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The doctor as patient : a thematic analysis of physician autopathographies on cancer

Claire Betterton

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I am submitting herewith a thesis written by Claire Betterton entitled "The doctor as patient : a thematic analysis of physician autopathographies on cancer." I have examined the final electronic copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Communication.

Paul Ashdown, Major Professor

We have read this thesis and recommend its acceptance:

Accepted for the Council:

Dixie L. Thompson

Vice Provost and Dean of the Graduate School

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We have read this thesis and
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James A. Crook

Acceptance for the Council:


Vice Provost and Dean of
Graduate Studies

**THE DOCTOR AS PATIENT:
A Thematic Analysis of Physician Autopathographies on Cancer**

A Thesis
Presented for the
Master of Science
Degree
The University of Tennessee, Knoxville

S. Claire Betterton
August 2003

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DEDICATION

To my husband, Andrew W. Cross, D.V.M., M.D.,
whose medical training experiences I have enjoyed and
learned from vicariously and whose perseverance
and humility I seek to imitate.

To my father and mother, Carl E. and Sara B. Betterton,
whose gifts of love and care thorough all the years would
take endless volumes to recount.

And to my sisters, Lauren and Rachel.

I love you all.

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ABSTRACT

This thesis documents an investigation into the literary genre of physician autopathography—physician-authored autobiographical accounts of personal experience with illness/disease, injury or disability. At a general level, it explores potential explanations for the growth of this genre over the last 25 years. In addition, it compiles the first known bibliography of physician autopathography. At a more detailed level, through comprehensive thematic analysis of nine selected autopathographies on cancer, this thesis provides the foundation for a taxonomy to capture the manner in which the physician authors respond to the illness experience across their dual roles of patient and doctor. Three main categories are revealed and elaborated. Five authors are high-doctor/low-patient (DOCTOR/patient), four are high-doctor/high-patient (DOCTOR/PATIENT), and one is low-doctor/high-patient (doctor/PATIENT). The DOCTOR/patients cling fast to the doctor role. They are least accepting of the necessary transition to patienthood and most vocally rebel against it. They maintain an active, authoritative physician persona throughout their experience with cancer. The DOCTOR/PATIENTS position themselves with one foot on each side of the so-called dividing line between the physician role and the patient role. Their illness is met with resistance because of their status as physicians, but they are also more willing or able than the DOCTOR/patients to accept the vulnerabilities the transformation to patient brings. The doctor/PATIENTS show only vestiges of the physician role in the experience of illness. They are the most accepting of the patient's passive status and demonstrate the smoothest transition from the role of doctor to that of patient.

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CHAPTER ONE

Introduction

Over one year, ending in 2001, researchers at Johns Hopkins University School of Medicine interviewed physicians who had been patients with cancer. In a petition calling for such physicians to share their experience, the researchers noted the little effort that has been made, even into the beginning of the 21st century, to understand how physicians experience patienthood.¹ Part of the problem is that physicians tend to be fairly reticent about publicly communicating a serious personal illness experience. For hundreds of years, physicians have documented observations about diseases they contracted, but for the most part, these have been in the form of anonymous case reports for research purposes or in minor segments of medical journals and essays. But beginning in the mid-1970s, U.S. physicians began publishing, in small number, autopathographies²—book-length autobiographical accounts about their personal experiences as a patient with

¹ A flyer highlighting the lack of research on physicians as patients and seeking physicians with cancer for interviews about their experience was posted on the Johns Hopkins Web site in 2000 (“Physicians With Cancer Study”). Erik Fromme, M.D., lead researcher, said in an e-mail message that the interviews were completed in June 2001, and a paper based on the findings is in review for possible publication in August or September 2003 (“Re: Physicians With Cancer Study”).

² This is the author’s preferred term for autobiographical narratives about an experience with illness/disease, disability or injury, although scholars have labeled works of this type with a variety of other names, including pathographies, illness narratives, and even stories of sickness. Jeffrey K. Aronson, a reader in clinical pharmacology at Oxford University, writes that the earliest use of “autopathography” that he has found is in a 1911 article by Clarence B. Farrar titled “Documented Delirium: An Autopathography” in the *American Journal of Insanity*, vol. 67, no. 4. The earliest modern example he has found is in an article by G. Thomas Couser titled, “Autopathography: Women, Illness, Lifewriting,” in the Spring 1991 issue of *a/b: Auto/biography Studies*, vol. 6, no. 1, p. 65 (“Re: Patient’s Tales”). Aronson writes that the term, ‘pathography’ was “originally defined in 1853 in Duglison’s *Medical Lexicon* as a description of disease, and later as ‘the study of the effects of any illness on the writer’s ... life or art ...’” He continues, “The word was probably first used in this sense by Sigmund Freud, in *Eine Kindheitserinnerung des Leonardo da Vinci* (1910).” (“Autopathography” 1,602).

significant illness, disability or injury. As the next two and a half decades progressed, the number of these works grew.

Literary scholars have come to view autobiography in general, which is among the strongest and most durable features of the modern publishing industry, no longer as a “pedestrian category of history” but as a type of literature worthy of study (Bjorklund 11). *Non-physician autopathography*, proliferating since the 1950s, is beginning to be analyzed by scholars doing textual and cultural studies, and American medical schools—in an effort to counteract patients’ complaints that their doctors don’t recognize or listen to the emotional aspects of illness in today’s increasingly mechanized health care industry—are even using these “patients’ stories” to augment students’ clinical training (McLellan, “Literature and Medicine: Narratives” 1,618). While the voices of physician-patients could also serve as an important resource in this regard, physician autopathographies have gone virtually unnoticed. Academics in various disciplines have indeed documented the rise in the number of these works, but they have not explained reasons for the phenomenon. Nor is there a bibliography that provides a comprehensive list of the works that comprise this relatively new genre.³

Probably the most widely known physician autopathography is Edward E. Rosenbaum’s *The Doctor: When the Doctor is the Patient* (first published in 1988 as *A Taste of My Own Medicine*). The book became a paperback bestseller in 1991, was made into an acclaimed movie the same year called “The Doctor,” and was published in nearly

³ A genre is a category of any kind of artistic work that can be established on the basis of form, style or subject. Autobiography itself can be “broken down into a series of genres” based on “story types in terms of subject matter”—such as war stories and hospital stories (Chamberlain and Thompson 11 qtd. in Koski 2). Physician autopathography can therefore be considered a genre.

a dozen languages.⁴ Like other physician autobiographies, *The Doctor* provides a unique “insider’s” account of the doctor-turned-patient experience.

What seems to capture people’s interest most in such stories is the issue of role reversal. Physicians and the public are intrigued, if not intimidated, by doctors becoming patients. Such ironic reversal of professional perspective was illustrated in the January 4, 2001, episode of the popular NBC television drama, “ER,” as Dr. Mark Greene submits to experimental brain surgery for a tumor (“Piece of Mind”). In such scenarios, the doctor wrestles with sudden helplessness. “He is used to having all the answers, but now somebody else holds the information. He is the one dictating orders in a white lab coat, but now he lies [...] in bed in a paper gown” (Zulkey par. 1).

“Patienthood is often the antithesis of doctorhood” (Schneck 2,042). As Mandell and Spiro explain, “When a doctor gets sick, his status changes. No longer is his role defined as deriving from *doctus*, i.e., learned, but as from *patiens*, the present participle of the deponent Latin verb, *patior*, i.e. to suffer, with all the passive acceptance of pain the verb implies. It is the connotation, not the denotation, of the word that defines the change of status” (vii). The one who is trained to restore health and maintain life now finds his health challenged and his life possibly at risk. The healthy physician develops defenses against disease in order to feel immune in the face of sickness and death. When a doctor becomes a patient, he or she faces an implied loss of control in a profession that prides itself on the control of illness in others (Lundin 1,082). A dividing line exists between the role of patient and the role of doctor, described by one physician diagnosed with breast cancer: “One part of her was a sick, frightened patient. [...] The other part

⁴ Rosenbaum, “Telephone Interview.”

was a disciplined observant scientist keeping track of [...] white blood cell counts, fever curves, and drug flow sheets” (Keoun 1,616).

Part of what the Johns Hopkins researchers were looking for relates to more thoroughly understanding the nature of this physician-to-patient shift. Physician autopathographies, like Rosenbaum’s text, are a source for detailing how physicians, as a unique class of patient, express the patient role. This thesis will integrate and extend the research perspective on that subject. It will explain the rise in physician autopathographies and provide the first organized bibliography of available books in the genre. Through thematic analysis of nine separate cancer autopathographies, it will explore how physicians experience illness and where they position themselves along the dividing line between the world of the doctor and the world of the patient.

CHAPTER TWO

Literature Review

The rise of physician autopathography

Physicians have written about their own diseases for centuries as parts of their autobiographies, in letters or journal entries, or in case reports (often anonymous) for research publications (Duffin 1,857). In the mid 17th century, for example, English physician Thomas Sydenham wrote, as part of his larger autobiography, a now classic description of gout. The description is based on the symptoms he himself suffered, but Sydenham writes in the third person point of view, objectively referring to the patient not as “I” but as “the victim”: “The victim goes to bed and sleeps in good health. About two o'clock in the morning he is awakened by a severe pain in the great toe; more rarely in the heel, ankle, or instep. This pain is like that of a dislocation, and yet the parts feel as if cold water were poured over them” (Sydenham 124).

Similar case reports can be found in *Aerzte als Patienten*, written in 1929 by Dr. Alfred Grotjahn, who culled through published medical autobiographies to produce his book (Pinner and Miller xiii). Like Sydenham’s technical disease description, Grotjahn’s reports are “singularly devoid of subjective interest” according to American physician Max Pinner, M.D., in the preface to the 1952 book, *When Doctors are Patients*. Pinner defines subjective interest as that which goes beyond expressed symptoms, such as nausea and fatigue, to include those experiences “related to the mental, emotional, social and economic aspects” of a disease (xii). *When Doctors are Patients*, written with Benjamin F. Miller, M.D., who argued “no adequate book on the subject existed,” is a

collection of solicited essays –“autobiographical sketches of disease”—by American physicians intended for both physician and lay audiences (xvi).

The essays do include subjective aspects of the disease experience, including the physician-authors’ tensions and anxieties, and nearly all are written in first person. However, one-quarter of the essays in the collection are anonymous, signifying reluctance, perhaps, on the part of those authors to be identified as a patient. Furthermore, even with fears and vulnerabilities expressed, the physician-authors on the whole make a point to emphasize triumph over their malady. Miller writes that even seemingly hopeless cases are overcome by these authors, who, unlike the average patient, are “armed by [their] knowledge of disease mechanisms” (xvii). Being in charge is emphasized in the essays. In one of them, Dr. John P. Darling, a pathologist in Mason City, Iowa, writes that his story “tells [...] how one patient discovered and controlled [...] numerous ostensible causes of his convulsions and consequent difficulties” (328).

By the 1950s, and into the 1960s, the idea that the vulnerabilities of physicians, even openly stated in subjective personal essay accounts of disease experiences, would be overshadowed by their triumphs over them is not surprising, given the public image of physicians in the culture of the time.⁵ U.S. physicians were enjoying increasing social prestige and scientific authority. Technological and pharmaceutical advances, including the use of antibiotics (discovered at the end of the 1930s) and the promise of an end to viral epidemics such as small pox and measles, increased physicians’ ability to cure acute diseases (Pollock “Training Tales” 342). Television enhanced this reverence with its

⁵ Into the 1950s, public opinion polls ranked physicians on a par with or better than Supreme Court justices (Raju par. 6).

American Medical Association-approved shows including “Medic,” televised from 1954 to 1956, and “Ben Casey” and “Dr. Kildare,” both of which ran from 1961 to 1966 (Chory-Assad 500). Only occasionally did television doctors allude to their own weaknesses (Chory-Assad 502), and physicians who authored book-length autobiographies into the 1960s were not writing about their own struggles with disease. On the contrary, the authors were usually older, famous doctors writing self-consciously heroic memoirs about distinguished careers, or they were the personal physicians of famous Americans writing about their exceptional experiences. They were doctors on the frontier, on the war-front, or on missions overseas with novel stories to tell (Kaplan; Briscoe, Tobias, and Bloom).

In contrast, by the 1970s, newly published volumes with titles such as *Surgeon Under the Knife* (1976) and *A Physician Faces Cancer in Himself* (1979) and written by non-anonymous physicians— William A. Nolen, M.D., and Samuel Sanes, M.D., respectively—were published. They were among the first full-length physician-written autopathographies in which the author’s candid experience of illness, disability or injury was the main subject, and they were anything *but* devoid of subjective interest. The books’ emergence began to comprise a genre that in 2003 is still on the rise. Little research exists to explain in cause and effect fashion this ascension of physician autopathography. While during the period in question the absolute number of physicians in the United States increased,⁶ this could at most only partially explain the growth in the genre. More interestingly, its escalation parallels the increase of other types of

⁶ The number of U.S. physicians per 100,000 people grew from just over 150 in 1970 to 226 in 1998 (Anstett, par. 20; American Medical Association Table 1.1).

autobiographies, including training tales (or the autobiography of medical education) by doctors and autopathographies by non-physician patients.⁷ A look at published ideas about the rise of these other forms and at cultural changes over time offers some suggestions for the growth of physician autopathography.

(1) The domination of the biomedical model. According to Anne Hunsaker Hawkins, the rise in book-length narratives about the author-patient's illness (her term for these is "pathography") is both a reaction to and a reflection of the growing domination of the biomedical model ("Reconstructing" 11-12). This conceptual model of illness includes only biological factors in an attempt to understand a person's medical problem, ignoring the psychological emotional, spiritual, and social factors (Pert 18). The impersonal aspects of modern medicine associated with the biomedical approach along with corresponding dissatisfaction with the medical "system" often provokes ill subjects to construct their illness as *they* experience it ... in contrast to the very scientific and objective medical 'case report'" (Rimmon-Kenan 11).

Following the 1950s "golden age" of medicine, continued rapid technological, pharmaceutical, and scientific advancement began to lead to a more specialized and reductionist view of patients. Indeed, sociologists studying medicine in the 1960s observed "detached concern" on the part of physicians (Charon "Narrative medicine: A Model" 54). "Medical practice was moving from being a personal activity that took place at the bedside, where the doctor listened to and touched the patient, to a technical,

⁷ The exclusive modern genre of pathography is "remarkable, in that it seems to have emerged *ex nihilo*"; pathographies are uncommon before 1950 (Hawkins "Reconstructing," 3). Aronson, who has collected more than 210 examples of what he calls "patients' tales" notes that the distribution of their publication dates shows a "striking increase in the numbers of such tales published during the last 20 years" ("Autopathography" 1,600).

impersonal activity that took place in laboratories and reading rooms remote from the patient” (Charon “Literature and Medicine: Origins” 25). Dialogue between patient and physician, once the key to diagnosis and treatment, had become superfluous because sophisticated medical devices could tell the story more accurately than patients. The patient would, in a sense, *become* his illness, and physicians might “refer to their patients as particular [malfunctioning] organs: for example, ‘the liver in 201’” (Baker par. 3).

With the 1970s came the introduction of “SOAP” the Subjective, Objective, Assessment, Plan of the Problem Oriented Medical Record (POMR). Though technically an advance in medical problem solving, SOAP also “dissected the patient’s narrative into the smallest common units, i.e. problems,”—with no categories for describing suffering or the intimate, inward accounts of experiencing illness—and forced practitioners to record in a linear process (Borkan, Reis, and Medalie 128). Then, starting in the 1980s, “managed care, third party accountability, and the electronic medical record brought greater emphasis on diagnostic codes,” demanding practitioners to take “the truly infinite variations of patient stories” and fit them “into a very limited number of diagnoses” (Borkan, Reis, and Medalie 128).

Dissatisfaction with impersonal medical treatment is a theme Hawkins finds in patient-authors writing about their experience with illness (“Reconstructing” 5). The authors include criticism of medicine’s narrow focus on disease and its disregard for the experiencing patient. They seek to integrate the experience of illness into a coherent sense of self, to restore the ignored patient, return him to the center, and give him a voice (Couser “Recovering” 19). They “humanize the experience of being ill in a manner that directly undercuts the medical objectification of the body, both for the reader and for the

writer” (Baker par. 4). Hawkins categorizes works whose authors are motivated most by a need to point out deficiencies in patient care, especially a lack of empathy, as “angry pathographies,” noting one pathographer’s observation about her long hospitalization: “I was no longer afraid of the disease, but of the system.” (“Reconstructing” 6).⁸

While Hawkins considers only non-physician narratives in her discussion of dissatisfaction with the medical system, the theme could apply to physician autopathographies as well. Physicians were beginning to express frustrations with the “system” as early as the mid-1960s. The changes in medical practice along with the general social disaffection, spirit of protest, civil rights and other liberation movements of the period “provided fertile ground for the publication of a new kind of medical autobiography” by doctors “that revealed the uncertainties of medicine, the clay feet of physicians, and the potential dangers of medical institutions” (Pollock “Training Tales” 343). Feelings of alienation and disaffection can be found in autobiographical accounts of medical training (Koski 31). Medical students, like their peers on college campuses, began struggling for their own voice in the 1960s. “Critical of teaching methods and objectives in medical schools,” medical students sought “reassessment of the priorities of both society and medicine” (Boren 123).

One type of this new physician autobiography is called the training narrative or the autobiography of medical education. The first autobiography of medical education, *Intern*, by “Doctor X” emerged in 1965 (Koski 1; Pollock “Training Tales” 343). It is not about the heroic doctor or his exceptional experiences; instead, it is by a physician who

⁸ A very early account of ill health spurring critique is *Sacred Orations* by Aelius Aristides (A.D. 170-171), the major themes of which are the praise of God (in this case Asklepios) and criticism of physicians (Aronson “Autopathography” 1,600).

comments on the pressures of training, criticizes the underpreparation of medical students for the extraordinary responsibilities of patient care, and argues that patients' welfare is being compromised as a result (Pollock "Training Tales" 343). Other physicians subsequently have written autobiographies about their medical education with varying viewpoints,⁹ but all of them offer readers an inside account the vicarious experience of the traditionally hidden process of becoming a doctor through a neophyte narrator—a "relatively powerless figure in a system of medical authority"—that readers can identify with. (Pollock "Training Tales" 345).

Physician autopathographies, like those of the general public and like physician autobiographies of medical education, seem also to spring from similar reactions to changes in the medical system and in culture. Doctors are frustrated both about losing their authority and by perceptions by the public that they have too much authority and are abusing it.¹⁰ Many sense that their ability to make decisions for patients is being taken away from them. They see bureaucratization (which originates with federal and state governments and also comes from health insurance companies, health corporations, and hospitals) as a morass of rules and regulations that are suffocating them with paper work

⁹ Cheryl A. Koski presents an original typology of how authors of autobiographies of medical education portray themselves with regard to their medical school, internship and residency training: as observers (who make ethical judgments about it), as outsiders (who seek ways to adjust to it), as activists (who try to change it), as malcontents (who bear a grudge against it), and as apologists (who defend it) (355).

¹⁰ One cultural reflection of the public's perception of doctors can be seen in literature and in the media. Progress in scientific medicine helped sustain the literary image of the heroic physician, but by the close of the 20th century, literary images of physicians tended to be satirical (Jones "Images" 734). Television continued to portray doctors as highly knowledgeable and "competent in all that they do" through the 1980s (Chory-Assad 503), but programs by the mid 1990s often seemed to depict "occasional uncertainties in diagnosis and mistakes in treatment" and "unflattering personal traits ... including adultery, arrogance, and avarice" (Pfau, Mullen, and Garrow 455). And in the movies, doctors appeared generally as "kindly, sympathetic healers" in the first half of the century, but by the middle of the latter half, Hollywood "attacks not only doctors but medical institutions" (Raju par. 14).

and robbing them of their autonomy (Pekkanen 54). On the other hand, some doctors humbly resist the cloak of authority and comment on the overwhelming nature of technology. Jamie Weisman, who wrote about coping with her chronic illness through medical school in her autobiography, *As I Live and Breathe: Notes of a Patient-Doctor* (2002) observes: “We’ve made incredible advances, but we’re still dwarfed by things we don’t know about the human body. For doctors, in a way, it’s hard to admit your humanity, but there’s something that’s almost a relief about it. You can approach the patient when you fail, which does happen. You’re not a deity” (Weaver 1F).

Another example of reaction to the biomedical approach is evident in the rise, since the 1960s, of Americans seeking complementary and alternative medical treatment, which covers therapeutic practices, approaches, and philosophies outside mainstream Western medicine. Many of these therapies are considered “holistic.” They take into account the whole person in the healing process—not just the person’s physical being but the mental, emotional and spiritual sides, as well. The 1970s showed increased use of biofeedback, energy healing, herbal medicine, and imagery. Massage and naturopathy increased in the 1980s, and the 1990s showed particular increased adoption of aromatherapy, energy healing, herbal medicine, massage, and yoga. From 1990 to 1997 there was a 50 percent increase in the number of visits (from 425 million in 1990 to 629 million in 1997) to herbalists, chiropractors and other providers of non-conventional therapies, which was more than the number of visits (386 million) to primary care physicians (“What is Alternative Medicine?” par. 1).

Physicians as well as non-physicians have written books—some of them in connection with an autobiography—about alternative medical treatment. For example,

in *My Healing From Breast Cancer* (1996), Barbara Joseph, M.D., alternates vignettes about her experience with cancer with commentary about the disease, the medical system, and, especially, about alternative treatment modes. She begins the first chapter claiming, “Conventional medicine treats breast cancer as an invader. [...] The medical establishment views the body as a war zone” (15). The therapies she recommends—“diet, supplements, and visualization thorough psychological understanding and spiritual awakening,” noted by the book jacket—veer from the approaches of conventional medicine.

Whereas the rise in physician autobiographies can be explained in one sense as a *reaction* to the biomedical model, these works and their counterparts authored by non-physicians may also be *influences* for reforming that approach. One of the earliest calls for changing the biomedical method comes from George Engel, who, in a 1977 essay in *Science*, suggests a “biopsychosocial” model, one that considers the mind-body-social connection, replace the traditional biomedical model (Hawkins “Reconstructing” xi).

Literary accounts of illness began to be used at around the same time as Engel’s essay in new literature and medicine and narrative medicine courses for medical students with the goal of re-invoking the patient’s voice and sensitizing students to the experience of ill patients. Such courses were being taught in 74 percent of U.S. medical schools by 1998; in 39 percent of those schools, the course was a requirement (Charon “Literature and Medicine: Origins” 23).¹¹ According to a review of the value of literature in clinical

¹¹ Examples of literary texts studied in literature and medicine courses can be found at New York University’s *On-line Database of Literature, Arts, and Medicine* (<http://endeavor.med.nyu.edu/lit-med/lit-med-db/index.html>) edited by Felice Aull. Medical journals that publish literary columns or discuss literature include *The Bellevue Literary Review* ([www. BLReview.org](http://www.BLReview.org)), *Annals of Internal Medicine* (“On Being a Doctor,” “On Being a Patient”), *JAMA: The Journal of the American Medical Association* (“A

practice noted by McLellan, studying literature helps physicians and physicians in training develop important skills in communication and moral reasoning, two areas vital to a biopsychosocial approach to treating patients (“Why” 110). Reading literary narratives of illness encourages a practice of medicine that is marked by empathy as well as accuracy:

One of the most fundamental challenges of modern medicine is that of making possible a fruitful coexistence between the objectifying ‘medical gaze’ and the interpretative effort of approaching the life world of an ill person—or in the words of philosopher Martyn Evans: ‘viewing the embodied self of the individual patient through the prism of biomedicine’s categories whilst remaining free to see the patient as (an) individual’ (Ahlzen 147).

(2) Publishing and readership changes. Changes in publishing and readership also correspond to the rise of physician autopathography. First, literacy rate growth and the paperback revolution in the United States during the twentieth century meant that a larger portion of the population was able to consume books—and indirectly shape their content—than in previous centuries. In earlier centuries, physician autobiographies were written for a different audience, one that distinguished itself in part by its very ability to buy and read such books. (Pollock “Physician Autobiography” 111). The paperback revolution enabled consumers to purchase books more inexpensively and publishers to distribute books in numbers large enough that one can find personal histories everywhere

Piece of My Mind”), *Mediphors*, a journal of writing by medical professionals, and the *Journal of General Internal Medicine*. Major literary magazines are doing pieces on medicine, too; *The New Yorker*, for example, includes columns in its “Annals of Medicine” section.

one finds other books: “on library shelves and in the syllabi of college courses; at the checkout counters of drugstores and supermarkets; on best-seller lists, as book club selections, and in reviews (almost weekly it seems) of *The New York Times*; in the knapsacks of high school students and hitchhikers” (Frank “The Wounded Storyteller” xiii).

Small presses and so-called “vanity” presses provide an alternative outlet for writers who are unable to interest a large publishing house in their life stories. Small presses often publish high-quality manuscripts that appeal to well-defined audiences. Vanity publishing is not necessarily an inferior route to the market; historically, many important works have been essentially self-published by authors. Hence, “those who have published their life stories over the years include miners, school superintendents, nurses, salesmen, auctioneers, church elders, beekeepers, insurance underwriters, waiters, bus drivers, and Cub Scout leaders, among many others.” (Bjorklund 10). Physicians are also a part of this list; several have used small presses or vanity presses to publish their autopathographies.

Second, as a type of autobiography, physician autopathography has provided fodder for reader interest in autobiography on the whole that began to rise significantly during the 1970s. Autobiography has become “the genre” in the “skittish period around the turn of the millennium” (Briscoe, Tobias, and Bloom ix).¹² Readers seem to be drawn to it because they perceive individual life stories as being not only authentic and

¹² An analysis using the Worldcat database shows “the number of new English language volumes categorized as ‘autobiography or memoir’ roughly tripled from the 1940s to the 1990s. The growth pattern over that period was approximately linear, rising from fewer than 1,500 in the 1940s to more than 3,000 in the 1970s, to over 4,000 between 1990 and 1996” (Gilmore 1).

compelling but also, as some have argued, because they are interested in voyeurism and confession (Schlesinger). James Atlas indicates the existence of this readership in the title of his May 12, 1996, article in *The New York Times* called, “Confessing for Voyeurs: The Age of Literary Memoir is Now.” Atlas describes the “confessing” writers as feeling they have a license to tell all and explains that “voyeur” readers are interested in authors’ experiences with such topics as alcoholism, mental illness, and physical ordeals (Atlas 25).

Physician autopathographers and their readers benefit one another. The physician writers provide an insider’s account of an experience (the account of which often serves as a type of catharsis) and a perspective unattainable by the general public, and readers who seek escape through stories of unique or unusual circumstances are offered the opportunity to see how a person whose public self is of interest “has negotiated the problem of self-awareness” through an often confessional-style account of what is usually a very private experience (Conway 6). As for pathographies on the whole, Couser suggests that “the appeal and popularity of such works may also satisfy readers with their old fashioned plot, vivid characters, life-and-death crises, and definite closure that much contemporary literature, with its minimalism and its self-reflective postmodernist conventions, does not” (Couser, “Recovering” 293).

(3) New considerations about disease and associated stigmas. Physician autopathography has risen at the same time that medical technology has contributed to improved general health and survival from formerly incurable diseases. As Hawkins observes, illness once was 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, however, 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” (Hawkins “Reconstructing” 11). Autopathographies have grown in number conceivably because making sense of or gaining control over the marginalizing illness experience becomes an impetus for crafting such works fully devoted to that experience. Furthermore, modern medicine has produced a fairly large group of people who are part of what Frank calls “the remission society.” Autopathographies are being written as a way of coping with the effects of long-term disease and with the speculation of re-occurrence following treatment of a major disease. “As acute, life-threatening diseases declined, they were replaced by chronic diseases less amenable to the administration of a ‘magic bullet.’ A generation that hardly knew serious illness came increasingly to view good health as a right rather than a fragile blessing” (Raju par. 7).

Finally, stigmas associated with diseases have softened over time. Instead of hiding in a closet, so to speak, after a diagnosis, people are more willing to talk about their disease and even to claim a place of honor through surviving it. Writing an autobiography is one way they do that.

Cancer is a disease that can be used to illustrate this transition. In earlier times, fears that cancer was contagious or inherited discouraged public discussion of it. In 1893, President Grover Cleveland hid his cancer from the public, fearing it would label him as “degenerate” (Harpham par. 4) As early as 50 years ago, it was taboo to use the word on the radio (Harpham par. 1). In 1977, Susan Sontag wrote a liberating, now classic essay

called *Illness as Metaphor* that encouraged the demystification of the fantasies and myths surrounding cancer (cancer as a curse, cancer as punishment, etc.) and showed it for what it is—just a disease that is highly treatable if caught early.¹³ She wrote that in contemporary imagination “the repression of violent feelings is imagined to cause cancer” (Sontag 27). This statement likely influenced, to some degree, cathartic “venting” of such feelings in the form of rising numbers of autopathographies and in the form of more open public discussion of cancer. By the time Ronald Reagan was diagnosed with colon cancer in 1985, for example, “cameras were all but invited into the operating room” (Harpham par. 4).

The “pride” and “liberation” organizations (Black Power, feminism, Gay Liberation, and more) of the latter 20th century also helped de-stigmatize cancer and other diseases according to Frank. They self-created separate systems of honor, and patients followed suit. Frank writes, “Individuals whose identity was once ‘spoiled’ now openly claim that identity and even claim it as a privileged state of being” (“Illness” 136). A disease or disease-related sympathy is openly displayed by wearing ribbons (with distinct colors for AIDS and breast cancer, for example), or by wearing T-shirts that express pride in identities, or even, it could be said, by writing a publicly available autopathography (Frank “Illness” 136).

The categorization of autopathography

The above exploration of potential explanations for the rise in physician autopathography touches on some of the reasons individuals—physician or not—write

¹³ According to Hawkins, Sontag’s focus on the negative or disabling aspects of metaphoric thinking about illness fails to take into account that myths may actually be enabling to some people who use them to cope and/or recover (“Reconstructing” 24).

accounts of their illness. These authorial motivations plus some additional ones (which are often interrelated), provide one way to categorize the genre. They include: to make money or to achieve fame through a hoped-for bestseller (Aronson “Autopathography” 1,600; Pennebaker 3), to promote a healing therapy or strategy (Hawkins “Reconstructing” 125), to counteract stigma (Frank “Illness” 136; Aronson “Autopathography” 1,599), to claim a place in the system of honor of those who share the illness (Frank, “Illness” 136), to offer commentary on the medical system and/or its practitioners (Aronson “Autopathography” 1,600; Hawkins “Reconstructing” 8), to complement an impersonal medical record with the perspective of the patient (Hawkins “Pathography” 127), to help others similarly afflicted (McLellan “Literature and Medicine: Narratives” 1,619), and to augment the patient’s own healing process,¹⁴ especially through catharsis that the writing process offers (Frank, “Illness” 135; Hawkins “Pathography” 129).

This last authorial motivation—to augment the healing process through the catharsis writing about it provides—is probably the most generalizable to most autopathographies. Scholars commenting on nearly any aspect of illness narrative, consistently describe the impetus behind what Hawkins calls the “pathographical act” as making meaning of the experience, as getting the illness under control, of confining

¹⁴ Research shows that writing about traumatic life experiences, including illness, has a beneficial effect on health and well being (Pennebaker 7; Pennebaker and Seagal 1,243). A 1999 article in *JAMA: The Journal of the American Medical Association*, reported that patients with mild to moderately severe asthma or rheumatoid arthritis who wrote about stressful life experiences showed clinically relevant improvement in lung function and reduction in disease severity at four months compared with those in the control group who wrote about emotionally neutral topics. “These gains were beyond those attributable to the standard medical care that all participants were receiving” (Smyth, J. M. et al. 1,304).

catastrophe, of imposing order, of understanding crises, of self-healing and self-recovery, “in conditions in which control is, or has been, particularly under threat” (Wiltshire 99).

Using authorial intent as a grouping mechanism, Hawkins places autobiographical narratives of illness into three categories: testimonial pathography—a chronicle of the events of an illness in which authors are often motivated by didacticism (desire to teach others) or altruism (desire to help others); angry pathographies, which reflect cultural discontent with medicine, and alternative pathographies, which advocate alternative modes of treatment (“Reconstructing” 10).

Besides authorial intent, Hawkins lists two other modes of categorizing the genre. The second is by the disease that is its subject, and the third is by dominant myths, metaphors and images (“Pathography” 128). Expanding on the third mode, in *Reconstructing Illness*, Hawkins says dominant myths found in pathographies include the journey myth, the battle myth, and the myth of rebirth, which she compares to spiritual autobiography. The journey myth draws on the powerful, ancient metaphor for any kind of heroic exploration of the dangerous and frightening unknown (78). The patient becomes the hero who travels into the perilous world of illness and returns to the world of the normal with some prize or knowledge (78). Writers see the journey as one into the territory of death and back (80) or one that explores the inner world of the psyche (81) or one that takes them into the other realms of the disease itself (81). The battle myth is full of military metaphors for combating illness. It is often found in patients’ stories about cancer, since cancer is so often compared to an alien intruder or an invading enemy and since its various therapies are compared to weapons with which to attack or destroy the disease (66). The rebirth myth has two primary components: the idea that the self is

transformed and the impression that the whole world appears new and different as a result (34). The traumatic illness, particularly if it brings one close to death, can also bring a sense of regeneration and renewal.

Frank categorizes autopathographies by dividing them into Quest stories, Restitution stories and Chaos stories (“Just Listening” 198). Quest stories, like the journey myth category Hawkins describes, involve a similar construct of journey and return. Frank also describes the illness in Quest stories as resulting in something that can be learned, something transformative, as with Hawkins’ rebirth category. Even if healing is impossible, personal growth occurs (Borkan, Reis, and Medalie 125). The Restitution story, the “culturally preferred narrative of sickness and health in the West” (Borkan, Reis and Medalie 125), tells of “getting sick, suffering, being treated, and through treatment, being restored to health” (Frank “Just Listening” 200).¹⁵ The Chaos story is orderless and provides no answers; it reflects on the disruption of illness and suffering from which nothing is gained (Borkan, Reis, and Medalie 125). If our culture prefers the Restitution story, it fears the Chaos story that “with illness, troubles multiply” (Frank “Just Listening” 202).

Finally, Aronson divides the book length medical narratives he calls “patient’s tales” into two simple categories: prosaic and poetic. The poetic accounts, he writes, “tend to be cast in more mythical terms,” and he cites themes Hawkins elaborates on, including “rebirth, battles, and journeys” (Aronson “Autopathography” 1,602). In addition to explaining this categorical approach to organizing autopathography, Aronson

¹⁵ Television advertisements and prime-time television “news magazines” provide models of the restitution plotline according to Andrea T. Wagner. “Someone is in pain, he purchases and uses a product, his pain is alleviated, and he is back to normal” (26).

notes a number of interesting connections in the nearly 300 accounts he has collected (some are by doctors but most are by academics, novelists, journalists and others who make their living wholly or partly through writing). More men (54 percent) write about their illnesses, and these conditions tend to be “serious, dramatic, or fashionable” –cancer for example—in contrast to “the agonies of backache or ingrowing toenails” (“Autopathography” 1,599). Aronson also points out that most of the accounts contain some form of the psychological defense mechanism of denial, including “ignoring or misattributing symptoms, causes, or the effects of therapy, deliberately hiding the illness from others, and anosognosia,” a type of denial which neurologist Oliver Sacks describes in his 1984 autopathography, *A Leg to Stand On*, in which he is unable or refuses to recognize his injured leg as his own (“Autopathography” 1,599).

The patient role, the physician role, and response to illness

It is appropriate to conclude this general overview of the categorization of autopathography with the idea of denial, since it is a reaction to the illness itself being written about and leads into the question of other responses to illness, those by patients and, especially, those by physicians—the basis for this study.

Just as Aronson and others discovered broad themes and patterns in autopathography regardless of the physician or non-physician status of the author, it is also true that, for anyone, becoming a patient has common features. According to the American Cancer Society, a person diagnosed with cancer often tries to maintain as much control as possible as a means of coping with feelings of chaos. Uncertainty, anger, sadness, fear, grief, frustration, disconnectedness, isolation, and resentment also

characterize patients in general who have been diagnosed with cancer (“What to Expect,” sec. 2).

But physicians have expert knowledge of disease processes, and they are members of a community that *treats* disease. It would be natural for them to have a different set of expectations about becoming a patient themselves and perhaps some different reactions to the transition than non-physician patients. For example, Frank writes that “to live in deep illness is to be constantly acutely aware of one’s differences,” (“Illness” 154) For physicians this awareness could be seen as particularly intense. They are normally in charge and the active agents in a hospital setting, but as patients in that same setting, they become that much more obviously not in charge and passive—insiders in an outsider’s shoes. Similarly, an expectation in Western health care, influenced by the biomedical model, is the idea that the role of patient demands relinquishing decision-making to the professional (normally a physician) and complying with the professional’s directives. When physicians become patients, they experience “violations of the self, including lack of privacy and direct physical defilement of the body” (Sakalys 1,471) and a loss of autonomy as any non-physician patient would, but their doctor role, their professional identity, is stripped much more patently than a patient of a non-medical occupation.

Stated in slightly different terms, the structure of medical practice involves a patterning of the roles of the physician and the sick person. In his 1951 work, *The Social System*, sociologist Talcott Parsons conceives of the roles of the physician and that of the patient as “complementary normative structures” (ten Have par. 4). But when *physicians* enter what Parsons calls the “sick role,” the pattern is displaced. Parsons conceives of

being sick as a social role. The situation of the patient is such that he or she is probably 1) helpless (passive) and in need of help, 2) relatively incompetent technically, and 3) emotionally involved—in shock, anxious, disturbed—and 4) vulnerable, making a high level of rationality of judgment particularly difficult (ten Have par. 9). In contrast, the role of the physician belongs to the class of professional roles. It is expected that the physician has, through training and experience, acquired a set of special competences, and on that basis is, unlike the sick person 1) in control and an active helper, 2) technically competent, as a result of training and experience and 3) objective, and reasonably unemotional in dealing with problems though specifically focused technical terms and 4) known for rationality and strength of judgment.

Though not found in large numbers, articles in medical journals and sociology and anthropology texts cover some aspects of the experience of patienthood by physicians. Most have to do with role-reversal, especially with regard to the imbalance of power, authority and control between the role of doctor and that of patient. Gautam and MacDonald mention personality traits that affect the course of a physician's illness, including perfectionism, a strong sense of responsibility, and a need for control and approval (336). Schneck outlines the "VIP syndrome" that affects many doctors and is especially evident upon inception of an illness. He cites one study that found fewer than half the treating physicians chosen by physician-patients could be considered high quality and associates this with the idea that "for many physician-patients, the loss of quality care seems less costly than the loss of rank, authority, and autonomy" (2,040). When the physician-patient felt equal to the treating physician, the relationship was more collegial

instead of a physician-patient association. But when the physician-patient chose a “superior” physician, the sick doctor was most likely treated as a patient.

Gautam and MacDonald, Schneck, and Osmun, Brown, and Munoz, all writing in medical journals, observe that physicians tend to delay getting help and treatment, minimize symptoms, and self-medicate. Not wanting to appear weak, bother colleagues, lose control of their care, or deal with confidentiality issues are all reasons given for these responses. Fear, embarrassment, guilt, anger, and denial are also seen in physician-patients. While these are also reactions experienced by non-physician patients, for physician-patients they are felt for some singular reasons. Denial experienced by physicians, for example, can be based on the fact that physicians often think of illness as affecting other people. Medical training “plays a large, if unintentional, part in such thinking” (“The Doctor is Unwell” 1,249). One reason for anger is being unable to prevent or fix the illness; a reason for guilt is the placement of added burden on colleagues; and a reason for fear springs from the idea of being disabled so much so that they are unable to function as doctors—“a huge part of their identity” (Gautam and MacDonald 336).

In the only analysis that devotes itself completely to the genre of physician autopathography, anthropologist Robert Hahn looks at three books, two articles in anthologies, and nine articles in medical journals to discover how physicians encounter affliction, bear affliction, and convalesce. He concludes, “When suffering breaks through, the process of translation—of the encounter within individuals of two cultures, two languages, two societies—is most often not a smooth but a cataclysmic sequence” (257). He then lists 14 features shared by physician-patients:

1. The damage is initially seen as someone else's.
2. It is minimized.
3. It is intellectualized, transformed into a subject for writing and teaching.
4. Physician patients diagnose their own conditions.
5. They may treat themselves and they may delay in seeking treatment by others.
6. They evaluate the diagnoses, prognoses, explanations, treatments, and care given by their colleagues.
7. They mistrust some of their physicians or their physicians' diagnoses, therapeutic prescriptions, or prognoses.
8. They discover a special need for understanding, explanation, support, and sympathy from colleagues, beyond what is strictly "medical."
9. They strive to have non-"crock"-like conditions and to be "good patients."¹⁶
10. They strenuously avoid passivity and lack of control.
11. They recall other patients whom they may have misunderstood or who may have had severe side effects with conditions similar to their own.
12. They continue to monitor themselves, medically hypervigilant for signs and symptoms indicating possible changes in their conditions.

¹⁶ According to Becker, medical social jargon defines a "crock" as a patient who has multiple complaints but no discernible physical pathology (par. 17).

13. They reexamine themselves and their histories in the search for etiology and broader explanation.

14. They reformulate their theory and practice of medicine in the light of their patienthood (257-258).

Summary

This literature review on pathography in general, and physician autopathography in particular, shows that the number of research articles is fairly small and their scope is relatively limited. Within the body of literature on the illness experience of physicians, the understanding of their responses to becoming a patient “remains largely fragmented and in its infancy” (Morse and Johnson 1).

CHAPTER THREE

Method

This study used a recognized qualitative approach—thematic analysis—to unobtrusively¹⁷ examine nine physician-written autopathographies on cancer in order to better understand how physicians experience illness and where they position themselves along what has been called a dividing line between the role of doctor and the role of patient. The unit of analysis was technically the individual autopathography, but in a defacto sense, through what was essentially a detailed case study in each instance, it was the doctor-patient actor.

Qualitative research “provides rich, descriptive detail” (Trochim 153) through the exploration, description, and contextualization of experience (Henwood and Pidgeon). Such experience can be studied in a variety of ways including “through written documents” (Trochim 163). Koski’s qualitative reading of the autobiography of medical education provided an initial framework for this study, which aimed to uncover “an integrating scheme within the data themselves” (Christians and Carey 370 qtd. in Koski 40)—with the data being physicians’ words through the text of their autopathographies.¹⁸

There are several ways to analyze the expression of experience in texts (Taylor and Bogdan), and thematic analysis is one such way. Thematic analysis is a qualitative form of content analysis, which is the analysis of written documents with the major purpose being to identify patterns in text (Trochim 165). In thematic analysis, such

¹⁷ According to Trochim, unobtrusive measures don’t require researcher interaction with the population of interest (165).

¹⁸ Russo and McClure assert that autobiographies can be rich sources of raw data (3).

patterns are called themes. They are identified by aggregating components or fragments of the authors' ideas or experiences (including, for example, conversation topics, vocabulary, recurring activities, and expression of feelings). These components or fragments, often meaningless when viewed alone, are brought into a comprehensive, meaningful picture by the analyst (Leininger 60).

The first step to a thematic analysis is to locate patterns of experiences from the data (Jodi Aronson par. 4), or expressed another way, to transform the raw data into categories based on a conceptual scheme (Babbie 328). The books were read once with a guiding question in mind: How do the doctor-authors manage and express their role as patient in relation to the metaphor of the dividing line? On second and third readings, extensive notes were taken of key phrases from direct quotations or paraphrased common ideas. During this iterative process, three overarching categories developed, in which the authors could be described in terms of high-doctor/low-patient; as high-doctor/high-patient; and as low-doctor/high-patient. The first group stood fast to the doctor side of the dividing line. The second group straddled the line. And the third group crossed the line to the patient side.

The next step to a thematic analysis is to identify aspects of the data that relate to the already classified patterns (Jodi Aronson par. 6). Egon G. Guba calls this looking for "recurring regularities" (Patton 154). Verbatim extracts were located to elucidate and exemplify each of the three categories, and care was taken, as good qualitative research demands, to clearly distinguish between what the respondent said and interpretation of it (Strauss and Corbin 22). During this stage, features of the research method of narrative

analysis were used¹⁹ to ask specific questions of the texts. Attention was paid to subtlety: nuances of vocabulary, the organization of a response, and other aspects of positioning the narrators use to construct self in autobiography—especially with regard to control and passivity (doctor-type versus patient-type roles).²⁰ Examples of questions asked include:

- To what extent do the authors self-diagnose and/or self-treat?
- How do they self-describe their symptoms and/or treatment, e.g., using technical medical jargon versus lay terminology?
- How does their use of pronouns disclose their role, e.g., the pronoun “we” may indicate inclusion with the treating physician or inclusion with other patients depending on the context.
- To what extent do they use their professional knowledge and credentials in seeking status and priority during treatment?
- To what extent do they criticize or praise their care or those providing it?
- What is the typical range of responses demonstrated, e.g., trust vs. distrust, expressed need vs. stoicism, cooperation or lack thereof with treatment providers?
- What kinds of emotions (e.g. anger, self pity, arrogance, fear, humility) are dominant?

¹⁹ According to Reissman, narrative methods can be combined with other forms of qualitative analysis.

²⁰ In a discourse on narrative analysis, Reissman writes that narrators can position themselves as victims of one circumstance or another in their stories, giving over to other characters the power to initiate action. Alternatively, narrators can position themselves as assuming control over events and actions: they purposefully initiate and cause action. They can shift among positions, giving themselves active roles in certain scenes, and passive roles in others.

Lastly, the recurring regularities were judged by their “internal homogeneity,” which is the extent to which the data that fall under a certain theme or category “hold together or dovetail in a meaningful way.” (Patton 154).

The next four sections describe: Criteria for defining physician autopathographies, Strategy for locating physician autopathographies, Results of the search for physician autopathographies, and Criteria for selecting primary sources. The following chapter then presents the findings of this thematic analysis of physician autopathography.

Criteria for defining physician autopathographies

To guide the search, the following criteria were adopted for a work to be considered a physician autopathography:

- published, book-length autobiographical narrative
- written by a U.S. physician
- completely or largely devoted to the author’s own experience as a patient with disease/illness, disability or injury.

“Published” means that the book is not in the form of a manuscript; that it is in print—not in electronic—form; and that it has been issued an International Standard Book Number (ISBN).

“Autobiographical” means the book is an autobiography, which comes from three separate words: “auto” for self, “bio” for life, and “graphe” for writing and as a unit means, “writing the life of the self.” This study adopted Philippe LeJeune’s conditions of autobiography, which he outlines in his autobiographical pact—“Le Pacte Autobiographique.” The text must be “*mainly* a narrative,” the perspective is “*mainly*

retrospective,” and, most important, “the author, the narrator, and the protagonist *must* be identical” (LeJeune 5). In addition, “the author of an autobiography cannot be anonymous [...] the contract of identity is sealed by the proper name” (19). Collaboration is possible, but LeJeune contends that it “blurs in a disturbing way the question of responsibility, and even damages the notion of identity” (192).

It should be noted that “truth” and objectivity in autobiography are subjects much debated among postmodern scholars who question the reliability of such introspective accounts. Indeed, “writing about an experience inevitably changes it,” because autobiographical narrative “organizes events of experience into a beginning, a middle, and an end and adds drama” (Hawkins “Reconstructing” 15). Some critics, though, go so far as to argue that the past does not exist—that there are only memories of it and that those are merely “scattered shards” (Pike 337); others even question the existence of the self (Elbaz). There are those scholars, however, who bypass the issue of the fictional status of self and uphold what Elizabeth Bruss calls the “truth value” of autobiography (Hawkins, “Reconstructing” 16). LeJeune, for example, states that, as opposed to all forms of fiction, “autobiographies provide information about a ‘reality’ exterior to the text” (22).²¹ He adds that autobiographies will include an implicit or explicit “referential pact,” in which are included “a definition of the field of the real that is involved” and “a

²¹ Aronson writes, “Fabrication is almost always unavoidable in autobiography, but if it adds verisimilitude to the account, is that to be regretted? Does it vitiate or strengthen it? Both, I think, are possible” (“Autopathography” 1,602). Bjorklund adds, “The subjectivity of autobiographies is precisely what is interesting” (9).

statement of the modes and the degree of resemblance to which the text lays claim” (22).²²

A “narrative” is “a pattern of events placed in an order of sorts, involving a succession of occurrences or recounted experiences from which a chronological sequence may be inferred” (Hurwitz 2,086) or more simply, a specific story of past events that follows a chronological sequence and always responds to the question, “and then what happened?” In general, narratives aid individuals in making sense of equivocal situations. When confronted by unclear situations, people will always tell a story to clarify and explain; in other words, narratives allow participants to bring order to what would otherwise be very “messy” conditions—including illness (Taylor and Lerner).

“Authored by a U.S. physician” means that the author must have completed the full course of post-graduate allopathic or osteopathic medical training, usually indicated by the title M.D. or D.O. after the author’s name or by an explanation of such training completed in the text.

A “patient” is a person under medical or surgical treatment (and the author’s account must be completely or largely devoted to the experience of *being* a patient).

In referring to what ails the patient, the terms, “illness” and “disease” for this study will be considered interchangeable (as synonyms).²³ The term, “disability” is

²² Most of the authors of the physician autopathographies do explicitly claim somewhere in the front or end matter of their books to have written a “true story,” sometimes adding a confidentiality statement that names (except their own) have been changed.

²³ Fleischman explains that the three ordinary-language terms available in English to refer to states of ill health—sickness, illness, and disease—all correspond to the single French term “maladie,” but some medical anthropologists are more widely adopting a distinction between the terms “illness” and “disease.” Illness implies “a pathology that has been incorporated into the self,” and a disease “remains outside the self” as more of a “conceptual entity” or category of clinical taxonomy (7).

defined as a physical or mental incapacitation or impairment, and the term, “injury” is defined as any physical damage to the body.

Strategy for locating physician autopathographies

A combination of search strategies was used to locate these texts, including a systematic culling through of more than 900 entries listed under the general subject heading “Physicians – Biography” in the WorldCat database; a search of large on-line bookstores (allbooks.com, amazon.com, barnesandnoble.com), bibliographies of autobiography (Kaplan; Briscoe, Tobias, and Bloom), and annotated bibliographies of pathography (Aronson, “The Patient’s Tale”; Hawkins, “Reconstructing”), which occasionally included some autopathographies by physicians.

Results of the search for physician autopathographies

Forty-five works were physically retrieved and examined. Fifteen of these books were eliminated because, although they appeared from the citation to meet the criteria for physician autopathography, they were lacking in one or more ways. Some books were eliminated because they were authored by non-U.S. physicians. Two of these were *Physician Heal Thyself* by Hugh Faulkner (1992), an English physician writing about his dietary recovery from cancer and *Dose of My Own Medicine* by Paul B. Campbell (1992), a Canadian, whose work is not about his own illness experience at all but about his experience as personal physician to Christian evangelist Frank Buchman.²⁴

Several other books seemingly had fitting titles for the list but a look inside them proved they did not meet the criteria. One with a rather early publication date was

²⁴ Buchman initiated an international movement calling for moral and spiritual renewal in the 1920s called “the Oxford Group.” After 1938 the name was changed to “the Moral Re-Armament,” and the movement became more involved in political and social issues, particularly during the Cold War period when its anticommunist orientation found a receptive climate (“Moral Re-Armament”).

Incurable Physician: An Autobiography by Walter C. Alvarez (1963). The introduction gave away its purpose as a whole-life memoir. Dr. Alvarez writes, “I have an interesting story to tell—of medicine and its remarkable development during the last 70 years [...]” (ix). Two other books with convincing titles were *Surviving the Fall: The Personal Journey of an AIDS Doctor* by Peter A. Selwyn (1998) and *Common Bonds: Reflections of a Cancer Doctor* by E. Roy Berger (1995). Each author actually wrote about his patients’ illnesses, not his own. Not just the title but the front of the dust jacket of Berger’s book is convincing: “In this candid medical autobiography [Berger] shows [...] ‘what it is like to be the person at the other end of the stethoscope’” But the inside pages confirmed that the book is about the oncologist author’s interactions with his cancer patients.

Another two books that didn’t make the list but are worthy of note are by physicians with disabilities. Philip Zazove, author of *When the Phone Rings, My Bed Shakes* (1993) is a physician with “profound hearing loss, one great enough so that he depends on speech reading for nearly all his communication” (vii). David Hartman, author (with Bernard Asbell) of *White Coat, White Cane* (1978) is a psychiatrist and “the first blind person in a hundred years to be admitted to a medical school” (4). Both works are memoirs that follow the authors’ struggles to prepare for and reach medical school. Hartman’s book ends once he has been admitted. Zazove is admitted three quarters of the way into his book. Although he does include some vignettes of his patients, very little mention is made of how his deafness affects his dealings with them.

Finally there is *A Coronary Event* by Michael Halberstam and Stephan Lesher (1976), which offers in alternating chapters the accounts of a patient who suffers a heart

attack and the doctor who treats him. The patient (Lesher) is not the physician, however, and the doctor (Halberstam) is not sick himself.

In conclusion, after the search, retrieval, examination, and elimination process, 30 books remained that can be considered physician autopathographies. They are listed in order of copyright date as “Physician Autopathographies” in Table 1. Illness type and physician author medical specialty as well as in-print status and sales rank information for the books are also included in the table.

Several of the works that made the list also need some qualification and explanation. Similar to *A Coronary Event*, Dahlberg and Jaffe jointly wrote *Stroke: A Doctor’s Story of His Recovery* (1977), but in the case of this book, both authors are physicians. Dahlberg, a psychiatrist, suffers a stroke, and his experiences as a patient are recorded in two thick chapters entitled, “The Incident” and “Recovery.” Jaffe, also a psychiatrist, then takes over in the second half of the book, providing “a somewhat tutorial commentary on Dahlberg’s story” (12).

One of the books was first published serially. Pathologist Samuel Sanes authored *A Physician Faces Cancer in Himself* as a series of articles for *The Buffalo Physician*, a quarterly alumni publication of the School of Medicine of the State University of New York at Buffalo, beginning with the issue of Summer 1974 and ending with Fall 1978. Sanes had been diagnosed with incurable disseminated reticulum cell carcinoma two years after retiring from his teaching position on the university’s faculty and died shortly after reading the proofs for the last article. The articles were subsequently published in

Table 1. Physician Autopathographies

AUTHOR(S)/ BIRTHDATE (IF KNOWN)	TITLE/ NUMBER OF PAGES	1ST ED. COPYRIGHT DATE/ PUBLISHER	ILLNESS	MEDICAL SPECIALTY	IN-PRINT STATUS & AMAZON.COM SALES RANK (AS OF APRIL 2003)*
William A. Nolen (b. 1928)	Surgeon Under the Knife/223	1976/New York: Coward, McCann & Geoghegan	Heart Disease	General Surgery	Out of print 1,325,171/1,421,173 (hardback/paperback)
Charles Clay Dahlberg (b. 1924) with Joseph Jaffe	Stroke: A Doctor's Personal Story of His Recovery/200	1977/New York: W. W. Norton & Co.	Stroke	Psychiatry	Out of print 1,219,475 (hardback only)
Samuel Sanes (b. 1906)	A Physician Faces Cancer in Himself/201	1979/ Albany: State University of New York Press	Cancer	Pathology	Out of print 1,894,402 (hardback)
Ann Marie Travis	From Hell to Health: An Autobiography of a Physician/316	1980/Pinson, AL: A.M. Travis	Depression	Neurology	Not listed on amazon.com or in Bowker's Books in Print
Joseph D. Waxberg (b. 1922)	Bypass: A Doctor's Recovery From Open Heart Surgery/165	1981/New York: Appleton- Century-Crofts	Heart Disease	Psychiatry	1,634,125 (hardback only)
Fitzhugh Mullan (b. ~1943)	Vital Signs: A Young Doctor's Struggle With Cancer/203	1982/New York: Farrar, Straus, Giroux	Cancer	Pediatrics	Out of print 1,421,251 (paperback only)

* In-print status was determined by individual title searches through the on-line site of Bowker's *Books in Print* (www.booksinprint.com/bip). Books are in print unless stated otherwise. Sales rank is included as a rough estimate of title popularity. The figures were collected from listings on Amazon.com, (www.amazon.com) which explains in "What Sales Rank Means" that regularly updated sales rank figures show how items in their catalog are selling, "much like *The New York Times* Bestsellers List, except it lists millions of items" (www.amazon.com/exec/obidos/tg/browse/-/525376/ref=br_bx_c_2_13/103-0055663-6393407). The lower the number, the higher the sales for a title. Amazon.com is a virtual on-line retailer with the "largest pool of transacting consumers on the Internet" according to Baker, L. et al. "Amazon.com" *Salomon Smith Barney*. 18 March 2003.

Table 1. (Continued)

AUTHOR(S)/ BIRTHDATE (IF KNOWN)	TITLE/ NUMBER OF PAGES	1ST ED. COPYRIGHT DATE/ PUBLISHER	ILLNESS	MEDICAL SPECIALTY	IN-PRINT STATUS & AMAZON.COM SALES RANK (AS OF APRIL 2003)
Anthony J. Sattilaro and Tom Monte	Recalled by Life/222	1982/Boston: Houghton Mifflin	Cancer	Anesthesiology	455,844/148,724 (hardback/paperback)
Oliver W. Sacks (b. 1933)	A Leg to Stand On/222	1984/ New York: Summit Books	Injury plus Neurological Disorder (Anosognosia)	Neurology	Out of print 1,436,018/65,192 (hardback/paperback)
Dr. Edward E. Rosenbaum (b. 1915)	The Doctor: When the Doctor is the Patient/181	1988/New York: Ballentine Books	Cancer	Rheumatology	Out of stock indefinitely 644,086/780,064 (hardback/paperback)
Dr. Earle M.* (b. 1911)	Physician, Heal Thyself!/246	1989/ Minneapolis: CompCare	Alcoholism	Obstetrics and Gynecology	Out of print 705,442 (paperback only)
Martha A. Morrison (b. 1952)	White Rabbit: A Doctor's Story of Her Addiction and Recovery/240	1989/New York: Crown	Alcoholism & Drug Addiction	Psychiatry	Out of stock indefinitely 1,092,397/610,765 (hardback/paperback)
Francesca Morosani Thompson (b. 1944)	Going for the Cure/295	1989/New York: St. Martin's Press	Cancer	Orthopaedic Surgery	1,550,962/ 453,737 (hardback/paperback)
Allen Widome (b. 1915)	The Doctor the Patient: The Personal Journey of a Physician With Cancer/246	1989/Miami: Editech Press	Cancer	Anesthesiology	2,401,026 (paperback only)
Edward G. Rozar with David B. Biebel	Laughing in the face of AIDS: A Surgeon's Personal Battle/160	1992/Grand Rapids, MI: Baker Book House	HIV/AIDS	Thoracic Surgery	Out of print 2,234,646 (hardback only)
Madeleine Meldin	The Tender Bud: A Physician's Journey Through Breast Cancer/212	1993/Hillsdale, NJ: Analytic Press	Cancer	Psychiatry	1,902,449 (hardback only)

* Author as published is "Earle M."; complete name is Earle Millard Marsh.

Table 1. (Continued)

AUTHOR(S)/ BIRTHDATE (IF KNOWN)	TITLE/ NUMBER OF PAGES	1ST ED. COPYRIGHT DATE/ PUBLISHER	ILLNESS	MEDICAL SPECIALTY	IN-PRINT STATUS & AMAZON.COM SALES RANK (AS OF APRIL 2003)
Jerry W. Haggard	I Had a Stroke and Survived/202	1994/Salt Lake City: Northwest Publishing	Stroke	Unknown	1,956,623 (paperback only)
Robert Jon Pensack with Dwight Arnan Williams	Raising Lazarus/317	1994/New York: G.P. Putnam's Sons	Heart Disease	Psychiatry	669,671/849,706 (hardback/paperback)
Richard Selzer (b. 1928)	Raising the Dead: A Doctor's Encounter With His Own Mortality/118	1994/New York: Viking	Legionnaire's Disease and Coma	General Surgery	2,166,973/355,769 (hardback/paperback)
Jody Heymann	Equal Partners: A Physician's Call for a New Spirit of Medicine/257	1995/Boston: Little, Brown	Epilepsy	Pediatrics (Resident)	697,355/636,084 (hardback/paperback)
Kay Redfield Jamison	An Unquiet Mind: Memoirs of Moods and Madness/223	1995/New York: Alfred A. Knopf	Manic-depression	Psychiatry	50,409/862 (hardback/paperback)
James E. Payne (b. 1935)	Me Too: A Doctor Survives Prostate Cancer/143	1995/Waco, TX: WRS Publishing	Cancer	General Surgery	Out of print 1,276,048 (paperback only)
Barbara Joseph	My Healing From Breast Cancer/389	1996/New Canaan, CT: Keats Publishing	Cancer	Obstetrics and Gynecology	166,007 (paperback only)
Mahlon Johnson (b. 1954) with Joseph Olshan	Working on a Miracle/301	1997/New York: Bantam Books	HIV/ AIDS	Neuropathology	Out of print 601,283/447,029
Claudia L. Osborn	Over My Head: A Doctor's Account of Head Injury From the Inside Looking Out/239	1998/Naples, FL: Peripatetic Publisher	Head Injury	Internal Medicine	20,142/17,489 (hardback/paperback)
David Biro (b. 1964)	One Hundred Days: My Unexpected Journey From Doctor to Patient/291	2000/New York: Pantheon	Blood Disorder (Hemoglobinuria)	Dermatology	84,765/165,795 (hardback/paperback)

Table 1. (Continued)

AUTHOR(S)/ BIRTHDATE (IF KNOWN)	TITLE/ NUMBER OF PAGES	1ST ED. COPYRIGHT DATE/ PUBLISHER	ILLNESS	MEDICAL SPECIALTY	IN-PRINT STATUS & AMAZON.COM SALES RANK (AS OF APRIL 2003)
Michael A. Dorso (b. 1942)	Seeds of Hope: A Physician's Personal Triumph Over Prostate Cancer/268	2000/Battle Creek, MI: Acorn Publishing	Cancer	Emergency Medicine	209,265 (hardback only)
F. Ralph Berberich (b. 1942)	Hit Below the Belt: Facing up to Prostate Cancer/211	2001/Berkeley, CA: Celestial Arts	Cancer	Pediatric Hematology and Oncology/ Pediatrics	194,311 (paperback only)
Jerri Nielsen (with Maryanne Vollers)	Ice Bound: A Doctor's Incredible Battle for Survival at the South Pole/362	2001/New York: Talk Miramax Books/Hyperion	Cancer	Emergency Medicine	1,354/42,223 (hardback/paperback)
Geoffrey Kurland (b. 1946)	My Own Medicine: A Doctor's Life as a Patient/251	2002/New York: Times Books	Cancer	Pediatric Pulmonology	30,060 (hardback only)
Jamie Weisman	As I Live and Breathe: Notes of a Patient-Doctor/244	2002/New York: North Point Press	Immune Deficiency (Congenital Autoimmune Deficiency)	Dermatology (Resident)	179,956/968,619 (hardback/paperback)

book form in 1979. The first half of the entire work is dedicated specifically to Sanes' illness; the second half focuses on his other patients and lecture-like tips on doctor-patient communication. According to the foreword of the book, written by his wife, Sanes never missed a deadline, even though writing became difficult as his disease progressed and he "felt that education of the public was as much a part of his responsibility as a physician as education of members of the health profession" (ix).

Four physician authors on the list—Morrison, Jamison, Pensack, and Weisman—suffer with the illness they write about even before they become doctors. These authors do provide substantial background about the nature of their illness and its progression before medical school graduation, but in each case the largest focus of their books is on the interaction between each author's role as both physician and patient.

Martha Morrison and Kay Redfield Jamison, both psychiatrists, are also patients with psychiatric illnesses. Morrison deals with alcoholism and drug dependency in *White Rabbit: A Doctor's Story of Her Addiction and Recovery* (1989), and Jamison, whose *An Unquiet Mind: Memoirs of Moods and Madness* (1995) became a bestseller, has manic depression. Morrison, who at one point was practicing medicine while abusing 12 drugs including alcohol on a daily basis, poignantly describes the tension of knowing she needs medical treatment herself but avoiding it at all costs: "Dr. Carter recommended hospitalization several times [but] I couldn't let them hospitalize me. I knew what psychiatric hospitals were like. I was the local expert" (122). Similarly, Jamison writes that her own psychiatrist tried to persuade her to enter a psychiatric hospital for her depression, but she refused: "I was horrified at the thought of being locked up. [...] I was

working on a locked ward at the time, and I didn't relish the idea of not having the key" (112).

Robert Jon Pensack, also a psychiatrist, has an inherited disease called idiopathic hypertrophic subaortic stenosis, also known as hypertrophic cardiomyopathy, an often-fatal heart condition. According to the book jacket of *Raising Lazarus* (1994), written with the collaboration of writer Dwight Williams, Pensack determines to become a doctor and be his own patient in order to "save himself," and according to the introduction, he wrote the book for "catharsis" (v). Pensack describes his wait for a heart transplant, details the operation, and shares his physical and emotional reactions to that traumatic experience.

Jamie Weisman, born with an incurable defect in her immune system called congenital autoimmune deficiency disorder (CADD), begins *As I Live and Breathe: Notes of a Patient-Doctor* (2002) as she graduates from medical school, and the action in the rest of the book takes place while she is a resident physician studying dermatology. She tells of the tension of being a doctor but needing doctors to treat her and also the frustrations of knowing a great deal about medicine herself but having her symptoms dismissed by other physicians. For example, one morning she wakes with pain in her jaw and knows she has an infection in her parotid gland. When she calls a doctor with the situation, he interrupts her with, "Parotid infections [...] are always caused by one of two organisms. [...] Go buy some lemon drops to suck on" (91). Weisman then explains that because of her immune deficiency she is prone to unusual infections, but the response from the doctor is, "Not in the parotid. [...] Look, I've got a really busy clinic. Patients waiting" (91). Weisman critiques the situation:

Somehow he had managed to turn the fact that I was a doctor back on me [...] I was only [...] an intern [...] and I was so used to clear and covert insinuations of ignorance that the doctor's condescending tone was not immediately apparent to me. He knew more than I, he said, and he implied that it was out of ignorance alone that I was calling him with petty questions and requests (91).

Similar to the previous four books mentioned is *From Hell to Health: An Autobiography of a Physician* (1980), by Anne Marie Travis, who was born with cerebral palsy, completes medical training and then writes of her experience as a neurologist in training with the added perspective of the only female in the program at the University of Minnesota in the late 1950s. But unlike the four books above, Travis writes more about the depression she is afflicted with following medical school than the cerebral palsy she already has. She is fairly critical of the care she receives: "The psychiatrists had little time for me or the other patients ... they had no time to listen" (139). Her book is the only self published one on the list, and it is also the only one that frames illness and recovery in spiritual terms. Travis writes in a preface, "It was never my intention to write a book. That was God's idea—not mine" (ix) and leads each chapter with Biblical epigraphs.

Two books on the list are by physicians who have suffered injury. Physician-writer Oliver Sacks, best-selling author of *Awakenings* (1973), which inspired a major motion picture in 1990 starring Robin Williams, and *The Man Who Mistook His Wife for a Hat* (1985) (both books are non-fiction clinical tales of unusual cases encountered during Sacks' years of medical practice), writes in *A Leg to Stand On* (1984) about his

strange recuperation from a severe knee injury he incurred after being chased by a bull on a mountain in Norway. He finds his immobilized leg no longer feels part of his body, a condition of denial called anosognosia. Claudia L. Osborn's *Over My Head: A Doctor's Account of Head Injury From the Inside Looking Out* (1998) recounts the internal medicine physician's recovery from a traumatic brain injury she sustained in a bicycle accident. The book was an Alternate Selection of the Literary Guild Book Club and a condensed book in the March 1998 edition of *The Reader's Digest* (Osborn "About Claudia Osborn" par. 4).

Many books on the market are written by physicians to promote alternative healing strategies. Only a small number of these combine the physician's outlined healing approach with a narrative about the author's own experience with illness. Two of the books that do so substantially enough to make the list are *Recalled by Life: The Story of My Recovery From Cancer* (1982) by anesthesiologist Anthony J. Sattilaro with Tom Monte, a medical journalist, and *My Healing From Breast Cancer* (1996) by Barbara Joseph, an obstetrician and gynecologist. Sattilaro integrates his recipe for complementary approaches to cancer with his story more seamlessly than Joseph. In his forties, Sattilaro is diagnosed with both testicular and prostate cancer with metastasis to the bone and is deemed terminal by his physicians. He tries a macrobiotic (vegetarian) approach to healing and defies the odds pronounced on him. Part of his tension comes from being not only a physician with cancer but also a physician practicing macrobiotics—an Eastern, philosophically based system—in a world of Western medicine. Joseph integrates italicized blocks of text describing her own breast cancer experience with medical information about breast cancer in general and her suggested

approaches beyond traditional medicine for treatment, including diet, supplements and visualization. The italicized narrative includes many allusions to Joseph's fears, which she notes are exacerbated by the fact that she is also a physician—"my experience in gynecologic oncology heightened my anticipation of the horror" (58).

Finally, the two books that made the list but which are most potentially problematic are *Physician, Heal Thyself!* (1989) by Earle M., an obstetrician and gynecologist, and *Raising the Dead: A Doctor's Encounter With His Own Mortality* (1994) by Richard Selzer, a general surgeon turned award-winning, full-time writer.²⁵ Earle M. begins the preface to his book: "I am a physician, licensed to practice in a western state. I am also an alcoholic" (xvii). He takes the reader on his journey to sobriety by way of Alcoholics Anonymous, describing his emotions and symptoms but also detailing the long-term recovery process of the AA program. In this way, the author is a physician with an illness, but his patient role is described for the most part as under the "care" of AA and not under conventional health care providers. Like other physicians writing about their illness, however, Earle M. has just as much difficulty dealing with issues of status. He writes of his first meeting, "I glanced around the table and realized that I, the Great Physician, was in the company of a butcher, a carpenter, a baker, and a kind of ne'er-do-well mechanic! I considered them to be four inferiors" (Chap. 2 page 1). Also problematic is the shortened name of the author. The use of a first name and last initial is common to AA; indeed, an informational "Anonymity Letter to Media" at the

²⁵ Richard Selzer, a former surgeon and professor of surgery at Yale University, is the author of numerous articles and collections of essays and short stories. He taught writing at Yale and is the recipient of dozens of awards and honors, including the Columbia School of Journalism National Magazine Award, the American Medical Writer's Association Book Award, and a Guggenheim fellowship. His work has been published in *New American Review*, *Esquire*, *Harper's* and other periodicals (Stripling, screen; Gannon 50-51).

organization's Web site proclaims, "Anonymity lies at the heart of our Fellowship" (par. 3). This is a direct contradiction to part of Phillippe LeJeune's autobiographical pact that states, "The author of an autobiography cannot be anonymous" (LeJeune 19). In a search for the author's identity, a past feature was discovered on a personal web site about Alcoholics Anonymous history titled, "Dr. Earle M's On-line Memorial Book," which listed his death as occurring on January 13, 2003 and provided an excerpt, still without the full name, from his obituary printed in the *San Francisco Chronicle*. A search of past obituaries at the newspaper's on-line site provided the answer: Earle M. is Earle Milliard Marsh, M.D. ("Marsh" E9)

Selzer's *Raising the Dead* is also problematic for the questions it raises about authentic autobiography. Selzer's story begins when in 1991 he falls, is rushed to the hospital where he formerly practiced, and is diagnosed with Legionnaires' disease by his former colleagues. He lapses into a coma for three weeks, is transferred to the intensive care unit, and subsequently recovers. His book is a "reconstruction of what he thinks might have happened during his serious illness" (Aronson, "The Patient's Tale"). But because he is not conscious while comatose, he essentially has to invent the story of what might have happened and in this sense is an example of an unreliable narrator. Aronson includes the work (one of few authored by physicians) in his annotated bibliography of autopathographies but cautions, "Nowhere does the issue of fabrication in autobiographical accounts rear its head so high as here" ("The Patient's Tale").

Criteria for selecting primary sources

Hawkins writes that one way of categorizing pathography is by disease type ("Pathography" 128) and also that there are certain patterns specific to individual diseases

(“Reconstructing” 4). Since 13 of the autopathographies found were about cancer, that category became an obvious one to use for analysis. To further limit the scope of this study and, especially, for the sake of consistency, two books with a focus on a particular healing strategy were excluded: Joseph’s *My Healing From Breast Cancer* and Sattilaro’s *Recalled By Life*. Also excluded was Jerri Nielsen’s *Ice bound: A Doctors Incredible Battle for Survival at the South Pole* (2001)²⁶ since it was the only remaining work on the list with a collaborative author specifically listed on the cover. Lastly, Sanes’ *A Physician Faces Cancer in Himself* was excluded not only because it was written serially (and lacks the same narrative flow as the other books) but also because little more than half of the entire work is dedicated specifically to the author’s illness. The nine autopathographies remaining are considered the primary sources for this analysis and are listed in order of copyright date in Table 2. Specific cancers are also included.

Three of the authors are pediatricians (Berberich, Kurland, and Mullan); two are surgeons (Payne and Thompson); one is a psychiatrist (Meldin); one is a rheumatologist (Rosenbaum); one is an anesthesiologist (Widome); and one is an emergency medicine physician (Dorso).

Five of the authors have cancers of the reproductive system: Berberich, Dorso and Payne have prostate cancer, the most common form of cancer in men; Mullan has testicular cancer; and Meldin has breast cancer, the most common form of cancer in women. Three of the authors have leukemia (Kurland), lymphoma (Widome), and myeloma (Thompson). These are blood-related cancers that originate in the bone marrow

²⁶ A made-for-television movie based on Nielsen’s autopathography was aired for the first time on CBS Sunday, April 20, 2003 at 9 p.m. Eastern Time. Susan Sarandon starred as “cancer-stricken physician” Dr. Jerri Nielsen “stranded at a South Pole research station” (“Ice Bound” screen).

Table 2. Primary Sources

AUTHOR/ BIRTHDATE (IF KNOWN)	TITLE/ NUMBER OF PAGES	1ST EDITION COPYRIGHT DATE/ PUBLISHER*	TYPE OF CANCER	MEDICAL SPECIALTY
Fitzhugh Mullan (b. ~1943)	Vital Signs: A Young Doctor's Struggle With Cancer/203	1982/New York: Farrar, Straus, Giroux	Testicular	Pediatrics
Dr. Edward E. Rosenbaum (b. 1915)	The Doctor: When the Doctor is the Patient/181	1988/New York: Ballentine Books	Vocal Cord	Rheumatology
Francesca Morosani Thompson (b. ~1944)	Going for the Cure/295	1989/New York: St. Martin's Press	Multiple Myeloma	Orthopaedic Surgery
Allen Widome (b. 1915)	The Doctor the Patient: The Personal Journey of a Physician With Cancer/246	1989/Miami: Editech Press	Non-Hodgkin's Lymphoma	Anesthesiology
Madeleine Meldin	The Tender Bud: A Physician's Journey Through Breast Cancer/212	1993/Hillsdale, NJ: Analytic Press	Breast	Psychiatry
James E. Payne (b. 1935)	Me Too: A Doctor Survives Prostate Cancer/143	1995/Waco, TX: WRS Publishing	Prostate	General Surgery
Michael A. Dorso (b. 1942)	Seeds of Hope: A Physician's Personal Triumph Over Prostate Cancer/268	2000/Battle Creek, MI: Acorn Publishing	Prostate	Emergency Medicine
F. Ralph Berberich (b. 1942)	Hit Below the Belt: Facing up to Prostate Cancer/211	2001/Berkeley, CA: Celestial Arts	Prostate	Pediatrics
Geoffrey Kurland (b. 1946)	My Own Medicine: A Doctor's Life as a Patient/251	2002/New York: Times Books	Hairy Cell Leukemia	Pediatrics

* Based on an April 2003 search of statistics on individual publishing companies listed in Bowker's *Books in Print* on-line (www.booksinprint.com/bip), five primary source publishers list fewer than 1,000 total titles published. These include Celestial Arts (726 titles listed); Analytic Press (383 titles listed); WRS (97 titles listed); Acorn Publishing (16 titles listed), and Editech Press (7 titles listed).

(in the case of leukemia and myeloma) or in lymphatic tissues (in the case of lymphoma).

Rosenbaum suffers from cancer of the vocal cord.

A look at the covers, some sleuthing between them, and some Internet hunting provided demographic data for the nine authors of the autopathographies. Table 3 summarizes these findings.

Thompson and Meldin are women. Meldin is the only author in the group who does not include her professional title after her name on the cover; the other authors' names are followed by "M.D." with the exception of Rosenbaum, who precedes his name with "Dr." But Meldin does indicate she is a physician by the subtitle of her book (*A Physician's Journey Through Breast Cancer*). Thompson and Berberich are the only authors with books that do not include this kind of reference to "doctor" or "physician" in the subtitle.

Although it's often unclear how long the illnesses of these physicians extended, the age at diagnosis is nearly always provided or able to be approximately calculated. Rosenbaum was the oldest, at 70; Widome was diagnosed at 67. Four of the authors were in their 50s, including Payne and Berberich at 57, Dorso at 54, and Meldin at 53. Two of the doctors were in their 40s—Kurland and Thompson were both 42. And Mullan, the youngest at diagnosis, was 32. In each case, treatment is concluded and remission or full recovery is pronounced by the end of the book. So, comparing author age at diagnosis to copyright date provides some interesting data. Even with some beyond-the-book research, Meldin's age at publication could not be determined, but of the others, the greatest lag time was with Kurland, who published his book 13 years after being diagnosed. Widome and Mullan follow; their books were published seven years after

Table 3. Primary Source Author Demographics *

AUTHOR	SEX	MARITAL STATUS	AGE AT DIAG.	AGE AT ©	LIVING?	RELIGION/DENOMINATION (IF SPECIFIED)	MED. SCHOOL/GRAD DATE	OTHER BOOKS PUBLISHED
Berberich	M	Married	57	59	Y	Jewish	New York Univ. School of Medicine/1968	Available Pediatrician: Every Parent's Guide to Common Childhood Illnesses (1988)
Dorso	M	Married	54	57	Y	Protestant/Non-denominational Christian	Univ. of Miami School of Medicine/1969	None found
Kurland	M	Married	42	55	Y	Jewish	Stanford Univ. School of Medicine/1973	None found
Meldin	F	Single	53	?	Y	Catholic	Unknown	None found
Mullan	M	Married	32	~39	Y	Catholic	Pritzker School of Medicine at the Univ. of Chicago/1968	Big Doctoring in America: Profiles in Primary Care (2002); Charting the Journey: An Almanac of Practical Resources for the Cancer Survivor (1990); Plagues and Politics: The Story of the U.S. Public Health Service (1989); White Coat, Clenched Fist: The Political Education of an American Physician (1976);
Payne	M	Married	57	60	?	?	Tulane School of Medicine	None found
Rosenbaum	M	Marricd	70	73	Y	Jewish	Univ. of Nebraska College of Medicine/1938	Dimethyl Sulfoxide (1971); Rheumatology (1980); The Doctor Tells All
Thompson	F	Married	42	45	N	Episcopalian	Cornell Univ. Medical College/1977	None found
Widome	M	Married	67	74	N	Jewish	George Washington School of Medicine	None found

* Authors were contacted where possible to confirm certain information, e.g. religion, age, and other books published. A list of questions posed to the authors appears in the Appendix.

diagnosis. Dorso, Payne, Rosenbaum, and Thompson published three years after diagnosis. The shortest lag time between diagnosis and publication was two years, and that record goes to Berberich.

All the authors are married except for Meldin, a single woman, and all are explicitly or implicitly heterosexual. Of the eight authors who provide reference²⁷ to a religious orientation, four (Berberich, Kurland, Rosenbaum and Widome) are Jewish, Thompson is Episcopalian, Dorso is Christian, Meldin is Catholic, and Mullan has Catholic roots.²⁸

At least two of the authors— Thompson and Widome—were discovered to be deceased. Thompson died seven years after publishing her autopathography. Her obituary, authored by Wolfgang Saxon in the February 21, 1996, issue of *The New York Times* states, “Francesca Morosani Thompson, a prominent orthopedic surgeon at Roosevelt Hospital who chronicled her struggle against cancer of the bone marrow in a book, ‘Going for the Cure,’ died on Feb 15, 1996 at the age of 51” (A17). A clue to Widome’s death was discovered in the February 2003 issue of the B’nai Israel Scroll,²⁹ the newsletter of the Jewish B’nai Israel Congregation in Rockville, Maryland. A scholarship endowment had been set up in Widome’s name, and a call to the synagogue’s

²⁷ One author, Michael A. Dorso, references “God” and his faith in his autopathography more than any of the other primary source authors, but clues in the text are not specific enough to identify him with a particular religious orientation or denomination. An interview with him revealed he was raised Catholic but now considers himself a “non-denominational Christian” (Dorso, “Telephone Interview”).

²⁸ Koski noted a similar pattern of religious orientation in her study of physician-written autobiographies of medical education; “many of the [...] authors mention that they are Jewish, if not in practice, then by heritage” (33).

²⁹ The newsletter (vol. 59, no. 6) was accessed April 9, 2003, at [http:// www. Bnaiisraelcong.org/ Actual%20February%20Scroll%202003.pdf](http://www.Bnaiisraelcong.org/Actual%20February%20Scroll%202003.pdf)

director of education, Fran Zavin, confirmed the endowment was a memorial for Widome who died “several years ago” (“Telephone Interview”).

One third of the authors have published other books besides their autopathographies.³⁰ Two of the three pediatricians—Berberich and Mullan— have written at least one other book, and Rosenbaum, the only rheumatologist in the group, has written three in addition to *The Doctor*, a bestseller that has been translated into 10 languages and made into a 1991 movie of the same name.³¹ Berberich published *Available Pediatrician: Every Parent’s Guide to Common Childhood Illnesses* in 1988 with co-author Ann Parker, M.D. Mullan has published four other volumes besides his autopathography. His first was an autobiography of his medical education entitled, *White Coat, Clenched Fist: The Political Education of an American Physician* (1976). After his own cancer experience, he wrote a book for cancer victims called *An Almanac of Practical Resources for the Cancer Survivor* (1990). And he has written two others: *Plagues and Politics: The Story of the U.S. Public Health Service* (1989) and *Big Doctoring in America: Profiles in Primary Care* (2002). *Plagues and Politics* reflects on politics and health policy based on Mullan’s 23 years as a physician in the U.S. Public

³⁰ Thompson did not publish other books besides *Going for the Cure*, but her autopathography was the only one of the nine primary sources to have been made into a condensed book in the U.S. edition of *The Reader’s Digest*. (Thompson “Going for the Cure” 197).

³¹ According to Rosenbaum, the first publisher he sent his manuscript to picked it up. “It was a lucky break. They bit,” he said. Random House gave him a “good editor” and also sent the manuscript to movie producers. “The movie gave it a lot of publicity.” Since then, he said, “I’ve written two more books—one about my adventures in the Army” that he has not found a publisher for (“Telephone Interview”). Hollywood, not surprisingly, took a number of liberties with the 1991 movie, “The Doctor” based on Rosenbaum’s book. The role of Rosenbaum is played by William Hurt, who in the film is a young, aloof, egotistic, order-barking resident heart surgeon “playing rock ‘n roll into his operating theater while literally holding the hearts of his patients in his hands,” not a 70 year-old rheumatologist, who, in the plot of the book, is never shown in action as a physician in practice—only as a physician in illness (Ebert, pars. 2-3). Hurt gets close to a female cancer patient “traveling the same path,” which also is not part of the book’s plot (Ebert par. 7), and the movie more dramatically and substantially than the book portrays the effects of Hurt’s transformation into a caring doctor and a “real person” with heart.

Health Service. *Big Doctoring* includes essays and interviews with primary care providers, whom Mullan considers a sort of endangered species in the specialized, managed care environment of American medicine. Mullan left government service himself in the mid 1990s to work as an inner-city doctor in Washington, D.C. (Mullan, “What one doctor learned” 31). Rosenbaum published two technical medical textbooks, *Dimethyl Sulfoxide* in 1971 and *Rheumatology*, in 1980. A few years ago he published a thin book of true patient stories written to help Japanese medical students learn English called *The Doctor Tells All* (Rosenbaum, “Telephone Interview”).

Medical school information was confirmed for all authors except Meldin; dates of graduation were identified for six of the authors. Berberich graduated from New York University School of Medicine in 1968; Dorso graduated from the University of Miami School of Medicine in 1969; Kurland graduated from Stanford University School of Medicine in 1973 and also did his residency there; Mullan graduated from the Pritzker School of Medicine at the University of Chicago in 1968; Payne graduated from Tulane School of Medicine; Rosenbaum graduated from the University of Nebraska College of Medicine in 1938; Thompson graduated from Cornell University Medical College in 1977; and Widome graduated from George Washington School of Medicine.

CHAPTER FOUR

Analysis and Findings

The manner in which doctors experience serious illness showed interesting variation across their dual roles of patient and physician. While each experience was unique, clusters of similarity became manifest through detailed evaluation of these cases. Thematic analysis of the nine physician-written autopathographies on cancer revealed three main categories descriptively labeled as (1) high-doctor/low-patient (or DOCTOR/patient); (2) high-doctor/high patient (or DOCTOR/PATIENT); and (3) low-doctor/high-patient (or doctor/PATIENT).

(1) The DOCTOR/patients cling fast to the doctor role. They are least accepting of the necessary transition to patienthood and most vocally rebel against it. They maintain an active, authoritative physician persona throughout their experience with cancer.

(2) The DOCTOR/PATIENTS position themselves with one foot on each side of the dividing line between the physician role and the patient role. Their illness is met with resistance because of their status as physicians, but they are also more willing or able than the DOCTOR/patients to accept the vulnerabilities the transformation to patient brings.

(3) The doctor/PATIENTS show only vestiges of the physician role in the experience of illness. They are the most accepting of the patient's passive status and demonstrate the smoothest transition from the role of doctor to that of patient.

What follows is an explication of each of the three categorizing themes based on sub-themes discovered through close analysis of the texts and informed by published literature.

(1) The DOCTOR/patients

Five of the authors are DOCTOR/patients: Edward E. Rosenbaum, *The Doctor: When the Doctor is Patient* (1988); Francesca Morosani Thompson, *Going for the Cure* (1989); Allen Widome, *The Doctor the Patient: The Personal Journey of a Physician With Cancer* (1989); James E. Payne, *Me Too: A Doctor Survives Prostate Cancer* (1995); and F. Ralph Berberich, *Hit Below the Belt: Facing up to Prostate Cancer* (2001).

The transition to patient is most difficult for the members of this group. Even when they are dressed in the patient's gown, which symbolizes "exposure, vulnerability, and helplessness," the white coat, which symbolizes "authority and potency" (Hahn 239), cloaks their comments. Maintaining a very high level of control and authority is most important to this group, as is expressing their training and technical competence, questioning advice offered by their physicians, nurses and others involved in their care, and diagnosing and/or treating themselves. They show more objectivity than emotional involvement in their illness experience, and when vestiges of vulnerability or fear are expressed, they are usually linked with an authoritative comment that brings the focus back to the authors' physician status. While some praise is offered for the medical system and the care received, it is criticism and commentary that is more prominent with these five.

Based on inferred reasons for writing their books, the four male authors seem motivated to offer commentary on the system and/or those working within it and to complement an impersonal medical record with their perspective; indeed, Berberich admits his autopathography allowed him to play doctor in his own case: “I was writing in the chart” (12). All but Widome directly state their authorial intent. Rosenbaum, Thompson, and Payne share reasons that correspond to two qualities of Hawkins’ “testimonial pathographies,” namely, the desire to teach (didacticism) and the desire to help (altruism). Rosenbaum tells what happened to him in hopes that both he and the reader would learn from it (vi). Thompson says a case of “survivor debt” inspired her to write “to inform” and that she feels “very strongly” that her treatment (the first-ever autologous bone marrow transplant) “shouldn’t be just for someone like me, in the medical elite, with special connections” (284). Payne writes hoping that if the reader or someone close to the reader must personally fight this cancer, that his account would “be of value in the struggle” (xi). Berberich says he wrote explicitly to augment his healing. He states:

I wrote to add to a sense of mastery” while treatment was underway. “I began [...] casually at first, jotting down reactions, ideas, random thoughts and reflections. An article had appeared in a leading medical journal presenting data showing that keeping a journal could have a positive impact on chronic illness.³² As my treatment progressed, I found I had more to say, both to myself and potentially to others. Those random records [...] eventually germinated and gelled into this book (135).

³² Berberich is most likely referring to Smyth, J. M. et al. “Effects of Writing About Stressful Experiences on Symptom Reduction in Patients with Asthma or Rheumatoid Arthritis: A Randomized Trial.” *JAMA: the Journal of the American Medical Association* 281.14 (1999): 1304-9.

All of the DOCTOR/patients are specialist trained, and all but Thompson are the oldest of the autopathographers at diagnosis. These authors begin their works with reference to past experience and are not shy about recording accolades and positive feelings for their profession. Rosenbaum writes, “Having spent time at the Mayo Clinic with Dr. Phil Hench, who shared the Nobel Prize for discovering cortisone, I was among the few physicians in the United States formally trained in the treatment of rheumatic diseases. I was the founder of the rheumatology clinic at University of Oregon Health Sciences University” (20). And he comments of his profession, “Doctors are the handmaidens of God” (25), and in medicine “you taste the power and glory of being supreme, and you like it” (66). Thompson, an orthopaedic surgeon specializing in foot and heel problems, is “a partner in a first-rate orthopaedic group” who confesses, “I’m very good at what I do” (60). She weaves in her background information with that of Anne Moore, a physician hematologist and friend she chooses for her care when she is first diagnosed with multiple myeloma. Payne is a retired Air Force general surgeon working as the medical director at the Texas Rehabilitation Commission in Austin. He couches his past in reference to his young internist, Dr. Judy Williamson. “Judy,” he says, “had been treating my medical problems for over a year. [...] She remembered me as her commander, Air Force Colonel Payne, during her residency years. [...] Judy seemed truly grateful to be my doctor” (1). He anticipates his experience to be helpful in his prostate cancer fight: “With my textbook knowledge of surgical disease and treatment complications, I was going to make one helluva great patient” (6). Widome describes himself as “a successful anesthesiologist” and “well respected by colleagues” (1). He remarks, “I had done well in medical school, graduating in the upper ten percent [...] and

had been a member of three honor societies. During my internship [...] I treated almost every possible ailment to which the human body is subject” (5). “In 1947, I replaced the primary anesthesiologist and began the formation of an anesthesia department at the hospital. [...] I remained here [...] a total of 36 years, developing a reputation that was a source of great personal pride” (7). He praises his field, noting that while anesthesia is a “quiet” medical specialty, the end result of any “heroic landmark surgeries” is “as much our doing as it is the surgeons” (28). And he elaborates on medicine as a whole as being “his *life*” (24) and an exercise in mental intensity that is “incredible,” so that “a physician’s family must be content with a small percentage of attention” (29). Berberich recounts his resume in seven pages, explaining that from his medical school days he “was impatient to be a doer, a fixer, a man of action” (4). He became a specialist in pediatric hematology and oncology and, after nine years, transitioned to general pediatrics, practicing for 20 years when he was diagnosed with prostate cancer.

All nine authors in this study explicitly mention at least once the disturbing transformation from doctor to patient when they are diagnosed. The control-dominated DOCTOR/patients, the most troubled by the role change, use words throughout their illness experience that emphasize both the need and desire for retained authority. With regard to the outwardly stated remarks specific to the transformation, nearly all occur at the start of the autopathographies as medical testing or diagnosis propels the authors into the beginnings of the illness experience. Themes include the stripping of power, identity, dignity, exclusivity, and even humanity. Berberich writes:

I typecast myself as the doctor in all doctor-patient interactions. This was my persona, and it extended well beyond the medical realm. Being The

Doctor in all facets of life has an enormous impact when you are suddenly forced into the role of patient. [...] How can you let someone take care of you when you are accustomed to taking care of everyone else? To whom can you relinquish that control? (9-10).

Payne, who says the transformation made him feel “out of place,” ranks patienthood even lower than personhood: “Linden and my sons joined me in my cubicle after I had removed my street clothes and transmuted from a human being into a patient” (30). Similarly, Thompson, looking at her X-ray results, writes, “It is not longer me on the board, just a patient, a case” (26). Widome also describes becoming a patient as “dehumanization” (21), humiliating, difficult (97) and an indignity (31). “Losing” his title is of special concern to him:

The young woman at the desk barely looked up. “Please have a seat. The doctor will be with you shortly.”

“I am Dr. Widome,” I repeated, thinking she hadn’t heard me.

“Yes, Please have a seat. We’ll call you when the doctor is ready to see you.” [...]

“Mr. Widome [...]” A voice cut through my thoughts.

Mr [...]? Was I also to give up the hard-won title of Doctor simply

because I was there as a patient? (14)

Rosenbaum expresses the difficulties of the role change from the beginning to the end, alluding to nearly all the associated themes. First there is the stripping of exclusivity: “On my seventieth birthday, I reported to the hospital to have a biopsy. [...] On fifteen thousand previous visits I had entered through a private door like a king. [...] But today

was different. I was one of the common herd” (3). Then there is the stripping of dignity: “I was subjected to the indignity: they took away all my clothes and gave me a skimpy piece of cloth. [...] When I tied that piece of cloth around my neck, it wasn’t long enough to cover the important parts. [...] I felt as nude as a newborn baby [...]” (4). And the stripping of power: “Lying in bed in a hospital room was a new experience too. I had been in similar rooms thousands of times, but in a different position. Then I was in command, neatly dressed, standing, looking down at a helpless patient in bed. [...] I was no longer in charge” (5). And finally, the stripping of identity, which, similar to Widome, especially plagues Rosenbaum; he writes, “I finally arrive at the record room, where I have to wait a half hour while my card is being changed. When they give me my new card, I look at it and find that my name is spelled right but they have left off my title, M.D. They have completely reduced me to the status of a patient” (97). Even near the end of his treatment, it’s an issue: “Today the receptionist greets me with, ‘Good morning, Mr. Rosenbaum.’ Five weeks of treatment, and I am no longer a doctor. A few months ago I was a captain, a man of position and power [...] now I am just a patient. Soon she will be calling me Ed” (141).

As a result of the DOCTOR/patients’ difficulty becoming patients, it is not surprising that the members of this group, more than those in the other two categories of autopathographies, most actively work to maintain physician-like control over their own care. They self-diagnose and treat themselves, and they are demanding of and critical of physicians, nurses, and others involved in their care. The DOCTOR/patients are especially critical of physicians when they feel they are getting short shrift as “colleagues.” Widome critiques his doctor’s physical examination because it covers only

a small part of his body. “Dr. Brody was interested in gastroenterology,” Widome writes, “and the entire exam had been geared to problems within that sphere. Suppose the problem initiated elsewhere? [...] I was not being treated as a medical colleague. Not by any stretch of the imagination” (19). Payne is even more blunt about his expectations of care from his physician: “Dr. Williams instructed Matt to set up a surgical tray for the suprapubic catheter placement and again disappeared from the room. Could it be that he hadn’t canceled all his other obligations of the day to devote 110 percent of his physical and mental energy to my needs?” (93). Rosenbaum elicits similar pronouncements:

At noon I was steeled to go [to surgery] when the nurse came with bad news: the surgical suite was ready but my surgeon was not; he was delayed by surgery at another hospital. [...] By the time he got to me he would be fatigued; he would rush the job in order to meet his afternoon appointments. I would get less than his best. It seemed a shabby way to treat a colleague (6).

Likewise, Berberich is stunned by the reaction he gets from an out-of-state prostate specialist who had trained at the same institution Berberich himself had. “We knew the same people,” he argues (97). Berberich calls him to corroborate his impression about hormone-alone therapy but also to “check out a small point” (97). But the doctor “curtly” informs Berberich that he does not offer professional courtesy and that Berberich would have to come see him to continue the discussion. “I had hardly taken advantage of this person and had become accustomed to, and reliant on, the understanding of professional colleagues,” writes Berberich. “This [...] negative experience smarted and made me angry” (97). Thompson, irritated that one of the doctors who will be performing her all-

important marrow transplant is not being as up front with her as she expects about a blood transfusion, barks to him: “What you’re saying is that you don’t know if you need to use blood or not, but once you thaw it, you use it, so everyone gets that unit of blood whether they need it or not, right? He is uncomfortable, we’re getting off to a bad start, I’m boxing him in.” She continues that she doesn’t want “some bullshit about how you’ll give me blood if I need it when you know you’re going to give me a unit in the recovery room because it’s thawed, and everyone gets a transfusion” (222).

Their desire to oversee their treatment also causes the DOCTOR/patients to be critical of physicians, nurses, and others when they feel their own care is better or their own knowledge of a specific treatment is broader. Berberich summarizes this problem well. “Having faith in one’s doctor is a visceral reaction,” he writes. “It need not be complete or blind, and in my case, it was always blocked to a degree by my background and knowledge” (56). It’s that kind of knowledge that causes Widome to question his care in several instances. In one instance, he writes:

The scope was finally removed, with no verbal discussion of what was or was not found. We finished up with the doctor checking my heart and lungs with a stethoscope. [...] It seemed a reverse order. Shouldn’t the consultation have come first? A discussion of complaints and symptoms, followed by the examination and tests that were indicated *after* a complete medical history [?] (19).

And in another instance, Widome records, “[Dr. Pearson] said that I would feel better in a few days. If not, he would schedule some additional tests. Additional? All that had been done was the blood tests; no chest x-rays, which struck me as odd. [...] An x-ray taken at

this point might have indicated fluid in my chest, putting the diagnosis on the right track with a degree of expediency” (25). Payne and Rosenbaum are also critical of their physicians. Payne is not impressed with the level of empathy displayed by the new partner of his treating physician and opines that “his professional persona didn’t impress this former surgeon” (16). He then notes how he had been a more empathetic doctor: “During my teaching rounds I had insisted that my students be ‘gentle doctors.’” (16). Rosenbaum, embarrassed that his wife, who is with him at one of his appointments, sees his doctor’s too-quick examination (“the whole visit is over in five minutes”) and his uncommunicative demeanor, remarks that in his own practice he ended appointments by asking patients if they had questions or anything more they wished to discuss. “More and more doctors are learning to use that technique,” Rosenbaum says. “But apparently not mine” (81). Thompson disregards a regimen for mouth care prescribed by nurses. “No way,” she writes, “I work out my own thing.” The nurses do not approve, but Thompson says, “I don’t care” (242).

Striving to maintain control by diagnosing and/or treating themselves is common to the DOCTOR/patients. Widome, in fact, rather boldly promotes these actions. He writes, “While I had heard the oft-repeated old saying that a doctor who treats himself is a fool, and has a fool for a patient, I didn’t believe that for one moment. No matter how ill a doctor may be, he has the ability and knowledge to reason, to decide what is best for anyone, himself included” (62). When Payne develops scalp lesions following his cancer treatment, he uses heavy “doctor-ese” to identify what he’s convinced caused the lesions. “I developed these problems because of the anticholinergic medication affecting my skin physiology. Its action somehow allowed overgrowth of pathogenic organisms—bacteria

and fungi—that flourished due to my altered perspiration” (104). Thompson self-medicates more than she self-diagnoses, but throughout her story she is involved in her treatment, sometimes acting as her own physician and the rest of the time partnering with her physician-friend Anne and her other doctors for her care. In self-doctoring mode, she writes, “Around 12:30 the chief resident comes in with scraps of paper. Before he can say anything, I say, I know. I called the lab myself. We discuss all the results” (9). And in self-treatment mode, she writes, “I dose myself with strong anti-inflammatory pills, freebies the drug detail salesman left as samples at our office. After some experimentation, I settle on Feldene, very strong, only take it once a day, very apt to cause gastric ulcers [...]” (12). Similar to Thompson, Berberich decides one night that there’s “no point” in calling his doctor for stomach problems; he himself just adds a drug, Prevacid, “to reduce the acidity caused by the anti-inflammatories he’s already taking” (185). Additionally, as he shares his analysis of various treatment regimens for his cancer—“the most rewarding part of his book”—according to one reviewer, Berberich frequently second-guesses expert medical advice, which gets “tedious” (Swanton 100). Rosenbaum’s idea of treating himself in at least one incidence is really an example of non-compliance. His physician gives him some sample antibiotics and allergy pills and recommends steam inhalations. But Rosenbaum returns home, throws away the samples and doesn’t use a steamer (10).

A major difference between the DOCTOR/patients and the authors in the other two categories of autopathographies lies in the extent to which—and the methods by which—they express needs (including support and sympathy) and vulnerabilities, especially the emotion of fear, a reaction common to anyone experiencing a serious

illness such as cancer. All of the DOCTOR/patients show at least some passive, typically patient-like fear in the face of their cancer, but examples for all but Thompson are sparse. At his non-Hodgkins lymphoma diagnosis, “the truth” is more than Widome can bear, even though he has previously been convinced he had cancer, no matter what his doctors said. “I could see my life ebbing away in a slow, tortured way,” he writes. “I burst into tears” (97). His wife Fay is his support through the tough times, and Widome confesses in the epilogue that without her “I would not have made it back to health” (150). Payne also writes that he cries upon reading actress and comedienne Gilda Radner’s 1989 *It’s Always Something* (a non-physician cancer autopathography) and shows vulnerability in his graphic descriptions of urinary incontinence and failed attempts to fix impotence problems resulting from his prostate cancer (138). He praises his family friends and co-workers for helping to “smooth the road considerably” (137). Rosenbaum and Berberich are the least openly expressive of needs and emotions, maintaining a high level of stoicism in their narratives. Rosenbaum twice suppresses tears (44-45) and admits to a “restless night” and “anticipating the worst” (159), and his family is named in the story. His most vulnerable state is expressed at a point late in his treatment when he is “no longer able to function as his own doctor” and “is terrified” at the thought of examining his own chart “for fear that someone has recorded in it a poor prognosis.” Claiming he knows his reaction is “illogical,” he admits that his “confidence has been worn down” by his “fears” about his cancer of the vocal cord (137). Berberich shares an episode of anxiety during a plane trip he takes on the way to the radioactive seeding of his prostate: “The fear of complications colored my thinking as I slipped into a mood of nervous anticipation” (153), but for the most part, he simply claims he “repressed” the anxiety

that shadowed him from diagnosis to the end of treatment through educating himself and staying in control (58). He gives credit to his wife “for sharing the highs and lows” and for letting him confide in her (179), and he adds that, while they could have made it on their own, the company of good friends was a bonus (179). Thompson, while just as control-oriented over her care as the other authors, shows the most emotive expressiveness. Her book contains six episodes in which crying is her response to fear—twice after she is diagnosed, twice in talking about her disease with her husband, once when thinking about how she will tell her two children, and once when talking with a friend. She is very secretive about her illness, but she needs support and counts on that from her husband: “Jim is literally holding me together” (248).

Examples of fear of the vulnerable kind for the DOCTOR/patients may be hard to find, but that’s because these authors tend to express fear in a way that deflects the seriousness of the emotion and, instead, highlights their knowledge and often downplays their patient status. In some instances, it is clear this can hardly be helped. The specialized training the doctors have makes some experiences they must undergo as patients especially anxiety stimulating because they’ve performed a procedure themselves or at least seen it done, understand consequences of actions or inactions, know the worst possible scenario, etc. Rosenbaum’s experience being prepared for a CAT scan, for example, alludes to anxiety because he understands the risks, but his medical explanation proves his professional knowledge and, in a subtle way, separates him from the role of a regular patient. He writes, “The technician started an intravenous line on me, a slow drip of a contrast material to help demonstrate the lymph glands in the neck. I knew there was iodine in the material and that occasionally a patient allergic to

the iodine could have a severe reaction, even die” (47). He adds, “Unlike the usual patient, I happen to know that tests are not necessarily innocuous” (84). Thompson and Payne also show fear colored by their physician role and prior knowledge. Thompson writes:

As the weeks go by and the appropriate time for the nausea and vomiting to abate is long past, I complain that the antibiotics are making me feel worse. [...] The dose is so high, especially the gentamicin, 150 milligrams three times a day, that’s twice the dose I used to use on very sick patients. I’m worried about the side effects of hearing loss and kidney damage gentamicin is known to induce in high dose (246).

Regarding Payne (but as well could be applied to the others) one reviewer explains, because he is a physician and “knows what can happen” he “relays his pessimistic reactions to various reports on his condition” (Beatty 1,544). An example of such a reaction takes place as Payne considers his cancer coming back: “The realistic concern I have about cancer recurrence or metastasis preys on my mind and probably will for many years. As a knowledgeable physician, I know the odds and possibilities only too well, especially that it will be at least five years before I can predict that recurrence is unlikely [...]” (135). Finally, like Berberich, who admits education about his condition helped him control his anxieties, Widome writes that he also “struggled to get a grip” on his emotions by intellectualizing—“by calling forward all of the scientific knowledge and professional detachment I had amassed through my years in medicine” (5).

The DOCTOR/patients, with their very high expectations, do offer praise for various aspects of their treatment experience, but dissatisfaction noted by critique is a

sub-theme that dominates the narrative in this group of autopathographies more than in the others. Again, it's often the case with these authors that statements of praise or critique are linked with references to experience or authority. With regard to praise, Payne writes, "As a surgeon experienced in academic medicine, I know that the professional competence of my surgeons, anesthesiologists, and radiation oncologists was unexcelled. I'm so thankful that I made the proper value judgments about my healers" (136). Nurses are also extolled. Widome writes of them, "The nurses were very efficient and competent—this duty was not for the fainthearted or the lazy" (92). Berberich, the most objective writer in the group, reports that the facility where he receives treatment is "impressive" and "inspired confidence" (154); his encounter with the university medical center's expert prostate surgeon is "pleasant" and "informative" (74); and the nurses in the oncology outpatient clinic were "cheerful, pleasant and encouraging" (111). Some of the same adjectives are noted in Thompson's praise of her radiation technician: "The technician is pleasant, efficient. Chest, abdomen, pelvis, lateral views of the spine. With each view she comes in, changes the large cold X-ray plate, arranging it just right" (25). Rosenbaum's very high remarks of praise for his own radiation technician, Debbie, are more descriptive: "Debbie [...] is a joy. [...] She doesn't wait for me to unbutton my collar, she unbuttons it for me and neatly tucks it in. [...] For almost the first time, I feel that someone's taking care of me and cares what's happening to me" (82). Unfortunately, Debbie is not perfect, and Rosenbaum later gets slighted by her: "I am left standing in a room that is bare except for the treatment table. I can hear the technicians quarreling in the hallway. Sweet friendly Debbie says, 'You treat him today. It's time for my coffee break.' [...] I am furious [...]" (166).

With regard to criticism of the medical system, the DOCTOR/patients share it frankly and frequently. Berberich complains about the traditional medical model (45) in general as well as traditional medicine's skepticism about alternative medicine (42), the problems with insurance plans (185) and HMOs (110), the slow authorization process for medications (186), and high drug prices (110). Widome shares his frustrations with the "absurdness" of hospital routine ("no need for alarm clocks here") (41-42), hospital food that is "basically inedible" (134), the lack of professional courtesy extended to physicians today ("In my day we would always see them [physicians] before any other patients, even if that meant bringing them in through the back door") (117), and "uncaring attitudes" of "some hospital personnel" (94, 148). Like Widome, it's the food—"lousy" (5), "inedible" (271)—and the routine, especially the early-morning sleep interruptions that bother Thompson, too. She writes, "My door crashes open at 4:30 a.m. An aide shoves in, pushing the blood pressure gauge and carrying the temperature machine and a notebook. Vital signs, she grumps. I'm pre-op, you don't need my vital signs at this hour" (10-11). Payne's biggest problem is with long waits: "After Matt had taken an eternity to set up the instrument tray, surgically scrub my abdomen and apply sterile drapes around my lower abdomen, it was another interminable wait for Dr. Williams" (93). Rosenbaum is the most vocal about his frustrations. He criticizes the big business of medicine that took over medicine he fondly recalls used to be a "cottage industry" (176). He writes, "Medicine [...] used to be a calling that catered to the public welfare, and our prime consideration was the patient. Now we are a business, and some of us practice as impersonal corporations, with the bottom line the profits, not the well-being of the patient" (163). He adds physician advertising (177), restrictions placed by insurance

companies and Medicare on what tests and procedures can be ordered for patients (177), the malpractice crisis (178), and the overabundance of paperwork (5) to the laundry list of problems brought by changes in the system. He also critiques over-reliance on technology, including computers, software (138), and modern diagnostic techniques, which give physicians “a false sense of security” and can replace “the physician’s good judgment” (129). Rosenbaum also is irritated by long waits (“One of the cruelest things a doctor can do is to keep a patient waiting. [...] I’d never thought of it before”) (63), and he tires of repeating his history: “I sat impatiently wondering how many times I would have to tell my life story. It was as if I had to make that payment every time I got some service performed” (48).

In the end, what do the DOCTOR/patients learn from their experience, and do they put it into practice? Criticism inspires some of the physicians’ new perspectives, as in Widome’s case. Widome is not able to return to practice after recovery but is idealistic about the way he thinks illness would have benefited his patients: “I had always done my best to treat patients in a caring way, but after my illness, the sky would have been the limit as far as humanity and caring were concerned” (149). Criticism also informs insight for Thompson as she is nearing the end of her treatment, although it is unknown whether she put this insight into practice after she recovers:

The attendings for March [...] tell me I should be up and around more and imply that my laziness is the cause of my nausea and malaise. They couldn’t be more wrong. I know me, and I know that if I felt better I would be doing more. I think about their unfeeling, blame-the-victim attitude, and recall with some remorse how many times I’ve laid that trip

on one of my patients, a little old lady struggling with the trauma of hip fracture surgery, for instance. Never again (249).

Following his recovery, Berberich writes that he thought his desire for more empathy and compassion from those who oversaw his treatment would lead to greater empathy on his part as a practicing doctor, but, he admits, “I cannot say that this has happened in a dramatic way” (209). Payne, retired from medical practice before his diagnosis, finds his illness experience to be a rite of passage he’s proud of for personal reasons, especially for the control he feels he maintained: “I had successfully weathered this torturous experience without losing my demeanor, and had also kept my dignity intact. I was surprised and quite proud of myself” (94). Recovery has also given him a new perspective on life—and golf: “I plan to gratefully live my life to the fullest until I die” (128), and “Never will I curse the weather or throw a golf club in anger” (138).

Rosenbaum’s list of lessons learned is the longest of the group. Some lessons are personal, similar to Payne’s: “I’d learned during the year of my illness” that “I, too, am an ordinary mortal” (173). In the same vein, he says he also learns that “Edward E. Rosenbaum, M.D., is not indispensable. That is a revelation. During the time I was ill, the office, the clinic, the medical school, and the hospital all seemed to function without me—though not quite as brilliantly, of course” (182). Other lessons apply more to the practice of medicine, which he does continue after his recovery: “I’m beginning to see that more [sympathy] may be required than I gave” (133). Rosenbaum shows some success with putting this lesson into practice. On the first day back to work after his illness, he is put to the test with a patient who has cancer. He writes, “When it is all over, I reflect that I haven’t handled the patient any better now than I would have done before. I

have kept her waiting; I haven't found a way to lessen her anxiety. All I have learned is to have her sitting down when I tell her the diagnosis was cancer. But today there is something different: my feelings. [...] I feel for [her]" (174). He says after his illness experience he takes his patients' misfortunes "more personally" and can no longer detach himself (174). At the end of the book, however, when it is late at night and the phone rings, he disconnects the line. "No more night calls" he tells his wife, who then begins to cry and says, "How can you do that? People may need you." He continues, "And I'm going to keep helping them [...] it's just that I'm not on the night shift anymore" (181).

(2) The DOCTOR/PATIENTS

Three of the authors are DOCTOR/PATIENTS: Fitzhugh Mullan, *Vital Signs: A Young Doctor's Struggle with Cancer* (1982); Michael A. Dorso, *Seeds of Hope: A Physician's Personal Triumph Over Prostate Cancer* (2000); and Geoffrey Kurland, *My Own Medicine: A Doctor's Life as a Patient* (2002).

Compared with the DOCTOR/patients, the transition to patient for this trio is only moderately difficult. Even when a desire to maintain control and authority is mentioned by the members of this group, it is tempered by an admitted uncertainty about their illness and a confessed need for the help of others. The DOCTOR/PATIENTS do share information about their training and technical competence, but on the whole, they do so more modestly than the DOCTOR/patients. They sometimes engage in self-diagnosis and treatment, but they are more apt to pose questions to doctors, nurses and other providers of care than to question the advice of these individuals. They display as much emotional involvement as objectivity in their illness experience, and fears expressed are balanced between those colored by knowledge acquired from medical training and those typical of

fears that might be communicated by a non-physician patient. Criticism of medical practitioners and the medical system is not absent, but it is not highlighted to the extent that it is in the works of the DOCTOR/patients; in fact, praise tends to be doled out more often in these books. All in all, these autopathographers maintain a relative equilibrium between the role of physician and the typical role of patient—the content of their narratives situates them soundly on both sides of the stethoscope.

The autopathographies of the DOCTOR/PATIENTS do not commence with biographical information emphasizing achievements, as the works of the DOCTOR/patients do. Although brief references are made to their being physicians within the narrative, general biographical information for the DOCTOR/PATIENTS, which happens to be non self-aggrandizing, is relegated to an introduction page written in third person (Dorso), to the book jacket (Kurland), and piecemeal in various spots within the text (Mullan). Dorso, an emergency medicine doctor (trained in internal medicine) and Fitzhugh Mullan, a pediatrician, are both primary care physicians whose books are about their reproductive cancers. Dorso has prostate cancer; Mullan has testicular cancer. Kurland is a specialist in the field of pediatric pulmonology and writes of his struggle with hairy cell leukemia. All three recovered and are currently in practice. Dorso is practicing emergency medicine at a community hospital in Roseville, California; Mullan, who was a physician in the U.S. Public Health Service at the time he wrote his autopathography, is now a pediatrician at an inner-city clinic in Washington, D.C.; and Kurland is a pediatric pulmonologist at Children's Hospital at Pittsburgh and a professor of pediatrics at the University of Pittsburgh.

Kurland is the only member of the group who does not directly state his reason for writing in his book. According to the acknowledgments at the end, Kurland's literary agent read his article in *Newsweek*³³ and convinced him to write the book (252). A telephone interview with Kurland unveiled more details.³⁴ He said writing the book "was only partly cathartic," and during the process, he didn't have in mind an audience for whom he was writing ("Telephone Interview"). Dorso writes to teach and to help. He explains that he wrote his autopathography because he saw "a desperate need for an informative, personal book about prostate cancer" (xii). He continues: "I've been able to speak as both a physician and patient" in counseling men with recently diagnosed prostate cancer who question what they should do. "I understood their shock, angst, fear, anger, and denial. I've been there. [...] During one of these dialogues, I realized I had to write this book" (ix). Mullan prefaces his narrative with an introduction elaborating on his reasons for writing, which are to teach, to help, and to heal: "It was less the journalist in me that was itching to get out than it was the fellow traveler—the companion and soul-mate of millions of other people and families who were dueling with cancer. I had survived my illness and had discovered that there was much that I wanted to share with others who were going through it" (xii). He then adds, "Sooner or later all doctors

³³ Kurland, Geoffrey. "A Doctor's Case" *Newsweek* 15 April 1991: 11. The citation for this article notes that it is a "commentary" about the "experiences of a doctor who underwent chemotherapy to treat his leukemia. His memories of the chemotherapy will stay with him for the rest of his life."

³⁴ In the April 22, 2003, interview, Kurland said a colleague encouraged him to join a local "writing group for medical people" led by Lee Gutkind. Gutkind is the former director of the writing program of the University of Pittsburgh and founding editor of the pioneering journal, *Creative Nonfiction* (Reid 83). Kurland joined and ended up writing an essay that Gutkind edited. He sent it to *Newsweek*, and it was published in the magazine's "My Turn" section. The literary agent Kurland names in his book called him "out of the blue," said she had read his article and wondered if he would be interested in writing a book about his experience. Because of his busy practice and teaching schedule, it took him a decade to finish ("Telephone Interview").

become patients, a role change that is never easy, although it does provide insights that are not learned in medical school. [...] My experiences [...] intensified my desire to describe what happened for the benefit of doctors and patients” (xiii). Mullan is the youngest of the nine primary source autopathographers (32 years old) at diagnosis, and his youth informs another reason for writing: “I came to believe that the problems of young people with cancer were far more complex and far less explored than I had ever realized. This made me the more eager to share my experiences in the hope that they would be helpful to other young adults facing cancer or similar life-altering crises” (xiv). Finally, there is the admission of writing to heal: “The telling of [the] tale makes the entire event a little more acceptable to me” (xvi).³⁵

The transition to patienthood is acknowledged as difficult and resisted, and all three DOCTOR/PATIENTS maintain their footing on the physician side of the dividing line during the process. Mullan, bothered by coughing and chest pain, asks a technician for an X-ray of his chest while he waits for X-ray film to be developed for one of his pediatric patients. He assumes he will find nothing on his own films, but his first glance of a “fluffy white density” the size of a grapefruit tells him something is wrong (4). His first reaction is objective, physician-like, unemotional: “The physician in me responded first and I instinctively looked at the grim information on the viewing box as a clinician. This was an unusual finding, a fascinating X-ray, I said to myself” (4). The radiologists view the results, and their casual demeanor changes. Based on their comments, Mullan begins coming to grips with the fact that the image represents cancer. In five minutes, he

³⁵ It is rare in the text of their works for autopathographers to outline the method used to craft their story. Mullan, however, explains in the introduction that he wore the hat of a reporter through the three-year course of his illness, making audiotapes and creating a folder of notes and observations that he then transformed into *Vital Signs* (xv).

is dressed in a hospital gown for another scan, requested by one of the radiologists. “The smock he gave me was absurdly short and as I padded down the corridor in my stocking feet with my knees showing I suddenly understood that I was a patient,” Mullan writes (5). He adds, “No amount of medical training and exposure could prepare me for so sudden and drastic an alteration in self-perception” (ix). He departs from his wife and daughter in Santa Fe that day to fly to Washington, D.C., where his parents live and where there is a large concentration of military hospitals through which he can get free treatment since he is a member of the U.S. Public Health Service.

Dorso, at age 54, is diagnosed with prostate cancer during a routine physical exam, which he admits was done only because his insurance company required it (he notes later that many physicians don’t think they need physical exams but “that egoism could have cost me my life”) (25). Upon hearing the news, he says his “mind began to rebel,” he feels “stunned and nauseated,” and writes, “I sensed the irony in this scene: Michael A. Dorso, M.D., has just become Michael A. Dorso, PATIENT!” (3). “In the natural order of things, I was the one who delivered the bad news. [...] I sensed that I had just crossed a major threshold in my life” (3). He adds how he was “especially struck” with the vulnerability he felt when he had to give up his clothes for the patient’s “thin paper gown” (26).

Kurland’s autopathography opens *in medias res* with a vivid scene of him lying feverish and vulnerable in a hospital bed: “My teeth begin to chatter, now in small spurts, then within moments, in full throttle, threatening to break my jaw, gnash through my own tongue, while my arms, shoulders, legs all shake with a false cold, now uncontrollable even with the meager remnants of a strength that has ebbed from me on a daily basis

[...]” (2). He is already a leukemia patient, but he backtracks following the scene to recall how the “nightmare” began, with a single, quick and remarkably innocent X-ray 15 months before that he got for himself hoping to explain a nagging cough and cold and a recurrent, sharp pain in his chest. In the X-ray room, he must, with reluctance, “remove the long, white coat containing my two stethoscopes, symbols of my physicianship” (6). Like Mullan, he looks over the shoulders of the radiology professionals at his own X-rays and sees a “large, first-sized blotch of white, a mass, a *something*. It pushes my windpipe far to the right, kinking it. My spine, as if in religious devotion, genuflects with a soft curve pointing to my left, as if it were bowing toward the white mass filling upper part of my chest” (8). He observes the irony of a chest specialist with a chest tumor (11) and writes, “Suddenly, I realize who I am, into whom I have been transformed at the moment I saw the white shadow on my film. And although I can’t possibly know it completely, my new persona is taking over as it melds itself unalterably into my being. I am no longer the doctor. I am the person with the disease” (9).

All three DOCTOR/PATIENTS respond to the first news of their illness in the physician role. Shortly after diagnosis, they react with physician-like responses, too. They work to stay in control by intellectualizing, which Hahn defines as regarding the event as an opportunity to teach or write (237), by participating in some facet of their medical care, by delaying treatment, or by emphasizing their “health” despite their diagnosis. Mullan, in a discussion with his literary agent about his book in progress—his autobiography of medical education called *White Coat, Clenched Fist: The Political Education of an American Physician*—“resists his affliction” in intellectualization fashion by seeing it as “a serendipitous literary event, an opportunity for another book.

His agent and friend is not so sanguine” (Hahn 237). Mullan writes that his agent responds to his idea with a ““Sure, sure”” and “viewed me as a friend with a catastrophe on the way rather than a client with a clever angle for a book” (x).

In addition to being involved in the reading of their own-X rays, Mullan and Kurland also participate early on in other aspects of their medical care. Mullan examines his own tumor. The surgeon passes a bronchoscope down his throat and then turns it 180 degrees for Mullan to investigate. Mullan comments, “For a crazy, order-defying moment I was doctor and patient all at once” (13). Kurland checks out his slides at the Mayo Clinic, the hospital where his famous-epidemiologist father works and the place he has chosen for treatment.³⁶ He walks to the lab with his carefully selected doctors, Ed Rosenow and Tom Habermann, and peers with them into the microscope, where he observes that he “doesn’t have to be a card carrying hematologist to see that my marrow is definitely not normal” (53). Like all the other primary source autopathographies, he uses such an opportunity to teach the reader, identifying the many abnormal structures he sees as hairy cells, which he, in his characteristic way, colorfully describes as cells with “tiny projections from their walls” that look like “undulating ruffles” (53). He concedes that the whole experience allows him to “return to being a physician for a few minutes” (53) and throws him into denial: “As the physician, I can look at my disease as a disease, a curious medical problem, not really my problem. [...] I can hide from the reality of the

³⁶ His book does say that “being a member of the medical staff [meaning at his own hospital in Sacramento] has its privileges” (164), which include quick service (“I’d had my counts done by the lab earlier in the day”) (164). But Kurland explained that he has been bothered by criticism from readers who have complained that he received special treatment due to his father’s connections at the Mayo Clinic. He said, “I was lucky my dad was at the Mayo Clinic, but anybody can go there. I sat in the waiting rooms just like everybody else. I didn’t feel that I was given super-special treatment. I was allowed into the clinical trial [for Pentostatin, an experimental drug] simply because I met the qualifications” (“Telephone Interview”).

situation within the white-coated persona of myself as the doctor” (57). Dorso also involves himself in his own care. He decides on drugs to take based on the fact that as a physician he has “a better idea of the risks involved” (134).

Both Kurland and Dorso head to the medical library to get more details about their respective cancers. Kurland states this reaction was “the physician role at work”—the part of him wanting to “keep control” of his care (“Telephone Interview”). When he tells his father he is going to the library, his father asks with concern, “Do you really want to read up on this? I mean, you’re the patient, not the doctor” (65). Kurland admits that “giving up being a doc is difficult” and “his feet find their way to the medical library” where he maintains his identity as a physician by signing in “not as a patient but as an assistant professor of pediatrics, University of California, Davis” (68). Dorso also uses library research to maintain control. One goal of his entire work is to educate himself (and therefore the reader) about prostate cancer treatment options. He writes, “I knew that I was in a unique position to research my disease and participate in my treatment. [...] I was determined to educate myself and take responsibility for my therapy. With that determination, I headed for the medical library at my first opportunity” (19). Regardless of his findings, however, Dorso also confesses to delaying treatment, even though he knows he’s being irrational. His doctor tells him he needs a biopsy, and Dorso replies, “I need time to think this over” and then adds, “An obvious stall. [...] In retrospect, it seems amazing that I was willing to dawdle while a cancer grew in my loins—not very rational” (31).

Even though Mullan is barely into his thirties when diagnosed, Kurland is the one in the group who emphasizes his health despite having cancer. He is an avid “extreme”

runner and “remarkably fit” as the book jacket explains, and his autopathography parallels his quest to run a 100-mile race. He is always running—after his diagnosis and even while he’s receiving chemotherapy, when he can barely make it the distance of a few light poles and back. It’s clear his Mayo physicians think he’s nuts; they say so. Kurland comes back with, “You are right, I am [nuts]. And proud of it” (52). Admittedly, says Kurland, the running is “a way of maintaining control” and was “a conscious decision” (Kurland, “Telephone Interview”).³⁷

Clearly, the DOCTOR/PATIENTS respond to the illness experience with characteristics of the physician role. But different from the DOCTOR/patients, Mullan, Dorso and Kurland—despite their training—are able to give up their physician-role authority and assume a more pure patient role. Evidence of patient role characteristics displayed by this group include admitted uncertainties, vulnerabilities, fears, and needs requiring the help of others and humble submission of control practically non-existent in the high-doctor/low patient group.

Dorso, for example, is not afraid to admit, “In the world of prostate cancer, I was a pediatric patient” (19). Even though he says he “knew the PSA was a blood test for prostate cancer,” he states, “quite frankly, it was out of my scope of practice” (28). He asks his doctor about the results—the number. The doctor tells him it was 10.4, and Dorso must ask, “How bad is that?” He adds, “I didn’t [...] know what was supposed to be a normal number” (28). His lack of knowledge inspires his admission that he had

³⁷ Kurland’s book ends with him 40 miles into the Western States 100-mile run. Does he finish? Again, it took going to the source to find out. Kurland said he did finish it. He also said that some readers had noticed a parallel between the 40 miles run at the end of the book and his mention of hairy cell leukemia’s 40 percent survival rate after five years or more without treatment (68). He said this was a fascinating connection but one that was unconscious (“Telephone Interview”).

“learned to trust [his doctor’s] opinion” (111). He also displays vulnerability with a nurse, sharing his feelings:

We entered an exam room where I went through the ritual of disrobing, weighing in, and vital signs. I thought I was looking like a fairly cool customer until the nurse asked me if I had high blood pressure. My blood pressure was higher than I had ever seen it. My body had betrayed me and announced the tension I was feeling. I told her, ‘It looks like you’ve found me out. I’m nervous’ (90).

Having cancer makes him more greatly admire the strength of his secretary, who is a breast cancer survivor. He appreciates her big hugs and encouragement. He also asks for and takes her advice—“Read everything you can get your hands on,” she says, and “talk to as many people as you can (62). He leaves behind the medical journals and takes up reading books by non-physician patients, comforted, he writes, “by [their] admissions of doubts and fears, many of which I was feeling” (48). He talks to friends who had been through cancer. One of them, Debbie, surprises him by telling him he will cry and that it’s OK to do so—“that’s when you will know that you are really dealing with your cancer” (119). Dorso admits she is right by sharing that at one point, grief and melancholy and anger swept him into an “emotional vortex,” and he “began sobbing uncontrollably” (120). He writes, “I surrendered to my grief. I haven’t cried like that since I was a small child. [...] When I awakened, I felt reborn. [...] I had been mourning the loss of my sense of immortality! [...] I wasn’t immortal and I wasn’t special” (121). Dorso also joins a telephone-based support group that he calls a “Godsend” (205) and

remarks, “Even though I never met many of these men face-to-face, I consider them friends” (205).

After his post-diagnosis stint of avid participation in his medical treatment, Mullan also positions himself on the patient side of the doctor-patient dividing line. He writes, “My true dependency as a patient was quickly impressed on me” (13) [...] “It was clear to me that my disease and my life were out of my hands” (14).³⁸ He places himself within the ranks of other patients prepped and on stretchers, like him, before his mediastinal biopsy by his use of the pronoun, “we”: “We were surely an unusual congregation, nude, pensive, and silent” (15). Before being put to sleep for the surgery, Mullan listens to the anesthesiologist tell him about the process. He writes, “I felt relaxed [...] and nodded assent. I was glad I didn’t have to worry about the appropriate dose of curare” (17). In other ways he submits control of his care to others. When he has to return for follow-up chest X-rays, the technician hands the films to him to carry to the oncologist. He writes, “I knew as much as anyone about X rays and easily could have examined my own on the way back to the clinic. I never did. The possibility that I would again discover trouble in my chest was so horrifying to me that it quenched my curiosity. I dutifully returned the unexamined films to the cancer specialist for his perusal” (104). His fears are manifest through tears, too: “Though I tried to keep my emotions in check [...] I did not do too well. My tears came from some deep sense of weakness and emasculation that I neither understood nor could control” (36). And: “I was to weep frequently and suddenly without immediate cause. The disease and its treatment so

³⁸ For Mullan, “pain, fear, and subjection to common medical procedures makes maintenance of the comforting medical stance less and less possible, and less and less desirable” (Hahn 243).

stripped me of my defenses that any event with the least bit of emotional content caused me to cry” (37). His fears get so serious that he confesses, “There seemed no way to escape,” and he admits suicidal thoughts (59). He recounts the needed help of a Navy psychiatrist, “who listened to my litany of troubles and then—without preamble—asked me if I would like to be held. I said yes. We sat together quietly for a few minutes clasped in an embrace, his hand patting my bony back. [...] My native embarrassment at being held by a man was totally overcome by my desperation. [...] His support was crucial” (59). This is Mullan’s nadir, his most vulnerable point in the book. Another admitted vulnerability is in his obsession about returning to the womb: “This fantasy, wild as it was, helped me through some awful times. When all my rationality as a physician, as a patient, as a son told me that I was cornered, it gave me a way out” (46). Like Dorso, Mullan, with his wife, join a cancer support group, which in those days (the mid 1970s), Mullan explains were not common. He writes, “I was feeling to share and compare my own experiences” (70). This need grew as his treatment progressed. He describes a 15 year-old boy, Billy, being treated for a similar cancer in the hospital with him and acknowledges, “I was scared of my disease and would have liked to talk to him about it” (134). Mullan’s final proof of being a physician with one foot deeply embedded in the patient role comes at the end of his book, following treatment, when he speaks to a group of medical students. He tells them, “We are all patients. [...] A few of us become physicians as well” (155).

Following his time in the medical library, during which he is unable to concentrate, Kurland tells himself that it’s “okay to accept my disease, accept its risks, accept my physicians, and accept their knowledge” even though medicine is imperfect.

(69). This decision marks his movement into the realm of the patient role. Before surgery to remove his spleen, he confesses, “I want to be comfortable, to have someone take care of me” (93). As he is coming out from under the anesthesia, he relays a helpless, embarrassing moment—one of subconscious fear—in which he writes, “I [...] call out for my mommy” (94). Kurland remarks that he has trouble expressing emotion, but he admits fear when considering how he should talk to his siblings, with whom he has not shared a special closeness: “Will I ever be able to talk with them about my fear, my confusion over the swerving turn my life has just taken? The oldest of the five of us, am I to be the first to die?” (103) He expresses his emotional vulnerability further when he writes, “The sense of aloneness in the face of my illness, despite the support of my parents and Karin [his girlfriend], is palpable and overpowering” (190). During preparation for a subsequent operation—a sternotomy and mediastinal mass resection—Kurland, desiring to avoid as much pain as possible, does not bark an order to the anesthesiologist to put an IV into his hand after he’s anesthetized as a typical DOCTOR/patient would; instead, he timidly pleads, “Um ... I was just wondering ... Is there any chance you could put the lines in after I’m asleep? If you can’t, well, that’s okay. I just was wondering if ...” (179). As he is convalescing immediately after that surgery, Kurland also demonstrates his submissiveness to the patient role. He writes that a nurse enters the room and says he has to have some chest physiotherapy. He writes, “After a moment of breath-catching sternal burn, I manage to say ‘okay.’” (180). Then he adds, “You’re the boss” (180).

With regard to amount of praise versus criticism of the medical system and its practitioners in these autopathographies, praise surpasses criticism significantly. Perhaps

because of Kurland's father's connection with the Mayo Clinic, or perhaps because of the system's efficiency, made clear in *My Own Medicine*, Kurland's autopathography doesn't criticize; in fact, Kurland remarked, "I didn't criticize a lot. I wanted to underscore how much hope we do have in medicine today, regardless of its imperfections" ("Telephone Interview"). Dorso remarks, too, on the imperfections of medicine, saying the history of the profession is "replete with blind alleys and misguided therapy" (136), and he makes two brief commentaries on the high price of drugs (132) and hospital bureaucracy (131). He spends more text space on praise, though, for his "reassuring" physicians and their "true commitment to my therapy" (144, 154, 184-185). Mullan criticizes the "depersonalization" of the modern medical system (125) and the "internal inconsistencies of the hospital"—things that "had never occurred to me as a doctor surprised me as a patient" (125). His autopathography notes praise, however, for the "skilled hands" and "warm and thoughtful attitudes" of therapists (24, 32, 34), for straightforward physicians (38), for the "ever-present, ever-faithful Navy corpsmen" (122), for his nurses (126), and for his "thoughtful and candid surgeon" (143).

Lessons are expressed in the autopathographies of the DOCTOR/PATIENTS as they are in those of the DOCTOR/patients. Mullan's experience taught him "patience and resilience" (167), and it broadened his expectations of doctoring: "A good physician was one who saw the patient as a whole person, a complex human being, rather than a series of organ systems. [...] A good doctor needs to love his patients at least a little bit" (152-153). Mullan also understands the "special apprehensions of cancer patients" (63), "what it means to be elderly, since I have had to live with degrees of physical compromise and incapacity that were previously unknown to me before" (168), and a "set of sensitivities

about illness and the young family,” which he and his wife had during his struggle with cancer. Dorso terms the lessons he has learned as acquired “seeds of hope,” mimicking the title of his book. He includes on the list, opening himself to vulnerability, putting trust in other people, being more empathetic, offering hope to others, and being accepting of mortality (241-242). A June 15, 2002, *Kirkus Reviews* assessment of Kurland’s work says it “fails to give any real sense of how, or whether, this doctor’s perceptions of his profession were altered by his experience with illness.” There is some evidence between the covers, however. After being diagnosed, Kurland writes, “I see clearly now what my patients and their parents must be going through” (115). He later observes, “It is too easy for a doctor to look back at the frightened patient and roll out some platitude, like, ‘I know just how you feel.’ How many times have I been tempted to say something like that?” (171) One would suspect, based on what these authors claim they have learned from their illness experience, that their patients have benefited.

(3) The doctor/PATIENTS

One author of the nine primary sources analyzed is a doctor/PATIENT:

Madeleine Meldin, *The Tender Bud: A Physician’s Journey Through Breast Cancer* (1993).

Doctor/PATIENTS are more patient than physician. The physician role is evident in a few passages, including the ever-present transformation-to-patient encounter, but the experience of illness is detailed almost entirely from the author’s stance on the patient side of the doctor-patient dividing line. High emotion, vulnerability, passivity, subjectivity, trust, and need are qualities that characterize the low-doctor/high patient.

Biographical information related to Meldin as a physician is the most limited of the nine primary sources. Her book, about her struggle with breast cancer through diagnosis, mastectomy, reconstructive surgery, and chemotherapy, includes within the text of the narrative only that Meldin is a psychiatrist in practice and that she had been a general practitioner for a time (13). No institutions of medical training could be identified, and no particular achievements are noted. Meldin is the only psychiatrist represented in the nine autopathographies analyzed and the only unmarried person in the group. She mentions that the family she has consists of “only a few relatives far away” (211) and alludes to some difficulties in her life, including her father’s prolonged illness when she was a child and of the social isolation of her family as a result, a broken engagement in her early 20s and the struggle to get her degree against the will of her family and without financial aid (44).

Meldin’s autopathography is in the form of an “editorially unembellished” journal³⁹ which she “wrote as soon as I could after the events transpired” (xiv). Her book is full of military metaphors (cancer as the “enemy” instigating a “battle” to be fought, etc.)⁴⁰ and also includes journey metaphors—“I had begun a journey” [...] I had become a pilgrim” (33)—aspects of two of the three dominant “myths” found in pathographies (Hawkins, “Reconstructing” 61). She writes, “The doctor’s sober statement, ‘You have cancer,’ awakens within us the clamoring of a thousand voices, calling every system of defense we have to battle, to rebellion, to revolt” (xii). The tone of her work, even with

³⁹ Thomson, the other female autopathographer in the group of nine analyzed, also writes in the form of a first-person journal.

⁴⁰ To a lesser extent, Mullan also includes military imagery. The second chapter of *Vital Signs* is entitled, “The Siege.”

its emphasis on the battle motif, is not that of aggressiveness; rather, it is, taking a word from the title, “tender,” as well as self-reflective, sometimes philosophical, and emotion-rich. Her psychiatry background may have some bearing on the references she makes to needs, so-called inner-child vulnerabilities, and expressions of the existential dimensions of her illness.

Even though she indicates some physician-like behavior in her response to illness, Meldin places herself from the outset in the patient role. She says she did not write initially for publication but “out of need” because she was “a patient trembling in dark uncertainty” (xiv). She describes her work as “a document, the narrative of an ordinary patient who happens to be a physician” (xiv). Colleagues and her own doctors, knowing she was writing, provided the impetus to make her work public. They “wanted to read what I was saying to myself” (xiv). What she says to herself, (and by publication, to others), is that “a deathly ill physician is simply a person in medical and existential crisis in need of competent colleagues and compassionate friends. Until health returns, the physician can only speak with a patient’s voice” (xiv).

Although the patient voice dominates, the doctor’s voice in Meldin does show up as she comes upon her tumor, is diagnosed, and makes the transition to cancer patient. She discovers a breast mass while showering and speaks to herself as a physician: “The medical fingers became professional. They examined, noticed, recognized, explored the neighboring areas. Then I said, ‘You have a small node in your right breast. The consistency is cystic, Wait a couple days. Examine it carefully. If it is still there, then get an examination at once’” (2). Then she demonstrates denial, through reporting the thoughts that fly through her mind: “You get all excited and imagine things. [...] All that

noise for a puffed rice size little lump. [...] The doctor will laugh when you, a doctor, arrive in a panic with such a lousy little thing” (3). She makes her medical knowledge apparent when her obstetrician aspirates the node in her breast and she participates in the action. But this same knowledge promotes fear. She asks to see the aspirate and writes:

I wanted to believe what I had seen: a cystic liquid, mischievously frightening me with the unthinkable word, ‘cancer.’ But I did notice something. I was afraid to fully inform myself about what I had noticed: the node did not disappear after the aspiration. I knew what that meant: either there was more liquid there in another cystic compartment (an unlikely hope), or there was a solid mass of tissue, of cancerous tissue (6).

A biopsy is needed, and it’s in preparation for this procedure that Meldin’s physician persona begins to fade to the background, as she writes about the specific moment of transition to patienthood, which is not as difficult as that recorded by the other autopathographers. She immediately identifies and assumes equal status with the other patients:

At 10:30 I was on the other side of the patient-doctor relationship. A bracelet was put on me to identify my body. I was given a unisex gown with a print of little blue flowers on a white background. We all—men and women—looked alike in the Day Surgery Waiting Room. Our feet were dressed in foam rubber green and blue gnome like slippers, and our bodies were covered with some piece of clothing called, with charitable exaggeration, a robe (8).

When she is told the biopsy shows cancer and a mastectomy is necessary, Meldin cries (14). The diagnosis of cancer completes her transition to the “deathly ill physician” she mentions earlier, who is in need and can speak only in the voice of a patient (xiv). Cancer infiltrates her “sense of self” and shatters her “self-assured feeling” that she is in possession of herself (21). She explains her submission to it: “I felt like a Russian doll, a doll inside another doll. The outer me was my usual me, a decisive person, moved by self-determination. The doll inside me was cancerous, rendering me incompetent to control my own destiny after having taken possession of me from the inside of my unsuspecting breast. A wish to surrender emerged within me [...]” (11).

Her submission and disconnection from “them” (other physicians) is illustrated by her reactions and observations before her mastectomy. Immediately before the procedure, during a consultation with her plastic surgeon, she is unable to hide the “scared child in need of holding and parental protection” (29). From her position on the operating table, she “could see them all dressed in green, surrounding me in a circle, only their eyes visible. I could see their concentration on the task, their becoming progressively a technical team to do their work on me” (29). When the surgery is over and Meldin is recovering in her hospital room, she offers another example of her separation from the physician role as the receiver and not the provider of care. She also emphasizes her need for friendship:

The rounds were to take place every morning as an early liturgy of hospital awakening. I noticed that we were becoming ‘ten minutes in the morning friends,’ and I was beginning to look forward to their collective visits. We seemed to be pleased with each other in a mild version of a

mutual admiration society. They kept me as well as possible in my sorrowful condition, and I, the patient, satisfied their sense of mastery by having my body behave as they medicated it (31).

Meldin often asserts her need for caring and friendship and describes it with heavy use of inner-child imagery. Of friends in general, she confesses, “I needed them, their help, their support, their compassion, their sorrow, their fear” (12) and she feels “tremendous gratitude” for their presence and their faces (30). “There was nothing I needed more than that: very familiar faces, faces to rest my eyes, my wishes, my fears on without trying to select what to show and what to hide. Resting on the face of another is the deepest feeling of trust I am able to experience. It must be what infants feel when they need to see their mother’s face” (30).

Such needs, she explains, extend to other physicians and nurses, too, and in a large number of accounts, she praises these individuals for meeting them. “When we become patients and are treated with kind respect and feel in emotional contact with the doctor, we become grown-up children, wanting the protection of a knowledgeable adult who can console us in our fears and dreads” (89). An oncologist, Dr. Nagle, is one such provider:

He was my doctor [...] the doctor of all of me, not just a cancer fighter or a body keeper, but a man concerned with a woman who found herself ill with cancer. We talked about my feelings, my worries, my immediate future. The visit lasted 30 minutes and was very satisfactory. I left with the feeling of being in good hands, understood as a person, respected as a human being in physical and psychical distress (91).

A nurse also supplies this needed emotional support. Meldin writes that she feels “a womanly camaraderie” with the nurse with whom she becomes “friends for the journey” during her chemotherapy treatments (53). “I felt a feeling of affection and attachment toward her, my assigned companion in my experiences of fear and actual danger. I smiled to myself. I had a wish to hold her hand and have her reassuringly press mine” (48).

It is the lack of such support that provokes a handful of critical commentary from Meldin in reference to the impersonal medical model and to a mechanistic office management system. Of the biomedical model she writes, “I felt very sorry for those who had no one to talk to them and very angry with my profession, the medical profession, for its inability to deal with our bodies as the living bodies of social persons” (70). An episode of miscommunication between her surgeon and his office staff in which an office visit date the surgeon gives Meldin does not corroborate with his secretary’s appointment book provokes another critique. Meldin writes:

I was dealing with technicians and bureaucrats. [...] Even Cora [the secretary], friendly as she appeared to be, did not show an ounce of concern about the havoc Dr. Keily had created for me. She talked like the mail clerk that has to fit letters and pieces of mail into slots. When she found no slot for me, I was handled with bureaucratic nonchalance until by some coincidence of factors I could be pushed into a space of sorts (107).

Like the authors in the other categories, Meldin—the doctor/PATIENT—is changed by her illness experience. She says she “had been used to taking life, people, the

world for granted” (206) and had become aware that she was “dispensable” and was “humbled” by her “superfluous existence” (206). She concludes:

I [...] discovered that we can get so immersed in our everyday lives that we forget how precious life is. I [...] found that the smallest of things count. [...] All things, big and small, count, every smile and every tear. Simply to appreciate what is there now is what life is all about. Simply to appreciate the riches in the temporal stream of our personal lives may be the deepest act of thanksgiving we can offer to the Giver of all Life (203).

CHAPTER FIVE

Conclusion

Of the nine physician autopathographies on cancer, five are DOCTOR/patients, three are DOCTOR/PATIENTS, and one is a doctor/PATIENT. Through thematic analysis, three categories emerged and were used in explicating responses to the physician authors' illness experience. Table 4 lists responses that were found in all the works analyzed and how they differed in concentration across the three categories.

The similarities and differences of the authors' expressions of illness elicit some other interesting connections (and questions). The DOCTOR/patients are all specialists, and, other than Thompson, are the most experienced at diagnosis and have had military experience. Their proclivity to remain control-oriented through their illness experience may be partly explained by these facts.

Specialists "partake in extensive studies beyond medical school," and are "niche players who know their territory and are masters in their fields" (Duong par. 1). The public has tended to confer elevated status on specialist physicians. "Besides the high salary figures of specialists, their extra years of study in a specific field raise their social status because society attributes prestige to those with more knowledge" (Duong, par. 1). It is not surprising that a master in a field, based purely on the features of personality that led him or her to such an occupation, would strive to be a master over illness, even when it is his or her own. In this case, being a DOCTOR/patient in one's autopathography is an unconscious necessity for the author.

Table 4. Characteristics of physician author response to illness across categories

	DOCTOR/patients	DOCTOR/PATIENTS	doctor/PATIENTS
	Rosenbaum Thompson Widome Payne Berberich	Mullan Dorso Kurland	Meldin
<i>Difficulty of transition to patient role</i>	Most difficult	Difficult	Least difficult
<i>Extent of authority/training emphasized</i>	High	Moderate	Low
<i>Desire to control treatment (self medicate, self diagnose)</i>	High	Moderate	Low
<i>Comments on medical care and medical system</i>	More criticism (discontent) than praise	Balanced criticism and praise	More praise than criticism
<i>Trust in physicians</i>	Low	Moderate	High
<i>Fear communicated as a result of illness experience</i>	Usually colored by the doctor role; rarely expressed in vulnerable terms	Balanced between vulnerable patient role fear and doctor role fear; occasionally expressed	Most honest, vulnerable fear without much hint of the doctor role coloring it; often expressed
<i>Admitted need for support/sympathy</i>	Low	Moderate	High

But it is also not surprising that the specialist autopathographers, in recounting their experience, choose words and phrases that emphasize control—even during the forced vulnerabilities of illness—in order to consciously maintain their “master” status in the eyes of readers.⁴¹ Writing involves choice, which DOCTOR/PATIENT Mullan references in a discussion of what he calls the “surviving autobiographer’s conundrum” in the introduction to *Vital Signs*. He asks, “How does one write about his doctors when some of them are still treating him? How does the survivor treat his family and friends when he is living and working among them? Most difficult, how does one dissect oneself before a public that is still very much with him?” (xvi). Regardless of the undeterminable conscious or unconscious aspects of the writing process, the resultant published work of the DOCTOR/patients is more like that of the solicited physician essayists who emphasize triumph, in-charge-ness, and authority when discussing their maladies in Pinner and Miller’s 1952 book *When Doctors are Patients*. The self-adulating discourse in these works contrasts greatly with the high concentration of humility and vulnerability in Meldin’s (low-doctor/high-patient) autopathography.

Second, the older these physicians are, the longer they have been in the physician role and thus the longer they have been practitioners under the biomedical approach to illness with its “proper, protective distance from patients”—its “detached concern” (Hahn, 257). When asked where he himself would place his own autopathography in relation to the physician-patient dividing line, Rosenbaum wasted no time in announcing,

⁴¹ Sarah Savitt asserts that autobiography of any kind “affords a unique opportunity to take charge of one’s public image” (343).

“I think I was more of a doctor. I’d been playing that role for a long time, and it’s hard to give it up” (“Telephone Interview”).

Third, military service and military training require a certain amount of stoicism in the face of difficulty and discomfort. Perhaps the military experiences of male authors in the group influenced, even to a small degree, the way in which they faced and wrote about their illness.

And a fourth and final note: Thompson, who is not one of the oldest DOCTOR/patients and has not had military experience, represents a unique case among the group. She is a female orthopaedic surgeon, unusual in 2003 and even more so in the late 1980s, when she was writing her autopathography. “In 1975, 513 orthopedists became board-certified, but only two of the 513 were women (0.39 percent). [...] In 1998, approximately 2.3 percent of active board-certified orthopedic surgeons are women” (Zillmer 1). Surgeons are connected with the idea of control—“cool, commanding and quintessentially male” (Ramey qtd, in Koski 322). Women who choose orthopaedic surgery often have many barriers to overcome, including those of entering a male-dominated specialty. They must be “strongly individualistic and prepared to take the flack that goes with pushing into inhospitable places” (Ramey qtd. in Koski 322). Having succeeded in navigating such barriers to acquire her position implies from the outset that Thomson would show characteristics of authority and control central to the DOCTOR/patients.

Two of the three DOCTOR/PATIENTS are primary care physicians, sometimes called general practitioners. Their more balanced response to illness—and especially their greater localization in the patient role compared with the DOCTOR/patients may be a

result of the training they received for their field. According to the American Academy of Family Physicians, primary care physicians— family practice doctors, internists (including emergency medicine physicians), obstetricians, gynecologists and pediatricians—are generalist physicians and patient advocates. They provide definitive care to the undifferentiated patient at the first point of contact, refer patients to specialists, and in certain cases develop long-term relationships with those they treat (“Primary Care” par. 9). Training in these fields stress patients’ general health needs, which are “not limited by problem origin, organ system, or diagnosis” as is specialist care (par. 10). “We generally expect more understanding and compassion to come from our family doctors” than specialist physicians (Duong par 3). Unlike the specialist “niche” masters, primary care physicians “work in too broad a field to command” (Duong par. 1). The greater exposure these doctors get to the “whole patient” in practice and perhaps the personality characteristics that led them to enter primary care may at least somewhat explain the DOCTOR/PATIENTS’ willingness over their DOCTOR/patient counterparts to accept vulnerabilities and give up some control as they navigate illness.

Kurland, the specialist (and special case) in the DOCTOR/PATIENT group, is not a surgeon but a pediatric pulmonologist; the fact that he chose to work with children in and of itself requires a unique sense of understanding and sensitivity. An alternate explanation is Kurland’s statement that in writing his autopathography he “tried not to be a physician”; in fact, he says he “fought the urge” but admitted to not completely relinquishing the physician-role control (“Telephone Interview”). Such a conscious decision of impression management resonates with the autobiographer’s conundrum mentioned by Mullan.

Meldin is her own special case, too, as the only author represented in the doctor/PATIENTS category. Her low-doctor/high-patient representation, as with the other autopathographers, could be conscious or unconscious; however, as that is impossible to determine, Meldin's field of medicine may speak for her somewhat. Koski writes that psychiatry "is said to attract the ultimate talkers" (32). Yet within medical institutions of training or practice, attention to self may be regarded as indulgence—unbecoming of the physician role and stigmatized; the unspoken rule of response to affliction in self and other is silence. Meldin's field explicitly considers personal and social facets of affliction (Hahn 257). Psychiatry cares for illnesses that affect the "core of our existence"—illnesses expressed in signs and symptoms that reflect mood and emotion, fear and anxiety, sensory perception, attention, impulse control, pleasure, language, creativity and imagination, consciousness, introspection, and "a host of other mental activities" ("What is Psychiatry?" 593). The patient Meldin becomes is similarly characterized, especially with regard to high emotion and vulnerability.

Suggestions for future research

A look at personality type and/or temperament of physician autopathographers, their medical specialty selected, and any connection of these variables to the three categories outlined in this thesis is one suggestion for future study on this subject. A personality and temperament typing model such as the Myers-Briggs Type Indicator® could be used for personality assessment, providing the authors were available and willing to be tested.

A second recommendation for future study is a comparative analysis of autopathographies by physicians who were patients before becoming doctors compared

with doctors who become patients after receiving their medical degree. Patients who become doctors have to face and deal with sickness and potential death before they learn to heal and save the lives of others. It could be hypothesized that in such cases prior experience in the patient role does not threaten the role of doctor for these authors and that their books would fall in the low doctor/high patient category.

A third idea for future research is related to gender issues. Are autopathographies by female physicians more personal and relationship oriented than those of male physicians? Comparing sex-specific breast cancer and prostate cancer autopathographies is one suggestion for answering this question.

Fourth, Aronson's look at non-physician "patients' tales" revealed that nearly all the authors' stories contain denial ("Autopathography 1,599). The illness response of denial was touched on in this thematic analysis, but an additional study of denial and other psychological defense mechanisms and their levels of concentration in physician autopathographies (and perhaps as compared to non-physician autopathographies) could add illumination to the subject of autobiographical illness experience.

A similar study could take a closer look at the three categories of physician autopathography in comparison to coping mechanisms, including religious and spiritually oriented coping strategies and alternative healing methods growing in prevalence today. Do more religiously oriented doctor-authors deal with patienthood more easily than those less religiously or spiritually inclined, for example? Or since those inclined toward whole-body fitness—somatic, mental, and spiritual—tend to be unhappy with the impersonal technology of medicine, would they be more high-doctor/low patient?

Finally, literary or rhetorical analysis could be performed on these works to investigate how physicians use language specifically to describe disease. As this study progressed, differences in the physician-authors' style of "reporting" their disease processes, symptoms and treatment became obvious. Some use an abundance of "doctor-ese" appropriate more for the reader with medical knowledge. Payne's reference to the "anticholinergic medication affecting my skin physiology" (104) that he claims caused his scalp lesions is one example of this kind of language. Others use less technical phrasing appropriate for a general reading audience and similar to the style of a medical journalist. Kurland and Meldin show the most literary style of the nine. Both use a good deal of figurative language that reads almost poetically in places, as with Kurland's analogy of hairy cell leukemia cells' projections appearing like "undulating ruffles" (53). In nearly all cases, the authors lean heavily toward one type of language or another but also combine the various stylistic approaches in their autopathographies.

Narration is another area of literary analysis that could be examined. Like Koski's description of the physician authors in her examination of autobiographies of medical education, physician autopathographers provide "insider reports" (vi), reports of disease from the doctor's perspective. At the same time, however, they convey to their colleagues and to the public a message from the perspective of the patient—from "the other side" (Hahn 236). Unlike the purer form of detachment and objectivity that usually characterizes journalists, who report on an event as outsiders, the physician autobiographers are a special case because they are at once both inside and outside an experience and yet are acting as its recorders. Even when most describe being disrobed from their white coat as a metaphor for the shift into the outside world of the patient,

these authors cannot ultimately detach themselves from their physician role. The subject as actor becomes the subject as object and visa versa. Ambiguity of the presenter is a result, a support for Tom Wolfe's assertion in *The New Journalism* that in spite having lived one's life, writers of autobiographies can make little claim toward being reporters (42).

The related concept of "unreliable" narration could be highlighted using these works. The unreliable narrator, explicitly defined for the first time by Wayne C. Booth in his 1961 study, *The Rhetoric of Fiction*, is a narrator (including first-person) who cannot be taken at face value. For one or more reasons, what he or she says is perceived by the reader as untrustworthy or contradictory. Examples of unreliable narration can be overt, as in Richard Selzer's account in his autopathography (*Raising the Dead*) of what he thinks might have happened while he was in a coma, or they can be subtle, making probing for them all the more interesting. A physician narrator in an autopathography may present himself as highly credible, self-assured and objective, for example, but he may reveal more than he intends through his emotional and psychological responses, causing the reader to question what he says about himself. The DOCTOR/patients would seem to be the foremost group to analyze for unreliable narration. The authors in this group tell much of their story with a self-absorbed, embittered tone that precludes belief and an exaggerated vocabulary, including words of negative import, that are symptomatic of unreliability.

Physicians over time have been fairly quiet about sharing details about their own affliction. "Medical training does not encourage either introspection or its public

disclosure. That most of these [authors] write [...] indicates that they believe their experiences professionally distinctive and noteworthy. Both the public and the medical profession are fascinated by physician-authored autopathographies, and their potential place in literature and medicine courses is finally being discovered. As this research transpired, a thread of discussion was carried out on “Lit-med,” an On-line Literature and Medicine discussion group sponsored by New York University School of Medicine, on the subject of “physicians as patients.” Catherine Belling, Ph.D., who teaches medical students at Stony Brook University School of Medicine, where she is course director for the required first-year Medicine in Contemporary Society course, initiated a request for “writing by physicians (or other clinicians) about the experience of being a patient (or the family member of one)” for a class on “the divide between professional and patient” (Belling “Physicians as Patients”). In response to the discussion that ensued, Koski wrote, “I haven’t seen a topic generate such interest in a long time” (“FWD: [Lit-med] Re: physicians as patients”).

Belling’s request and the Johns Hopkins “Physicians with Cancer” study are just two examples of how researchers are trying to understand more about the shift from physician role to patient role when illness in doctors occurs. The analysis carried out in this thesis—linking common features and themes and also noting differences between the illness response of the afflicted physician—sheds light on the phenomenon at a timely juncture in which a rise in the number of physician autopathographies is documented. The wide-ranging bibliography of such works developed in this study is presented as a resource for other researchers interested in the topic.

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APPENDIX

Of the nine primary source authors, three were interviewed by telephone after the thematic analysis for this thesis was concluded: Rosenbaum on April 10, 2003, Kurland on April 22, 2003, and Dorso on May 5, 2003.

The following questions were asked of the authors to confirm demographic information mentioned or hinted at in their books:

- What is your marital status?
- What was your age at diagnosis?
- What was your age at your book's publication?
- What is your religion?
- From what medical school did you graduate and in what year?

In addition, the following questions were asked to garner responses that might add more context and interest and to the findings of the analysis:

- Why did you decide to write your book?
- How did you go about finding a publisher?
- It is said that there is a dividing line between the role of patient and the role of physician. Where would you place your autopathography in relation to that line—on the doctor side, on the patient side, or on both sides?

In all cases, the authors conversed outside the bounds of the questions asked, and where appropriate or of interest, the information they provided was added.

VITA

S. Claire Betterton was born in Norfolk, Va., on September 22, 1972. She attended kindergarten in Blacksburg, Va., and elementary school at Riyadh International Community School in Riyadh, Saudi Arabia. In 1982, she entered Beechwood School in Fort Mitchell, Ky., and remained there until graduating from high school in 1990. After summer study in Japan, she entered King College in Bristol, Tenn., graduating magna cum laude with a Bachelor of Arts degree in English in 1994. She has been a reporter for The Recorder Newspapers of Northern Ky; a writer and researcher for a TAI, a management consulting firm and its publishing subsidiary in Knoxville, Tenn.; a laboratory research assistant at the James H. Quillen College of Medicine at East Tennessee State University in Johnson City, Tenn.; a copywriter and publications manager for the Mountain States Health Alliance hospital system in Johnson City, Tenn.; a lecturer in English and writing at King College in Bristol, Tenn.; a medical writer for Greenville Hospital System in Greenville, S.C.; and an English and business communication instructor for international expatriates at BMW in Spartanburg, S.C. In 2003, she received a Master of Science degree in communications from the University of Tennessee, Knoxville.