

RECONSTRUCTING ILLNESS

Studies in
Pathography

SECOND EDITION

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To my father and mother
Robert Lee Mitchell and Mae Brooks Mitchell

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assistance. I am fortunate in my editor, Margaret Hunt. With her enthusiasm, sense of humor, and background as a scholar, she has made the long process of turning a manuscript into a book almost a pleasure. Most of all I want to thank my husband, Sherman Hawkins, whose encouragement, patience, and love have sustained me through the years it took to complete this project and whose extraordinary insight has enabled me, like Diomedes in that other *aristeia*, to discern the gods from the mortals.

Lastly, I want to express my gratitude to all the authors whose pathographies I comment on in this book. I realize that I have taken what for them is a very personal story and analyzed it, sometimes critically. I ask their forgiveness if I have misinterpreted any portion of their work or distorted their meaning. I also ask them to understand that my aim in writing this book, like the stated aim of so many of these authors in their pathographies, is to help us all understand better what it means to have a chronic or life-threatening illness in America today.

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A version of my discussion of the myth of rebirth and pathographies describing heart disease in chapter 2 appeared in "A Change in Heart: The Paradigm of Regeneration in Medical and Religious Narrative," *Perspectives in Biology and Medicine* 33, no. 4 (Summer 1990), 547–59. © 1990 by the University of Chicago.

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The Society for Health and Human Values has provided a forum for my work more than once in addresses and speeches.



Introduction

Robinson Crusoe—that is what I think of. Surviving a terrible storm at sea; then being shipwrecked; waking from catastrophe and finding oneself alone in a new, alien, and dangerous world" (Pond, 4–5). This was written not by the survivor of a shipwreck but by a woman who suffered a brain tumor and the operation that removed it. Her book, entitled *Surviving*, is an example of what I call *pathography*,¹ a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death. "What it is like to have cancer" or "how I survived my heart attack" or "what it means to have AIDS"—these are the typical subjects of pathography. Such books are remarkably popular today: Gilda Radner's pathography about her cancer experience stayed on the *New York Times Book Review* best-seller list for months; Martha Weinman Lear's description of her physician-husband's long illness and eventual death from heart disease was available at supermarket checkout lanes; Norman Cousins's *Anatomy of an Illness*, an account of his recovery from a rare collagen disease using unorthodox therapeutic measures, is a book often found on a hospital patient's bedside table. And these are only a few examples of the many pathographies now in print.

In some sense, the pathography is our modern adventure story. Life becomes filled with risk and danger as the ill person is transported out of the familiar everyday world into the realm of a body that no longer functions and an institution as bizarre as only a hospital can be; life in all its myriad dimensions is reduced to a series of battles against death; and there is the inescapable sense, both for the sick person and his or her family, of being suddenly plunged into "essential" experience—the deeper realities of life. Given this presence of the dramatic and the terrifying, it is not so

surprising that these “adventurers” are moved to write about their experiences. As Anatole Broyard observes, “Like anyone who has had an extraordinary experience, I wanted to describe it. . . . My initial experience of illness was as a series of disconnected shocks, and my first instinct was to try to bring it under control by turning it into a narrative” (21,19).

In their concern with illness, pathographies are like survival stories about natural or environmental disasters: the battle simply to stay alive despite exposure to shark-infested waters, or freezing temperatures, or marauding cancer cells, or antibodies that turn against the body that has produced them—these are all variations on a long-standing heroic paradigm of the struggle of brave individuals confronting what appear to be insurmountable forces. Since they also concern therapy, which is a cultural and not a natural activity, and hospitals, which are not jungles or oceans but societal institutions, pathographies can resemble accounts of political or racial oppression: one author remarks that her mother, hospitalized for cancer treatment, reminds her “of hostages and concentration camp prisoners who at first resist their captors and then try to appease them by good behavior” (Schreiber, 262).

Pathography offers us cautionary parables of what it would be like if our ordinary life-in-the-world suddenly collapsed. And indeed most of us, at some time or another, have recognized that the apparent orderliness and coherence of our lives is something of an accident, or a gift, or a miracle that renews itself day after day. Yet most of us behave as though this miracle were quite natural—a constant around which we can organize our lives. Thus we plan for the next day, and we go to sleep at night in confidence that the world (and we ourselves) will be the same the following morning. Pathographical narratives offer us a disquieting glimpse of what it is like to live in the absence of order and coherence. They show us the drastic interruption of a life of meaning and purpose by an illness that often seems arbitrary, cruel, and senseless; and by treatment procedures that too often can appear as likewise arbitrary, cruel, and senseless—especially to the person undergoing them. As one author of a pathography observes, “I exist in the world as most people see it, but I live in the world of the person with terminal cancer” (Shapiro, 130). Pathographies concern the attempts of individuals to orient themselves in the world of sickness—the world Susan Sontag calls “the kingdom of the sick” (1979, 3)—to achieve a new balance between self and reality, to arrive at an objective relationship both to experience and to the experiencing self. The task of the author of a path-

ography is not only to describe this disordering process but also to restore to reality its lost coherence and to discover, or create, a meaning that can bind it together again.

This need to bind things together again makes pathographical literature a rich source for the literary critic. My purpose here is to analyze pathography as illustrative of cultural myths, attitudes, and assumptions about various aspects of the illness experience in America today—the disease itself, therapy, recovery or death, medical personnel, and medical institutions.² In exploring these myths, I have for the most part limited my study to narratives that describe bodily (not psychiatric) illness, narratives that concern sickness (not disability or handicaps), and narratives that are written by or about an adult (not about children).³ Another category of ill persons not represented in my book is the economically and socially disadvantaged—the poor and the homeless—a group that, to date, is minimally represented in pathographical literature. Each of the groups excluded could itself provide a subject worthy of a book-length study.

I will be treating pathography as a subgenre of autobiography, especially in the way I use literary theory, and will include as autobiography collaborative works as well as pathographies utilizing a journal format. Though some pathographies are technically biographies—narrative accounts of the death of a loved one—they are as much autobiographical accounts of the author’s experience as witness as they are biographical accounts of another’s illness and death. Unlike the case history or the conventional biography, with their supposedly disinterested perspective, biographical pathographies are almost always written by someone with a close relation to the ill person who is the book’s subject, and thus they override the conventional boundaries of self and other or biographer and subject. Pathographies about an illness that has culminated in death form a part of the process of grieving; into the narrative of illness and death is interwoven the witnessing author’s feelings, thoughts, and organizing images and metaphors, as he or she goes about the work of mourning.

An Overview of Pathography

As a genre, pathography is remarkable in that it seems to have emerged *ex nihilo*; book-length personal accounts of illness are uncommon before 1950 and rarely found before 1900. To do justice to the range and variety of these books is difficult. One way to organize them is in terms of disease categories—indeed, this is the way preferred by the Library of Congress.

Such an approach is useful in showing us which particular diseases are popular subjects for pathography. An informal EPIC computer search for titles from 1988 to 1992 reveals three entries under stroke, nine under heart disease, thirteen for multiple sclerosis, thirty-one for AIDS, and one hundred two for cancer (twenty-four of which refer to breast cancer). My concern here, however, is not with nomothetic generalizations about disease entities but with the way an individual deals with his or her illness—the myths, attitudes, and beliefs of our culture that a sick person uses to come to terms with illness. Though there are certain patterns specific to individual diseases—patterns that are discussed in the following chapters—it seems more appropriate that an overview of pathography should emphasize persons rather than their illnesses. Therefore, I will try to suggest some sense of the genre as a whole by flagging the author's explicit or implicit intent in writing the pathography.

If we use authorial intent as an organizing principle, pathographies tend to fall into three groups: testimonial pathographies; angry pathographies, and pathographies advocating alternative modes of treatment. Those in the first category, written for the most part in the late 1960s and the 1970s, are like religious "testimonies," public professions of faith that are meant to bear witness to the truth and strengthen other believers by relating an experience of spiritual trial or conversion. The intent of these pathographical testimonies seems to be simply to tell the story of an illness experience, focusing primarily on the author's thoughts, feelings, and behaviors as complementary to medical treatment that is generally accepted as appropriate and helpful. These books almost always project a positive attitude toward medicine. Since they are often written with the expressed purpose of helping others, pathographies in this first group can be seen as motivated by didactic or altruistic principles.

Pathographies written with an overtly didactic intent blend a personal account of illness with practical information. Descriptions of experience with breast cancer almost always fall into this category: these are books that have enabled women to be aware of therapeutic alternatives and to deal with postoperative trauma. An example is Marilyn Snyder's *An Informed Decision*, a book explicitly written for women with breast cancer who might be helped by surgical reconstruction. Joyce Slayton Mitchell's *Winning the Chemo Battle* is addressed to people undergoing chemotherapy, its stated goal being to help readers "plan and work toward your own quality of life" (10). Yet this same pathography also emphasizes the

distinctiveness of its personal narrative: "If you have had chemotherapy, you will recognize the 'truth' in this book, even though your own may be different" (9). Other didactic pathographies are concerned with negotiating changes in life-style. Thus Bea Keiser's *All Our Hearts Are Trump* concerns the adjustments her family has had to make when her husband suffers a heart attack. The book is a kind of manual for families of heart-attack victims, giving advice on everything from reassessing values to changes in eating habits. Another example of didactic pathography is Herbert Conley's *Living and Dying Gracefully*. The book, "written for all those who are presently walking a similar path" (x), is just what its title suggests, a sort of manual that blends the author's own experience in confronting pain and death with what he has learned in his role as minister to sick and dying parishioners.

Pathographies of this kind are often written with the expectation that the author's experience might serve as a mirror, or a model, for the prospective reader. Thus authors with heart disease will direct their narratives to potential readers with heart disease; women writing about breast cancer will write for other women with the same problem. To some extent this assumption of the "generalizability" of illness is a part of our modern nomothetic mythology about disease, which assumes a uniformity of experience within a diagnostic category.

At the end of the 1970s, pathographies begin to change dramatically in tone and intent. Trust in physicians and tolerance of hospital routines are no longer the norm but now the exception; in fact, they are replaced by a striking lack of confidence in physicians and an overt fear of hospitalization. Pathographies written in the 1980s signal an important cultural shift away from several of midcentury America's favorite cultural myths: that of the medical encounter as comforting and reassuring—a myth perfectly epitomized in the popular Norman Rockwell image of a portly, benign, and paternal physician ministering to a snub-nosed child—and that of medical science as invincible in its march to eradicate disease, a myth celebrated in the *Reader's Digest's* "Miracles of Modern Medicine."

Recent pathographies demonstrate our cultural discontent with traditional medicine in two different ways: by the expression of anger at callous or needlessly depersonalizing medical treatment and by a concern with alternative medical therapies. Both suggest a revolt against the benign medical mythology communicated on the covers of the *Saturday Evening Post* or in the pages of the *Reader's Digest*. Moreover, both reflect and help

create a new cultural attitude, one which recognizes that the onset of serious illness brings with it not only problems occasioned by the illness itself but also problems caused by therapies, by the medical institution where treatment takes place, and by the physicians who oversee that treatment. As one author observes during a lengthy hospitalization, "I was no longer afraid of the disease, but of the system" (Baier, 100).

Angry pathographies are intended to expose and denounce atrocities in the way illness is treated in America today. These books testify to a medical system seen as out of control, dehumanized, and sometimes brutalizing; and they are written from a sense of outrage over particular and concrete instances of what is perceived to be the failure of medicine to care adequately for the ill. So one author, in a section that begins, "I hate Mom's doctors," expresses with great bitterness her frustration at the way her mother's physicians fail to deal with pain. Doctors, she observes, "are specialists trained to intervene at moments of crisis, to cut, to radiate, to alter chemistry, then move on to the next patient. But why is there no place in this elaborate medical system for sustained care of the human being who continues to feel the effects of the doctors' knives and beams and chemicals?" (Schreiber, 138). Another author, hospitalized for cancer treatment, observes: "I find myself apologizing for being a person rather than a case, for having feelings and wanting—needing—to understand what they are doing to me . . . what is happening to me" (Cook, 209). Yet another author writes: "The first urologist . . . I saw treated me as if I were a specimen. Instead of speaking to me after he examined my testicle, he called over a resident, pointed out a 'calcification' . . . and began talking to him about 'surgery'" (Fiore, 3).

In a sense, these are "case histories" of the way Western scientific medicine is practiced today, especially in the United States. Two factors emerge again and again in these "cases": the tendency in contemporary medical practice to focus primarily not on the needs of the individual who is sick but on the nomothetic condition that we call disease, and the sense that our medical technology has advanced beyond our capacity to use it wisely. These books show how an ill person today can be both the beneficiary and the victim of a health-care system whose very excellence—its superb technological achievements—is at the same time potentially dehumanizing.

The angry pathographies seem to begin in 1980 with Martha Weinman Lear's very popular *Heartsounds*, a book that painfully and bitterly catalogues everything that went wrong during her physician-husband's many

hospitalizations for heart disease and every way in which his doctors failed him. The book begins with irony, as she describes *Doctor Lear's* confident diagnosis of a pain in his chest as heartburn and not heart attack (it is a misdiagnosis). The author goes on to describe an infection that results from an intern's refusal to attend to a minor inflammation from a needle, a coronary angiography where anesthesia is given after the procedure is completed, and another occasion when severe irritation of the stomach lining results from huge doses of potassium given without liquids; it describes a doctor who gives wrong medical advice and then blames the patient for his own mistakes, and other doctors who wish their patient dead when they have done all that they can and he does not recover. The book ends as it began with a medical failure—the failure of the autopsy report to provide the "answers," the medical explanations that Ms. Lear so desperately feels she needs. Overall, the book leaves us with the sense of a man and his wife victimized by a medical system consistently portrayed as incompetent and uncaring.

A more recent pathography of this kind is Sue Baier's *Bed Number Ten*, an angry description of callous and indifferent treatment by medical personnel during her long stay in an intensive care unit. The book is prefaced by a brief but bitter statement, allotted an entire page: "The names of the hospital and all medical personnel have been changed to protect those who were less than kind." Her anger is directed not at the medical management of the course of her disease, which seems to have been exemplary, but at the impersonal, dehumanizing way in which she is treated. Afflicted with Guillain-Barré syndrome, Baier is totally paralyzed but also totally conscious. Thus she is in a terribly vulnerable position: she retains normal sensitivity to pain, but since she cannot move or talk, lacks any way to signal when she feels it. The actual incidents of mistreatment she records seem relatively minor, taken separately. They include such unnecessarily painful nursing procedures as flushing out her ears with cold water and cleaning her mouth with undiluted peroxide, and the way her physicians repeatedly ignore the fact that she is conscious and sentient. These minor mistreatments, she believes, together add up to a style of medical care that seems to disregard the reality of bodily pain and consistently ignores the subjective dimension of illness. Baier asks, "Was I paranoid to want to be treated as human? To be asked how I felt? Did you sleep well, Sue? Are you comfortable? . . . There were so many little things, constantly, one after the other—indignities that led to my desperation" (194).

Another kind of experience that can result in an angry pathography begins with the cancer patient's search for the "top" cancer specialist and the "best" research protocol. One such book is Jean Craig's *Hello and Goodbye*, the story of her fifty-nine-year-old husband's decision to "fire" the oncologist who offers him little hope for reversing a cancer of the colon metastasized to both lungs, and his subsequent determination to hunt down promising cancer treatments. After several interviews and examinations, Craig decides on a particular protocol and enrolls in a randomized cancer trial with a very new, very experimental regimen. All goes well, despite the terrible side effects of his treatment, until it becomes evident that his illness is not going to be reversed. At this point the Craigs respond with bitterness and increasing anger toward his doctors for their reluctance to share pertinent information, their sense of "entitlement," their indifference to their patient's comfort, their emotional remoteness, their focus on the disease and not the patient, and their "insultingly, offensively patronizing" answers to questions posed by patient and family (305). The anger in this pathography stems from the Craigs' sense of betrayal in their conviction—a conviction encouraged and possibly shared by the research oncologists whom they seek out—that an aggressive, militant approach to cancer will result in a cure. As one research oncologist whom they consult points out, the difference between medical research and medical practice is the difference between doctors who "attack" and doctors who "treat" (21). In a sense, the Craigs get what they thought they wanted.

Pathographies like these, however, while not infrequent, are really not characteristic of the genre, though they do seem to be the pathographies highlighted in the media. In fact, not many pathographies are dominated by a need to expose the outrages of modern medicine—"doctor-bashing," as this is sometimes described. Most pathographies do include criticisms of doctors or therapies or hospital care, but they include praise as well. It is important to remember that the focus in most pathography is really not on the medical enterprise, whether this is judged to be good or bad, but on patient experience. And patient experience includes a good many dimensions beyond conventional medical treatment: the subjective aspects of illness; its effect on family, friends, and work; alternative therapies and the individuals associated with them; and exposure through the media to lay and pseudoscientific understandings of illness and treatment. Increasingly, the medical establishment is only one part of an illness experience.

The third group of pathographies begins with Norman Cousins's popular *Anatomy of an Illness*, published as a book in 1979 (and before that as an article in the *New England Journal of Medicine* in 1976). Like their angry counterparts, these pathographies seem to stem from a sense of dissatisfaction with the way medicine is practiced today. They differ, though, in that their authors are concerned not so much with criticizing traditional medicine as with finding alternative treatment modalities—modalities that sometimes supplement traditional therapies and sometimes replace them altogether. These books reveal a patient population empowered by a belief in the nearly limitless capacities of the mind and the emotions to facilitate healing, and eager to find some objective correlative in holistic therapies to the inner resources of psyche and spirit.

The authors of these pathographies assume that therapeutic success derives in part (some would say primarily) from the patient's attitude—the "will to live" that has by now become a battle cry for many ill people. Moreover many, like Cousins, assume that the will to live is actually based in physiology, a notion that challenges the Cartesian dualism of mind and body that has been a cornerstone of modern scientific medicine. Growing support for this position—that mind and body are interrelated and that healing always involves an interplay between mental and physical—can be found in the new science of psychoneuroimmunology and in the many forms of alternative medicine now available.

Unlike the angry pathographies, with their predilection for "doctor-bashing," pathographies concerned with alternative therapies commonly project a positive attitude toward the author's physicians. Even so, this positive attitude goes hand in hand with a sense of the diminished importance of the physician and of orthodox medicine in general. Indeed, orthodox medicine is accorded the role in the world of illness that medicine itself tends to claim as its rightful province—attention to biochemical aspects of bodily structure and function. And the biochemical is felt by these patients to be only one aspect of treating illness and maintaining health. Mental attitude, nutrition, exercise, response to stress, even personal and societal goals and values—these are judged at least as important as the narrow biochemical focus of orthodox medicine. Pathographies written in the 1980s fairly bristle with holistic and alternative therapies—therapies ranging from such relatively conventional practices as attention to diet and exercise, acupuncture, and visualization exercises to more unusual treatments: the use of quartz crystals, lucid dreams, and various naturopathic remedies.

Underlying the differing purposes of all three kinds of pathographies is a common motive—the need to communicate a painful, disorienting, and isolating experience. Indeed, the need to come to terms with a traumatic experience often involves the need to project it outwards—to talk or write about it. As Max Lerner observes of his own motive for writing a pathography: “I passed through a searing experience that tested and changed me in ways I never foresaw. And like the Ancient Mariner I want to tell my story, to whatever listeners it finds” (20). Though few patients do go on to write book-length narratives about their experience, the urge to tell others seems to be a common response to medical trauma. The intensity with which a casual acquaintance will describe his or her illness, especially when it involves hospitalization, is familiar to all of us. Pathography, then, can be seen as a literary expression of this need.

Furthermore, if there is a strong need to tell about one’s own illness, there would also appear to be a strong urge to read about the illness of others. The proof of this is the remarkable popularity of pathographies. For the thousands who read them, pathographies serve as models suggesting attitude and behavior during illness. Lucy Shaper’s *Never Say Die* provides a convincing example: it is a book directly inspired by another book, Cousins’s *Anatomy of an Illness*. Other authors, too, will at times mention the impact of a pathography they have read. Le Anne Schreiber quotes Sontag’s metaphor of illness as a “more onerous citizenship” (in *Illness as Metaphor*), using it to discuss the way she feels set apart by her immersion in her mother’s sickness (70). David A. Tate in his pathography describes the way he uses Cousins’s *The Healing Heart* in preparing for a postcoronary treadmill test; Lenor Madruga cites Betty Rollin’s pathography about breast cancer; Beata Bishop is encouraged by Jaquie Davison’s *Cancer Winner: How I Purged Myself of Melanoma* to begin her own detoxification diet.

Not all pathographies so used may be helpful, however. The pathography cited in *Heartsounds* is ominously appropriate to what happens to Harold Lear: after his heart attack and after heart surgery that results in brain damage, Lear reads a magazine article entitled “The Unnecessary Death of My Wife”—a story about a woman who undergoes open-heart surgery and dies from a series of postoperative mistakes (196). A different though also negative response to reading pathographies is discussed in Barbara Webster’s *All of a Piece*. Webster, when she finds out she has multiple sclerosis, reads the pathographies about her disease but finds them

unhelpful—limited by a too-narrow focus on the physical adjustments required, as well as unrealistically optimistic and hopeful in outlook.

For readers who are themselves ill, pathography articulates the hopes, fears, and anxieties so common to sickness, organizing them into a coherent whole and suggesting by example ways of thinking and acting. Didactic pathographies are read as guidebooks on how to find a good doctor or how to buy a prosthesis or how to adapt one’s life-style to a heart attack; angry pathographies legitimize patients’ demands for more humane medical care; pathographies describing alternative medical treatments alert ill persons to the fact that there are other ways of treating sickness and encourage their use. And for readers who are not themselves sick, pathography serves a preparatory function, so that when they do encounter some life-threatening illness (and most of us eventually will), this experience will inevitably be informed by what they have read.

In its capacity to serve as a model for others, pathography plays an important role in the way it both reflects and helps shape our current mythology about illness. As I hope to show, pathography embodies dynamic constructs about how to deal with disease and treatment: its images and metaphors and myths are not just decorative and fanciful but highly influential models of how to negotiate an illness experience.

Pathography as the Patient’s Voice

It is striking that autobiographical descriptions of illness should belong almost exclusively to the second part of the twentieth century. Though in previous eras diaries and journals can be found in abundance, few of these take the author’s experience of illness as their only subject. Why should this be so? One explanation is that in earlier times illness seems to have been considered an integral and inseparable part of living (and dying)—illness thus takes its place in journals and autobiographies along with other facets of a life. It is only in the twentieth century that serious illness has become a phenomenon that can be isolated from an individual’s life—perhaps because such illness is set apart from normal life by hospitalization or perhaps because we now tend to consider health as the norm and illness as a condition to be corrected, never simply accepted.

Yet another way to look at the popularity of pathography today is to see it as a reaction to our contemporary medical model, one so dominated by a biophysical understanding of illness that its experiential aspects are virtually ignored. Medicine today has been criticized for its narrow focus on

disease and its disregard for the experiencing patient. One result of so divorcing spirit or personality from body is that the experiential side of illness is relegated to the category of the epiphenomenal. The patient, observes Richard Baron, is in a sense "subtracted out" of the medical paradigm: "One obtains the idea of a pure disease which is, ideally, distinct from any particular patient. The disease manifests itself through the patient, and the patient comes to function as a kind of translucent screen on which the disease is projected" (7-8). Pathography restores the person ignored or canceled out in the medical enterprise, and it places that person at the very center. Moreover, it gives that ill person a voice.

Pathography, then, returns the voice of the patient to the world of medicine, a world where that voice is too rarely heard, and it does so in such a way as to assert the phenomenological, the subjective, and the experiential side of illness. What the voice of the patient tells us can be shocking, enlightening, or surprising. Is it possible that a highly respected hospital can be so deficient in patient care that needless suffering is caused by the indifference or incompetence of medical personnel? According to *Heartsounds*, this is what happened to Harold Lear. Is it possible to disregard conventional medical advice and recover from a severe illness by generous doses of laughter and vitamin C? In *Anatomy of an Illness*, Norman Cousins assures us that he did. Is it possible that a man with advanced, metastatic prostate cancer should enter remission by following a rigid macrobiotic diet? Physician-author Anthony Sattilaro in *Recalled by Life* reports that this is what happened to him.

In a sense, the pathography written by the patient or a loved one can be seen as the logical counterpart to the medical history written by the physician or by the medical staff assigned to a particular patient.⁴ It would seem that they should be very similar, since both genres are concerned with the sickness and treatment of a specific individual. In fact, however, they are radically different in subject, purpose, structure, authorial persona, and tone.

The subject of the case report is a particular biomedical condition, the individual reduced to a body and the body reduced to its biophysical components ("the disease in the body in the bed"), while the true subject of pathography is illness and treatment as experienced and understood by the ill person who is its author. The purpose of the case report is to record diagnosis and treatment; the purpose of pathography is to draw out the meaning of the author's experience. The medical report is usually com-

posed of brief factual statements about present symptoms and body chemistry, whereas a pathography is an extended narrative situating the illness experience within the author's life and the meaning of that life. The ideal medical report disavows any authorship at all (the first person pronoun is almost never used); on the other hand, the authorship of a pathography is never in question. Moreover the ideal case report omits any reference to the emotions either of physician or of patient. As Baron observes, the physician is encouraged to ignore the intuitive insight, the obvious observation, the common-sense solution—all in the service of an ideal of scientific objectivity. Pathography, at the other extreme, tends to focus on the emotional components of a medical experience, sometimes with unavoidably theatrical results.

Pathographies do tend to dramatize the events of illness. The drama in pathography, however, is no worse a distortion of reality than is the biomedical myopia of the case report. Indeed, if pathography is compared to the case report, the patient's own account will appear not so much a grossly exaggerated rendition of what happened as a corrective to the stark, depersonalized account of tests and procedures written up by medical personnel. Case report and pathography function as mirrors set at an oblique angle to experience: each one distorts, each one tells the truth.

An analysis of pathographical narrative suggests that a medical model which aims at rendering the patient transparent so that the physician may focus more clearly on the disease may indeed be misguided. Physicians sometimes need to be reminded that "disease" cannot exist apart from a diseased person: as Kathryn Montgomery Hunter observes, medicine is first and foremost "a science of individuals" (1989, 193). Pathography is a narrative reminder of this all-too-easily-neglected truth. The need somehow to put the patient back into the medical enterprise—to return the experiencing, suffering human being from the periphery to the center of medicine—this is the burden of many recent studies.

Elliot Mishler, writing about the medical interview, remarks on the way "the voice of the life-world" (the psychological and sociocultural contexts of a patient's experience) is dominated by "the voice of medicine" (a technological, bioscientific frame of reference). Rita Charon describes the way she implements Mishler's critique in an unusual method of teaching interviewing skills to medical students: she has them write semifictional accounts of an interview *using the patient's own voice*, in an attempt to restore to the medical encounter that "voice of the life-world." In *The Illness*

Narratives, Arthur Kleinman asserts that good clinical care involves not only the recognition of the patient's "explanatory model" of his or her illness but the affirmation of that model and the ability to incorporate it into an effective therapeutic approach. In this explanatory model, which is usually tacit, Kleinman includes all aspects of the patient's understanding of illness: what it is, why it happened, and what is expected or hoped for in regard to treatment.⁵ Howard Brody, in *Stories of Sickness*, is similarly concerned with the need to restore patient experience to a position of primacy in the medical encounter, though he approaches the subject from the standpoint of a philosopher. Eric Cassell, in *The Nature of Suffering*, observes that "a shift is now taking place in medicine away from a primary concern with diseases and towards a focus on ill persons" (81). He urges that to complete this shift, "the concept of person" replace the Cartesian dualism basic to contemporary biomedicine. In all these books, there is a recognition of the need in medicine to perceive patients not in terms of laboratory tests and fever charts but in relation to their lives as persons. Pathography records the voice of the ill person: it is thus the exemplary illness narrative, the missing part of the patient history.

Autobiographical Theory and the "Truth" of Pathography

If it is true that pathography restores to the therapeutic paradigm the missing voice of the patient—the phenomenological, the experiential dimension of illness—then one may be tempted to assert that the patient narrative gives us the "true" or "real" story of what the experience was actually like. And we all share, to some extent, in the intuitive assumption that the person to whom the experience occurred is in the best position to describe it truthfully. Pathographies may indeed be read as "true stories," but the emphasis must be as much on the word "stories" as the word "true." For these books cannot be taken as accurate records of experience: they are too highly charged, as the ambivalence and prosaic quality of everyday living is resolved into sharp contrasts and clear-cut issues.

To emphasize the "story" element in these narratives is in no way to denigrate their truth-value. It is important, though, in analyzing pathography, to remember that the narrative description of illness is both less and more than the actual experience: less, in that remembering and writing are selective processes—certain facts are dropped because they are forgotten or because they do not fit the author's narrative design; and more, in that the act of committing experience to narrative form inevitably confers upon it

a particular sequence of events and endows it with a significance that was probably only latent in the original experience. Narrative form alters experience, giving it a definite shape, organizing events into a beginning, a middle, and an end, and adding drama—heightening feelings and seeing the individuals involved as characters in a therapeutic plot. Writing about an experience—any experience—inevitably changes it.

The assertion that there is a significant difference between the original "real" experience and the retrospective autobiographical narrative is now a commonplace among critics and theorists of autobiography. Most critics see this difference as caused by the author's creative imposition of order, pattern, and meaning on what is remembered of one's life. Thus in *Design and Truth in Autobiography*, Roy Pascal discusses autobiography not as a chronicle but as an interpretation of a life. Pascal emphasizes that the way the autobiographer shapes the past reflects the author's particular standpoint at the moment of writing. The past, then, is not simply recorded in the autobiographical act but given a structure, a coherence, a meaning. Thus the process of autobiographical recollection is part self-discovery and part self-creation.

Pascal's careful qualifications about the factual authenticity of autobiography seem to have ignited a fierce critical skepticism about the ontological status of the autobiographical self and its past. The once solid self of autobiography now dissolves into a shimmer of critical qualifiers: we have Richard Olney's *Metaphors of Self*, Michael Sprinker's "Fictions of the Self," John Morris's *Versions of the Self*, Patricia Meyer Spacks's *Imagining a Self*, John O. Lyons's *The Invention of the Self*. In the last decade or so, the similarity between the task of psychoanalytic reconstruction and that of autobiographical reconstruction has come to seem almost an identity. Borrowing from recent psychoanalytic insights, autobiographical critics question our assumption "that a person's life is recoverable, all 'there' ready to be unearthed and transplanted" or maintain that "the past does not exist. There are memories of it—scattered shards of events and feelings—but they are re-created within a later context" (Mandel 1972, 324; Pike, 337).

An even more extreme viewpoint doubts not just the existence of the past but also the existence of the self, seeing it as a fiction of language. The self, claims Robert Elbaz, belongs to "the dimension of imagination and not of memory, an entity that must be renewed ceaselessly" (144). As James Cox observes about recent critical theory: "Language is thus the signifier presumptively making the self it signifies increasingly so absent that it can

only be traced like a ghost between the long sequence of lines and text that make up a convention or a tradition" (3). So seen, the self is total invention—the only reality being the literary artifact: "the text takes on a life of its own, and the self that was not really in existence in the beginning is in the end merely a matter of text and has nothing whatever to do with an authorizing author" (Olney 1980, 22).

The question whether the self is a category prior to language or a construct of language is at present (and not surprisingly) still unresolved, but some critical approaches are able to move beyond this question without entirely dismissing it. One critical position that simply bypasses the issue of the fictional status of the self is the focus on what Elizabeth Bruss calls the "truth-value" of the autobiographical report and Philippe Lejeune, the "autobiographical pact." This pact is an explicit commitment of the author not to try to replicate all the facts of his or her life but to try instead to offer an understanding of that life: the "aim is not simple verisimilitude, but resemblance to the truth. Not 'the effect of the real,' but the image of the real" (Lejeune, 22).

Another critical viewpoint explains (and protects) the now fragile self by endowing it with a mystic ineffability. Thus Leo Braudy, writing about Defoe, refers to the autobiographical subject as "the mystery at the heart of human personality" (95); Germaine Brée, writing of Michel Leiris, alludes to the "inner self" of autobiography as a "center around which all else is articulated" though itself unreachable through language and as belonging "to the enigmatic realm of the 'sacred'" (200–201); and Barrett Mandel sees autobiographical reflection as the discovery of "the mysteriousness of [the author's] own existence" (1972, 323) and roots autobiography in "the deeper reality of being" (1980, 50).

Still other critics emphasize the difference between the author-self and the protagonist-self of autobiography. Louis Renza distinguishes between authorial person and authorial persona, alluding to the "split intentionality" in autobiographical writing whereby the "I" becomes a "he" (279). Paul John Eakin has it both ways: he prefaces *Fictions in Autobiography* with the assertion that "the self that is the center of all autobiographical narrative is necessarily a fictive structure," but elsewhere in the book he claims, "I regard the self finally as a mysterious reality, mysterious in its nature and origins and not necessarily consubstantial with the fictions we use to express it" (3, 277).

Most recently, the issue is again bypassed by implying an ideological and political, if not an ontological primacy for social and cultural reality

over the much-disputed reality of selfhood. In a sense this marks a return to Roy Pascal, who remarked, more than thirty years ago, that autobiography "involves the philosophical assumption that the self comes into being only through interplay with the outer world" (8). So Albert Stone, arguing against the recent tendency to treat autobiography solely as a fictive enterprise, cites as equally important the "complex processes of historical re-creation, ideological argument, and psychological expression" (19). Considered as "social document," autobiography, he observes, "affords a special kind of information about a culture and the individuals embedded in it" (7, 6). In similar fashion, Burton Pike observes that certain contemporary autobiographers "take their present experiences and attitudes as representative of certain forces at work in their culture"—a stance that he calls "extrospective" (342).⁶

Thus in autobiographical criticism and theory, three central issues emerge: the question of the ontological status of the self; the "extrospective" social and cultural dimensions; and the question of whether the past is reflected, reordered, or created in the act of writing about it. Pathography offers its own perspective on these various critical stances. First, in regard to the autobiographical self: neither the self as fiction nor the self as ineffable mystery are adequate formulations for the self encountered in pathographical narrative. In narratives describing illness and death, the reader is repeatedly confronted with the pragmatic reality and experiential unity of the autobiographical self. Pathography challenges the skepticism of critics and theorists about the self, making that skepticism seem artificial, mandarin, and contrived. The self of pathographical writing is the self-in-crisis: when confronted with serious and life-threatening illness, those possibilities, fictions, metaphors, and versions of self are contracted into a "hard" defensive ontological reality—primed for action, readied for response to the threat of the body, alternatively resisting and inviting the eventual disintegration of the self that is death. Perhaps it is true, as Freud maintained, that the ego is first and foremost a bodily ego and that "self" is bound up with the biological integrity of the body.

Second, pathography validates a critical stance that emphasizes the importance of sociocultural elements in writings about the self. Pierre Macherey and others see a text not as a creation by an author but as a product of a society, with the authorial role diminished to that of a facilitator, or producer. Pathographies support this emphasis on society and culture, though they do so in a way that does not diminish or efface the self. For

illness in pathography is always experienced in relation to a particular configuration of cultural ideologies, practices, and attitudes—and these inform the various components of our health-care system: professional personnel, particular diagnostic tests and particular therapies, and institutions such as the hospital and the clinic. All pathographies, even those that eventually discard traditional medical approaches, are situated within the social praxis of modern medicine; therefore, they all can serve as commentaries on it.

Lastly, if pathography challenges recent critical skepticism about the self and confirms the recent emphasis on cultural context, it significantly advances the critical position about autobiography as a re-creation of the past. As most autobiographical theorists maintain, the past in any autobiography is not simply recorded but is changed, reordered, even re-created in the act of writing about it. The study of pathography is important to this position because it discloses the particular ways in which the author changes the experiences he or she claims to be faithfully documenting. As I will show, this change is one that, in achieving a formulation of the experience that the author finds satisfying, exposes certain metaphoric and mythic constructs about illness in our culture.

Mythic Thinking

As we have seen, the “pathographical act” is one that constructs meaning by subjecting raw experience to the powerful impulse to make sense of it all, to bind together the events, feelings, thoughts, and sensations that occur during an illness into an integrated whole. Pathographies answer the need for what Sam Banks has called “meaningful, satisfying closures in a slippery world always threatening to open at the seams” (24). It is this *constructive* aspect of the autobiographical act—autobiography in its creative dimensions—that is the object of my concern in this book. Pathographies interpret experience, and they do so in a way that discloses certain important mythic attitudes about illness and treatment. Mythic thinking of all kinds becomes apparent in that delicate autobiographical transition from “actual” experience to written narrative, since this transition is one that constructs necessary fictions out of the building blocks of metaphor, image, archetype, and myth. Furthermore, as I hope to show, these heuristic mythologies of illness are formative: they serve not only to organize experience and to open it up to interpretation but also to shape it.

This word *myth* is problematic but necessary to my analysis of pathography and, thus, requires further explanation. Today, *myth* has two

contradictory meanings: the first (and probably more common) definition is *illusion or fiction*, the second refers to a deeper significance or a more profound truth. Myths are illusory or fictive in that they are epiphenomenal: the myth of progress, for example, is a conceptual scheme superimposed on human history, but it does not describe human history itself. On the other hand, myths are profound in that they embody significant patterns of human thought and behavior that emerge in cultural practices and beliefs: the myth of renewal, for example, is reflected in rituals of initiation both ancient and modern. I use the word *myth* in discussing pathography in both these senses of illusion and profound truth.⁷

Plato's use of myth in his dialogues is an ancient but still valid example of the mythic as inclusive of contradictory meanings. The *Euthyphro* is a dialogue between Socrates and Euthyphro, a young priest who is about to demonstrate what he considers his outstanding piety by bringing suit against his own father. As proof of the exemplary nature of this action, Euthyphro first refers to Zeus, “the best and most just of the gods,” who punished his father, Kronos, with imprisonment, and then to Kronos before him, who punished his father with castration. Socrates responds that he finds it hard to believe such stories and observes that this is why he, Socrates, is being prosecuted for impiety by the state. The point that Plato is making is that myths like these are fantastic, fictive, and certainly not true in any literal sense. Yet in a deeper-than-literal sense, the dialogue demonstrates that the myth *is* true: Euthyphro is the living embodiment of this myth—he is acting out the myth of the son who turns on his own father. And though Euthyphro appears a fool for his naive belief in stories like this, he is a dangerous fool, for he is a type of the pious citizen who will execute Socrates for not believing the stories about the gods as literally true. For Plato, then, a myth is at one level a fictional story about the gods and, at a deeper level, a figural narrative that points toward a universal truth or pattern of behavior. At this deeper level, myth is not explanation but embodiment, a “symbolic activity where the symbol participates in what it represents” (Dardel, 45). Moreover at this level, the mythic is conceived as functional, as dynamic.

In modern times, though, myth is often seen as something that is invented or imagined. This notion of myth as invention was one encouraged by the “science” of mythology, originating in the nineteenth century and represented by such scholars as the anthropologist Edward Tylor. Writing out of a Darwinian perspective, Tylor conceives of myth as stories invented

by the "savage" to explain the world around him. Mythology here is understood as primitive science or false science; the myth of Apollo the sun-god driving his chariot through the heavens each day is thus an explanation of the perceived motion of the sun, a story that is at the same time fictional, mythic, and pseudoscientific. Our contemporary notion of myth as a fiction derives from this nineteenth-century academic understanding of mythology as a false, incorrect explanation of how the world works—an explanation now replaced by science, which supposedly offers the only true and correct account.

For many scholars and thinkers today, from a great many varied disciplines, myth is not an explanatory fiction but a way of articulating deep personal and cultural truths. Freud and Jung are seminal figures in this restoration of myth to the status of embodied truth: the Oedipal myth is central to Freud's theory of sexuality; quest myths are key to Jung's emphasis on spiritual fulfillment in realizing the true self. Though a full discussion of modern theories of myth is beyond the purview of this book, it may be helpful to suggest the variety of thinkers who use myth in this way. There are myth critics Mircea Eliade and Joseph Campbell; anthropologists Claude Lévi-Strauss, Arnold van Gennep, and Victor Turner; philosophers Ernst Cassirer, Lucien Lévy-Bruhl, and Leszek Kolakowski; theologian Rudolf Bultmann; and literary critics Northrop Frye, Maud Bodkin, Philip Wheelwright, and Roland Barthes.⁸

For Cassirer, the mythic is a primary and irreducible element in human thinking. Myth is expressive, not explanatory: as he observes, "The 'image' does not represent the 'thing'; it *is* the thing; it does not merely stand for the object, but has the same actuality" (38). For Bultmann, myth must be interpreted anthropologically, or existentially: "the real point of myth is not to give an objective world picture; what is expressed in it, rather, is how we human beings understand ourselves in our world" (9).⁹ For Wheelwright, the mythic is a way of thinking, a way of knowing, a way of perceiving: it is not "a fiction imposed on one's already given world, but . . . a way of apprehending that world"—a "radically cognitive" act. The mythic offers a unique perspective on things, "a set of depth-meanings of perduring significance" that transcend the limits of what can be expressed in ordinary speech (159).

What all these thinkers share is the understanding of myth as embodied truth. I suggest that myth and its function be further defined as integrative, as connective, and as analogical. First, myth is integrative in that

it involves a synthesizing activity of mind: it does not break up experience into its component parts but brings it together into unity, organizing experience into a unified whole. Second, myth relates the particular and individual to some larger dimension. Though myths are usually transcultural and transhistorical, they can also be related to a particular culture or subculture. Whatever the circumference of the particular mythos, it always places events and characters in a wider context, so that the individual is part of the whole and the particular is seen in relation to the universal. Third, myth substitutes analogy for explicit meaning. Meaning in the usual sense seems almost irrelevant to myth, since the meaning of a myth is not something articulated but something felt or apprehended: in the dimension of the mythic, meaning is encoded in metaphor. A myth thus does not interpret or explain; it works analogically to embody or picture meaning. Not surprisingly, its primary epistemic devices are the image, symbol, and archetype. It is these elements, then, that will be central to my analysis of mythic thinking in pathography.

The myths about illness that one finds in pathographies may well be fictions, in the sense that when people write about their "journey" into the realm of illness, they may have traveled no further than their local hospital. But myths about illness must also be seen as profound truth in that they describe the inner configuration of the ill person's experience. For example, the myth of illness as a battle between two opposed forces is the way illness *is* actually experienced by a surprisingly large number of people who write pathographies and by some of the even larger number of people who read them.

In addition to seeing myths about illness as both fictive and profoundly true, it is important that we recognize the *dynamic* nature of myth—its potential impact on every dimension of an illness experience. Cassirer stresses this dynamic aspect of the mythic, observing: "It is not by its history that the mythology of a nation is determined but, conversely, its history is determined by its mythology . . ." (5). Myths about illness not only reflect experience but they also determine its actual shape. For example, if individuals perceive their illness as an adversary, an enemy to be defeated, then they usually acquiesce to any and all therapies their doctors deem possible "weapons." This is a myth that is medically syntonetic; that is, consistent with the metaphors and myths inherent in Western medicine. However, if the ill person believes that the key to recovery from illness is right attitude, then the effectiveness of purely medical treatments is more

questionable. This is a myth that, for obvious reasons, can be at times medically dystonic.

Myths about illness are not restricted to the patient population: physicians also have their myths about illness, though these may not be the same as those held by their patients. And doctor myths are just as powerful as patient myths, or perhaps more so. For example, the metaphor of the human body as a machine, a metaphor basic to contemporary biomedicine, is itself a kind of mythic thinking. In pathography, the mechanistic myth quite often works dystonically to create an impasse between what the patient actually feels and what can be determined by chemical analyses and technological monitors. Too often, symptoms for which physicians can find no organic cause (and which are thus often considered untreatable) are in one way or another simply dismissed. So one pathographer writes about a subjective condition experienced as "fog": "The thing fits no clinical profile. It yields no diagnosis. It submits to none of their tests, invites no techniques, and so what are they to do? . . . Whatever cannot be diagnosed or treated by technique is suspect, vaguely inauthentic, and quite possibly does not exist" (Lear, 187). The mechanistic metaphor so central to Western medicine has little place for the subjective components of body function. How patients feel, their understanding of what is happening to them, and the sense of how their illness may alter their lives are peripheral to a mechanistic model.¹⁰

Although contemporary medical theory and practice are rife with analogical thinking of all kinds, the ideal of modern medicine is to eschew mythic thinking at every level. Thus it is recognized that the less a phenomenon is fully (i.e., scientifically) understood, the more it tends to be described in metaphoric language; correspondingly, the more it is understood, the fewer concessions need to be made to image and metaphor. The medical ideal, then, is a language fully purged of mythic thinking.

Susan Sontag, in *Illness as Metaphor*, aligns herself with this medical ideal in her crusade against metaphoric thinking about illness, which she sees as harmful and destructive. Though not literally a pathography, *Illness as Metaphor* is inspired by her personal experience of cancer. Ironically, the book participates in the very mythic thinking it criticizes. The myth of "metaphorlessness" is the organizing myth of *Illness as Metaphor*. This is the notion that illness can and should be experienced without recourse to metaphoric thinking, a functional myth that appears to help Sontag endure and recover from her illness. It is of interest that though she declares "that

illness is *not* a metaphor, and that the most truthful way of regarding illness—and the healthiest way of being ill—is the one most purified of, most resistant to, metaphoric thinking," she introduces her book with an elaborate geographical metaphor comparing illness to a sojourn in a distant kingdom: "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" (3).

The discrepancy here between precept and practice is important. For even if we agree with Sontag that illness should be stripped of metaphor, myth, and symbol—and not everyone will agree with her about this—it is an expectation that few of us could live up to.¹¹ Metaphoric thinking is built into our very mental faculties. Ironically, pathographers cite as helpful Sontag's metaphor of illness as the "kingdom of the sick" far more frequently than they do her idea that illness is best experienced without recourse to metaphoric thinking (Callen, 65; Creaturo, 92, 103; Schreiber, 70). As Robert Jay Lifton so aptly remarks, "We live on images. As human beings we know our bodies and our minds only through what we can imagine. To grasp our humanity we need to structure these images into metaphors and models" (1979, 3). Even Sontag realizes this, observing in *AIDS and Its Metaphors*, "Of course, one cannot think without metaphors" (5).

Pathography is invaluable to us as a way to study the metaphoric dimensions of the medical enterprise. Just to consider the titles of these books gives some indication of the metaphoric thinking that lies behind them: *Coming Back, Voyage and Return, Signs of Spring, Second Life, A Private Battle, Cancer Winner, Embracing the Wolf*. Not only does pathography restore the phenomenological and the experiential to the medical encounter, but it also restores the mythic dimension our scientific culture ignores or disallows.

Formulation

Pathography, then, provides us with a "taxonomy" of mythic attitudes about illness; it also helps us see just how a particular myth functions in a given situation. Sontag decries metaphoric thinking about illness because she focuses on its negative dimensions: for example, the myth that cancer is caused by "the repression of violent [or sexual] feelings," or that tuberculosis is "a disease of the soul" (1979, 22,17), or that AIDS is "a disease

not only of sexual excess but of perversity" (1989, 26). What she fails to see in both her books is that myths about illness may be enabling as well as disabling: enabling, in that they can actually help the sick person who believes them to recover or, at least, to deal better with the circumstances of illness or death; disabling, in that they can impede a patient's ability to recover and even augment suffering. Pathography is a superb idiographic document because it shows us these myths and metaphors as they are "lived in"—for better or for worse.

In pathography, then, not only is mythic thinking pervasive, but it is functional—medically syntonic or dystonic, and personally enabling or disabling. But it is functional in a larger and deeper sense. The subject of these books is a kind of experience that is so painful, destructive, and disorienting that it results in a counterimpulse toward creation and order. This counterimpulse is what Lifton, in his celebrated study of the survivors of Hiroshima, calls "formulation," a reparative process that deals with trauma by imagination and interpretation. Formulation, Lifton remarks, is a kind of "psychic rebuilding," the construction of certain inner forms or configurations that function "as a bridge between self and world"—a psychological process whereby the individual suffering from trauma "returns" to the world of the living (1967, 367, 525–26). Formulation involves the effort to re-establish three elements essential to psychic function: the sense of connection (between self and other), the sense of symbolic integrity (seeing one's life as meaningful), and the sense of movement (the capacity for change) (367).¹² Lifton further describes the formulative process as "intimately bound up with mastery"; successful formulation "not only enhances mastery but, in an important sense, contains the mental representation of mastery" (536, 367). The act of formulation, then, involves the discovery of patterns in experience, the imposition of order, the creation of meaning—all with the purpose of mastering a traumatic experience and thereby re-establishing a sense of connectedness with objective reality and with other people. It is these things that enable human beings not only to live through severe illness or the death of a loved one but also to live beyond them.

Pathography can be seen as *re*-formulation of the experience of illness, as the artistic product and continuation of the instinctive psychological act of formulation: it gathers together the separate meanings, the moments of illumination and understanding, the cycles of hope and despair, and weaves them into a whole fabric, one wherein a temporal sequence of events takes

on narrative form. Roy Pascal, describing autobiography, nicely sums up the narrative extension of this process of formulation: successful autobiographies, he observes, "seem to suggest a certain power of the personality over circumstance, not in the arrogant sense that circumstance can be bent to the will of the individual, but in the sense that the individual can extract nurture out of disparate incidents and ultimately bind them together in his own way, disregarding all that was unusable. Painful as well as advantageous experiences can thus be transformed into the substance of the personality" (10–11). The psychological process of formulation as articulated by Lifton and the narrative act of reformulation embodied in pathography are in some sense parallel: both involve an individual's mastery of a set of circumstances, both suggest the act of constructing or piecing together a set of disparate events into a coherent whole, both concern the aesthetic act of seeing pattern and design and its epistemological analogue—the imposition of meaning or the discovery of significance.

Pathography can also be seen as the final stage in the process of formulation, completing the bridge between the suffering self and the outside world by an overt act of communication. Moreover, in pathography the need to *tell* others so often becomes the wish to *help* others: perhaps the movement from catharsis to altruism is a signal of the success of the formulation. As Bernice Kavinoky remarks of her pathography in a letter accompanying the manuscript: "This was a book that *had* to be written. I wrote it originally for myself, because it clarified my thinking and emotions. Then I began to ponder over it and felt perhaps it was for everybody—not only those who had my operation but everyone who had been through an experience of shock and loss, and who had eventually—after the flying of flags and lifting of the chin—to face it, in his own waiting room, alone" (71–72).

Myth in Pathography

Pathography is an immensely rich reservoir of the metaphors and models that surround illness in contemporary culture. These books are of value to us not because they record "what happened"—for they are not, as we have seen, factual accounts—but precisely because they *are* interpretations of experience. And as interpretations they must be understood as constructs, revisions, and, in some cases, creative distortions that expose a variety of ideological and mythic attitudes about illness today.

Many patient-authors will use a particular metaphor, mythic construct, or ideological paradigm to describe and explain their experience.¹³ Quite often this central image functions as an organizational principle encompassing all aspects of an illness—disease, treatment, medical institutions and personnel. Some organizing myths are highly idiosyncratic. Thus Joanna Baumer Permut's pathography about lupus—the disease that takes its name from the Latin word for wolf—is shaped around her thoughts about the wolf. Each chapter is preceded by an epigram or quotation about wolves; each chapter title bears some reference to the wolf. The use of the name of the disease as an organizing metaphor seems successful in helping her come to terms with her condition. The pathography moves from an initial sense of victimization (the first chapter is titled, "The Wolf Stalks His Prey") to a final accommodation (the last chapter is called "Wolf and Patient Negotiate Peace"). As Permut observes, "the wolf image works for me. The metaphor serves the disease, and therefore my self positively" (163).

Eleanor Clark's pathography is also unusual in the choice of an organizing metaphor: the personal story of illness is set within the context of Homeric epic. Suffering from macular degeneration in both eyes, Clark spends her days writing her pathography and her evenings listening to readings of Homer's *Iliad* and *Odyssey*, an activity that she considers "inseparable from the rest of the story" (ix). She sees both epics—hers and Homer's—as similar in their concern with the theme of justice, and of course both are composed by a blind author. In general, though, the glorious world of Homer serves as a foil to which she contrasts the modern world, which she sees as deficient in heroism and lacking in any sense of death as meaningful. Clark's pathography is a very angry one, and the contrast she finds between the ancient and the modern serves as an apt expression of this anger.

A final example is Patricia Hingle's *A Coming of Roses*, intended primarily as an inspirational book for those who have (or will have) cancer. Life itself is the rose; cancer the thorn. Convinced that cancer has made her come to terms with the choices she has made in life, she begins her pathography with the words, "Cancer saved my life" (1). The metaphor is clearly an enabling one. The last chapter is titled "Regeneration": her rose garden has come into bloom, but, of course, the roses still have thorns. To Hingle, a rose garden in full bloom seems an apt metaphor for her condition, a rich and satisfying life in which her cancer is in remission.

But it would be a misnomer to call Permut's wolf or Clark's Homeric allusions or Hingle's rose garden "myths." Though they touch on mythic issues—the threat of the bestial other, the image of heroic excellence, and natural cycles of loss and renewal—they are really closer to elaborate metaphors in being conscious, artful, and "literary." In contrast, the mythic paradigms one finds in most contemporary pathographies seem at once more conventional and more "archetypal."

What is striking about pathography is the extent to which these very personal accounts of illness, though highly individualized, tend to be confined to certain repeated themes—themes of an archetypal, mythic nature. Over and over again, the same metaphorical paradigms are repeated in pathographies: the paradigm of regeneration, the idea of illness as battle, the athletic ideal, the journey into a distant country, and the mythos of healthy-mindedness. Why should the same paradigms recur with such frequency in pathography? George Rousseau notes that although "patients in Shakespeare's England will not describe themselves like those in Proust's Paris or Schnitzler's Vienna," nevertheless "similarities do appear: categories of thought so consistent in their metaphoric coherence (the patient as hero, disease as predatory invader-villain . . .)—so coherent that one wonders if there could be a heritage of myths about suffering in the Jungian archetypal sense" (169). The reader of pathographies must attend to both these differences and these similarities. It is not surprising that certain significant motifs and patterns—especially those concerned with phenomena that all human beings experience, such as growth and change or suffering, illness, and death—should recur over and over in very different periods and cultures. But it also makes sense that these deep-lying patterns should emerge in forms that are culturally inflected, shaped by a particular place and time. If pathography is an imaginative reformulation of experience that reconnects the isolated individual sufferer with his or her world, the connecting "formula" needs to be both culture-specific and transcultural, for the patient's world includes both a particular society at a certain moment in history and the larger and more timeless human community that underlies it.

Occasionally, the mythic and metaphoric themes one finds in pathography are overt and carefully elaborated. This is especially the case when the pathographer is a professional writer, with a writer's self-conscious concern for artistic craft and form. More often, though, the patterns are tacit and instinctive, surfacing in such isolated and unselfconscious phrases as "my battle with cancer" or "my journey to recovery."² To the literary critic

such paradigms may at first appear less interesting because they are so rarely artistically developed and because they are so often latent rather than overt. Indeed in some pathographies, the signifier almost disappears because the signified operates at so instinctive a level, resonating with deep, transpersonal images and patterns of meaning. The "fight with cancer" may be a throwaway phrase, casual and conventional, but it may also signal a way of dealing with illness that remains inarticulate because it is so profound: for such a patient or pathographer, sickness actually becomes a form of war. For the social critic, then, it is precisely the lack of literary sophistication and conscious development of such patterns that marks them as mythic and, thus, of interest.

For the literary critic; however, it is the richer and more elaborated pathography that best repays critical analysis. As one might expect, pathographies differ greatly in quality, ranging from sincere though unsophisticated works published by small denominational presses to profound literary explorations of illness and death such as John Donne's seventeenth-century *Devotions Upon Emergent Occasions* or Peter Noll's modern *In the Face of Death*. Importantly, Donne and Noll are individuals with an impressive range of intellectual and spiritual commitments as well as experienced writers. It is not accidental that the pathography offering the fullest and most imaginative version of the journey myth is authored by a skilled writer, Oliver Sacks. This is true of the military myth, too, where the pathographies that best deploy the myth with depth and insight are the work of professionals—Cornelius Ryan and Paul Monette.

Each of the mythic paradigms I have found repeated in pathography—battle, journey, rebirth, and "healthy-mindedness"—will be analyzed and explored in the chapters that follow. Division among them is inevitably arbitrary to some degree: the patient who experiences illness as a form of death and rebirth, for example, may also see it as a quest for a renewed life. Such blending is natural to myth and inevitable in literary works that evolve from it: to cite only one example, the *Aeneid* combines motifs of quest, regeneration, and war. In pathographies, too, there is necessarily some overlap between one mythic paradigm and another. But these paradigms must also be seen as disjunct: the myths do not organize themselves into any necessary or logical sequence. Consequently the chapters that analyze them can have no "through line" of developing argument. Such a unifying metamyth would exemplify mythic thinking at its most factitious, imposing pattern where it does not exist.

Nevertheless, the final discussion of healthy-mindedness provides a kind of closure and at the same time a significant reversal to the earlier chapters. Unlike the other myths to be considered, healthy-mindedness is not obviously archetypal; indeed, it is not really a narrative pattern at all. It is for this reason that I refer to this constellation of mythic ideas and values as "mythos" rather than "myth." Furthermore, whereas the myths of battle, journey, and rebirth inform the way individuals *understand* their illness, healthy-mindedness concerns not just the epistemological but also the pragmatic and the practical. I use the term to refer to a congeries of attitudes, assumptions, and practices that emerge in recent pathographies and that challenge the corresponding assumptions and practices of orthodox medicine.

Healthy-mindedness at every point differentiates itself from the scientism of the biomedical model: in its reliance on nature rather than *techné*, its appeal to anecdotal rather than statistical evidence, and its basis in a logic of symbols rather than the scientific logic of testing and experiment. It is thus not surprising that the therapies it offers often approximate mythical ways of thinking and behaving: to see love as the source of all healing borders on the religious; to give oneself injections of a substance made from red ants because these insects are "incredibly quick at bringing dead matter back into the life cycle" verges on the magical (Siegel and Melton; Chester, 133). The mythic dimension of healthy-mindedness is evident in both its contrast to science and its affiliations with other forms of mythic thought. It is a cultural myth—that is, a constellation of beliefs, values, and practices—that attracts our allegiance not because it can be proved but because in our culture it is felt by many to be true to their experience of illness.

Given its mythic character and lack of any specific narrative pattern, it is not surprising that the mythos of healthy-mindedness subsumes many of the myths we have been examining. Though these myths tend to reappear in healthy-minded pathographies, it is with a striking difference. Myth, we have observed, is analogical and dynamic. In most pathography, mythic analogies tend to translate the literal facts of illness and therapy into metaphors and symbols. Such metaphors and symbols, however, tend to be absent from healthy-minded pathographies: here, metaphor is translated into fact, so that mythic paradigms surface as actual practices rather than heuristic devices. For example, in a pathography organized around the journey or the battle myth, the paradigm serves as a way of metaphorically

understanding the process of an illness. In a healthy-minded pathography, however, the myth of journey or battle actually *becomes* the action—meaning turns to praxis. So an AIDS patient, traveling to Tijuana to buy an illegal drug, is caught up in a literal quest for the “elixir” that will cure AIDS. And patients who visualize their white blood cells as knights fighting and defeating the invading cancer are attempting to convert symbolism into therapy, figure into fact. The dynamic tendency of all mythic thinking here achieves its fullest realization, as the battle myth is consciously used as an actual therapeutic device. We see why healthy-minded pathographies have no need of imagery that transforms the medical into the mythic: here, at last, myth has become medicine.



The Myth of Rebirth and the Promise of Cure

Rebirth Narratives: Tradition and Transformation

One explanation for the popularity of pathographies today is simply that they provide “a good read.” Pathographies are compelling because they describe dramatic human experience of real crisis: they appeal to us because they give shape to our deepest hopes and fears about such crises, and in so doing, they often draw upon profound archetypal dimensions of human experience. If this is so, one might wonder why it is that pathographies were not more in evidence in previous eras and cultures. Why is it that these books are so rarely found before the mid-twentieth century? One answer to this question is that such narratives do exist in earlier periods, but they exist in a different form. It is my belief that our contemporary pathographies have their closest counterparts in a kind of literature that at first must seem radically different: autobiographies describing religious conversion. Indeed, it almost seems as though pathography has replaced the conversion autobiography of earlier, more religious cultures.

It is of interest that these two kinds of autobiographical narrative seem to preclude each other in the eras where they occur most frequently. Thus in seventeenth-century England, when autobiographies describing religious conversion flourished, extant personal accounts of illness in book-length form are quite rare. When we do find an autobiographical account of physical illness in this period, it is deflected toward the primary cultural mode—that is, the spiritual dimension. Thus John Donne’s *Devotions Upon Emergent Occasions* not only treats physical illness as a means for spiritual growth but also consistently interprets the physical dimension as a metaphor for the spiritual. In contrast, the popular literature of America