

# Pathography: patient narratives of illness

## Introduction

In ever greater numbers, people are writing autobiographical accounts of their experience of illness and treatment, narratives that are often called pathographies or autopathographies.<sup>1,4</sup> Increasingly patients are turning to these narratives for anecdotal information about particular illnesses and their treatments, conventional and alternative. Hence the remarkable popularity of such books, many of them bestsellers.

Pathographies not only articulate the hopes, fears, and anxieties so common to sickness, but they also serve as guidebooks to the medical experience itself, shaping a reader's expectations about the course of an illness and its treatment. Pathographies are a veritable gold mine of patient attitudes and assumptions regarding all aspects of illness. These narratives can be especially useful to physicians at a time when they are given less and less time to get to know their patients but are still expected to be aware of their patients' wishes, needs, and fears.

There are some 60 pathographies now in print about breast cancer alone. They describe orthodox treatments from lumpectomy to bone marrow transplant and alternative treatments from orthomolecular therapy to psychic healing. Prostate cancer pathographies are on the increase. In many, authors detail the way they aggressively seek out "the best" urologist and "the best" cancer center. Pathographies about HIV and AIDS are plentiful: an Online Computer Library Center search reveals 31 were in print in 1992, and the number had increased to 74 by 1997.

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Personal narratives about psychiatric disorders, especially bipolar disease, are also flourishing. Pathographies about disability become more varied as the mortal illnesses of yesterday are transformed into chronic illnesses today. Reynolds Price emphasizes the problems of living with paralysis rather than the spinal cord tumor that is its cause;

similarly, Barbara Barrie focuses not so much on her colorectal cancer as on how she leads a happy and productive life with a colostomy.<sup>5,6</sup> Neurological disorders of all kinds are subjects for pathography, from common diseases like epilepsy and Parkinson's to rare illnesses such as facial neurofibromatosis and Tourette's syndrome. There are now personal narratives by individuals who are so severely disabled—some hooked up to respirators and feeding tubes and some with conditions such as endstage ALS, locked-in syndrome, and autism—that the act of writing itself is an extraordinary achievement. Auto-pathographies about dying (often including near-death experiences) and biopathographies about the death of a loved one are becoming more numerous. Many reflect national trends, describing a hospice death or some form of assisted dying.

Physicians will want to read some of these books to find out just what it is that makes them so compelling to patients. The annotated appendix in this author's *Reconstructing Illness*, organized around disease categories, might be useful in directing readers to particular pathographies.<sup>2</sup> Individuals with a particular interest in breast cancer, HIV/AIDS, or disability will want to look at Thomas Couser's discussion of such pathographies in *Recovering Bodies*.<sup>4</sup>

My aim in this discussion is to provide an overview of pathography that addresses the following questions: (1) What kind of people write book-length narratives about their experience of illness? (2) Why do they write them? (3) What can physicians learn from these narratives?

## The tradition of pathography

Well-known authors and public figures do write pathographies.<sup>5,7-11</sup> For the most part, though, authors of pathographies are a heterogeneous group: movie stars, hairdressers, housewives, ministers, journalists, athletes, truck drivers, and college teachers. They do not include the very poor; indeed, most are middle class. Racial minorities are better represented in recently published pathographies, though such authors tend to belong to the middle class. Religion—Christianity in particular—provides the perspective on illness in a substantial number of pathographies.

A striking aspect of the genre is that it appears to be a recent phenomenon. With a few exceptions, such as John Donne's 17th-century Devotions or sanatorium narratives from the 1920s and 1930s, pathography seems to

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belong exclusively to the second half of the 20th century.<sup>2,12,13</sup> There are innumerable diaries and journals from earlier eras that include descriptions of illness, but few of these take the author's experience of illness as their only subject.

Why should people be writing illness narratives today in such numbers? One explanation is that in earlier times, sickness was considered an integral and inseparable part of living and dying. Thus sickness took its place in an individual's memoir alongside other experiences in life. Another explanation points to the sense of depersonalization that many feel about medical treatment today. By writing pathographies, patients not only restore the experiential dimension to illness and treatment but also place the ill person at the very center of that experience.

In a sense, the autobiography about illness can be seen as complementing a patient's medical record.<sup>2,14</sup> Both kinds of writing concern the sickness and treatment of a specific individual, but the contrasting points of view—the patient's versus the medical staff's—make an enormous difference. Case reports are generally about a

biomedical condition and its treatment; pathographies, on the other hand, concern illness and treatment as it is understood by the ill person. They differ in subject and in composition. The medical report is usually made up of impersonal statements by medical caregivers about symptoms, test results, and response to treatment. A pathography is an extended single-author narrative, situating illness and treatment within the author's life and linking them with the meaning of that life. Pathographies provide the story of illness from the perspective of the individual patient.

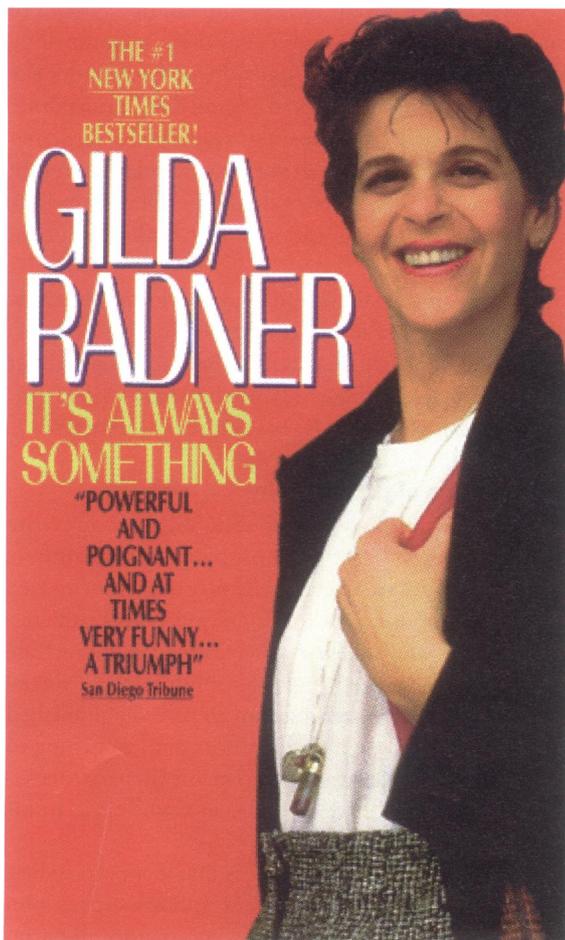
What value is it for physicians to read a single book narrating a single individual's illness experience? Are these books generalizable in any way? The answer is yes. One can categorize a pathography by the disease that is its subject, by dominant myths, attitudes, and assumptions, and by the author's intent in writing the book.

#### Four types of pathography

Four different groups of pathographies emerge when one analyzes them according to authorial intent.<sup>2</sup> The first might be called "didactic pathographies." These narratives are motivated by the explicit wish to help others. Often they blend practical information with a personal account of the experience of illness and treatment. Descriptions of breast cancer experience, for example, have enabled women to become aware of therapeutic alternatives—both within and outside conventional medical practice. Other pathographies concern culturally problematic issues, such as assisted death, HIV discrimination, or the use of alternative medicine, and are based on the assumption that the author's experience can serve as a mirror or a model (whether positive or negative) for prospective readers.

A second category consists of "angry pathographies." Authors of these are motivated by a strong need, based on personal experience, to point out deficiencies in various aspects of patient care. Nearly always, these are deficiencies of empathy. As one pathographer observes about her lengthy hospitalization, "I was no longer afraid of the disease, but of the system."<sup>15</sup> Pathographies of this kind are important in alerting all of us to important problems in medical practice. They vividly depict how an ill person today can be at the same time the beneficiary and the victim of a healthcare system whose very excellence—its superb technological and pharmacological achievements—is at the same time potentially dehumanizing.

A third type of narrative, the "alternatives pathography," is also critical of our medical system, but without angry denunciations or doctor-bashing. Like their angry counterparts, these pathographies stem from dissatisfaction with medicine. They differ in that the author is concerned not so much with criticizing traditional medicine as with finding alternative treatment modalities. One can



Autobiography of Gilda Radner.

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find pathographies about every conceivable kind of alternative. A surprising number of authors describe how they combined conventional treatment with one or several alternative therapies, most without telling their doctors. This group of pathographies can be invaluable in alerting physicians to the appeal of alternative medicine and to the specific treatments that attract patients with particular illnesses.

A fourth and very recent group, which might be called “ecopathography,” links a personal experience of illness with larger environmental, political, or cultural problems. In these books, illness (usually AIDS, certain cancers, or chronic fatigue syndrome) is perceived as cultural disease, “the product of a toxic environment,” as one author observes.<sup>16</sup> The motive of the authors of ecopathographies is prophetic: they are warning the rest of us that their illnesses are the signs and symptoms of much larger problems confronting our culture as a whole. As Kat Duff writes in her pathography, “Illness is the shadow of Western civilization, the antithesis of the rampant extraversion and productivity we so value.”<sup>17</sup>

### The uses of pathography

The common denominator of all pathographies, whatever the ostensible motives of their authors, is that the act of writing in some way seems to facilitate recovery: the healing of the whole person. For most of us, really serious illness is a painful, disorienting, and isolating experience. It is a trauma, an insult not only to the body but also to the self. As Robert J. Lifton has shown, coming to terms with a traumatic experience often involves the attempt to project it outwards by talking or writing about it.<sup>18, 19</sup> Writing about an illness experience is a kind of psychic rebuilding that involves finding patterns, imposing order, and, for many, discovering meaning. Pathography, then, is not only a description of how awful it is to be seriously ill, but also a testimony to the capacity to transform that experience in ways that heal.

For physicians, pathographies can provide a unique “window” into the experience of their patients, often revealing aspects of patient experience that remain unarticulated in the medical encounter. These books can be medically useful for a number of reasons:

- They embody the patient’s point of view on a variety of aspects of a medical experience.
- They offer a longitudinal view of illness as it is experienced before and after the patient encounters the physician.

- They describe common issues in medical encounters that are often problematic, demonstrating both helpful and harmful ways in which a physician can deliver bad news; providing concrete examples of physicians who express (or fail to express) empathy; illustrating the patient’s dilemma when confronted with conflicting advice from different medical experts.
- They provide information about alternative medical treatments from the perspectives of the patients who use such treatments.
- They reveal cultural attitudes and assumptions about illness, treatment, and recovery (the idea that illness is a battle or a journey, for example), showing how these can help (or fail to help) patients to better deal with their medical situations.

In these ways, pathographies can be helpful not only for the people who write them and the patients who read them, but also for physicians.

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