, "The Compression of Morbidity," *Milbank Memorial Fund Quarterly/Health and Society* 61:3 (Summer 1983), 397-419.

Muriel R. Gillick, "Is the Care of the Chronically Ill a Medical Prerogative?" *New England Journal of Medicine* 310:3 (January 19, 1984), 190-93.

E. Schneider and J. Brody, "Aging, Natural Death, and the Compression of Morbidity: Another View," *New England Journal of Medicine* 309:14 (October, 1983), 854-56.

Lois M. Verbrugge, "Longer Life But Worsening Health? Trends in Health and Mortality of Middle Aged and Older Persons," *Milbank Memorial Fund Quarterly/Health and Society* 62:3 (Summer 1984), 475-517.

THE  
HASTINGS  
CENTER

255 Elm Road  
Briarcliff Manor, NY 10510

The Hastings Center, founded in 1969, is a nonprofit and nonpartisan research and educational organization devoted to ethical problems in biology, medicine, and social and behavioral sciences, and the professions.

The Center carries out an active research program on timely and crucial subjects. Working in a variety of fields—law, medicine, science, philosophy, religion, among others—its research work strives to provide non-partisan information, analysis, and recommendations. A resident staff, elected Fellows, and invited consultants form the nucleus of each research group.

The Center is presently engaged in ethical problems of aging, AIDS, care of the dying and termination of treatment, genetic screening, ethics committees, cost containment, artificial reproduction, and the study of professional ethics.

The *Hastings Center Report* is sent bimonthly to Associate Members of the Hastings Center. Membership is open to professionals and interested laypersons; annual dues are \$42 for individuals, \$35 for full-time students (applicable for two years only), and \$55 for institutions and libraries.

Additional copies of this Special Supplement are available from the Publications Department, The Hastings Center, 255 Elm Road Briarcliff Manor, NY 10510. Prices are \$4.00 each for 1-9 copies; \$3.00 each for 10-29 copies; and \$2.50 each for 30-100 copies. For prices on orders over 100 copies, contact the Publications Department.