Life Writing from Medicine: Biography and Memoir of Patients

Jacek L Mostwin MD, DPhil (Oxon) Johns Hopkins School of Medicine Brady Urological Institute Berman Institute of Bioethics Baltimore, Maryland Considering how common illness is [...] it becomes strange indeed that [it] has not taken its place with love and battle and jealousy among the prime themes of literature.

Virginia Woolf. On Being III. 1930





When I was finally dressed, the ritual could begin. Two attendants seized me by the shoulders and feet, lifted me off the bed, and dumped me unceremoniously into the wheelchair. I had graduated from being a patient whose prognosis was uncertain to an official paraplegic...

"You can handle the wheelchair," said the occupational therapist, with a smile intended to make the remark somewhat good news, whereas to my ears it had the ring of a life sentence. In one flash I saw the frightening truth. It was as blinding as an atomic explosion and keener than a guillotine blade. They all left.

Jean-Dominique Bauby, The Diving Bell and the Butterfly, Knopf, 1997



With an Afterword by Ann Patchett

A New York Times Notable Book Autobiography of a Face LUCY GREALY



The school year progressed slowly. I felt as if I had been in the sixth grade for years, yet it was only October. Halloween was approaching. Coming from Ireland, we had never thought of it as a big holiday, though Sarah and I usually went out trick-or treating. For the last couple of years I had been too sick to go out, but this year Halloween fell on a day when I felt quiet fine. My mother was the one who came up with the Eskimo idea. I put on a winter coat, made a fish out of paper, which I hung on the end of a stick, and wrapped my face up in a scarf.

We walked around the neighborhood with our pillowcase sacks, running into other groups of kids and comparing notes: the house three doors down gave whole candy bars, while the house next to that gave only cheap mints. I felt wonderful. It was only as the night wore on and the moon came out and the older kids, the big kids, went on their rounds that I began to realize why I felt so good. No one could see me clearly. No one could see my face. The memory of an illness is very much like the memory of a nightmare.

Joseph Conrad, Preface to Twixt Land and Sea, 1920









I show her my notebooks, explaining that I am writing about what it is like to have cancer. Why? Because writing is what I do. It helps me sort out ideas and emotions and find out what I really feel.









Mystery. What a mystery this life is. The plants are filling out. The garden outback of our house sprouts one-half-inch here, an inch there, and I am changing too; cancer plods on from node to node, remarkable and not remarkable at all, like summer itself. Just another growing season after all. Is this resignation? I hope not. I do not intend to give up without a struggle, but more and more I see myself as a thread in a huge and royal tapestry – important to the central design but having an end, a place, a physical destination.... think of the young daughter in Satyajit Ray's [film] Pather Panchali, spinning, whirling in the rain, her hair flying out like a flag the night she died. I think of Sally Powers [a fellow patient], who had just turned seventy. No one is special, are they, when all is said and done? And of course, each of us is very special, very singular, carrying weight. I matter. Sally mattered. I would like to open the window tonight and yell outside. I matter. Or go down and lie next to the grass and whisper it.

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RECONSTRUCTING Studies in Pathography SECOND EDITION Anne Hunsaker Hawkins

"Robinson Crusoe - that is what I think of. Surviving a terrible storm at sea; then being shipwrecked; waking from catastrophe and finding oneself alone in a new, alien and dangerous world."

This was written not by the survivor of a shipwreck but by a woman who suffered a brain tumor and the operation that removed it. Her book, entitled <u>Surviving</u>, is an example of what I call pathography, a form of autobiography or biography that describes personal experience of illness, treatment, and sometimes death.

Hawkins. Reconstructing Illness: Studies in Pathography.1993

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.24 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 alterive 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 puter Library Center search reveals 31 were in print in 1992, and the number had increased to 74 by 1997.

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.

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 proctive life with a colostomy.5.6 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. Autopathographies about dying (often including near-death experiences) and biopathographies about the death of a

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loved one are becoming more numerous. Many reflect national trends, describing a hospice death or some form of assisted dving. 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.² Individuals with a particular interest in breast cancer, HIV/AIDS, or disability will want to look

Recovering Bodies.4 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?

at Thomas Couser's discussion of such pathographies in

The tradition of pathography Well-known authors and public figures do write pathographies.5-7-13 For the most part, though, authors of pathographies are a heterogeneous group: movie stars, essers, 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 particularprovides 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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By writing pathographies, patients not only restore the experiential dimensions to illness and treatment but also place the patient at the very center of that experience

Patients' perspectives

Autopathography: the patient's tale

Jeffrey K Aronson

The case history was invented by Hippocrates. Since then medical practice has been straitjacketed by its artificiality, to the detriment of the patient's own narrative. But patients have found ways of expressing themselves other than by talking to their doctors. Over the past two years I have been collecting a bibliography of book length autobiographical medical narratives, each completely or largely devoted to the writer's personal experience of drug use or illness. My growing list currently runs to about 270 titles

The usual term for a narrative of this sort is a hography, originally defined in 1853 in Dunglison's Medical Lexicon as a description of disease, and later as "the study of the effects of any illness on the writer's (or other artist's) life or art, or the effects of an artist's life and personality development on his creative work" The word was probably first used in this sense by Sigmund Freud, in Eine Kindheitserrinerung des Leonardo da Vinci (1910), and Oliver Sacks in the 1990 revised edition of Anakonings said that "the most perfect examples of ... pathography are the matchless case-histories of Freud" (although in earlier editions he wrote "pathology"). However, no one has, to my knowledge, made the important distinction between pathography and autopathography; indeed the latter term seems not to have been coined at all. The critic Mark Lawson, recognising the genre, has called autopathographies "medical confessionals,"² but I prefer to call them "patient's tales"-or, as Kipling might have put it, "plain takes from the ill."

All of the unreferenced volumes that I mention in this review are listed in my partially annotated bibliography.³ From their wide variety some common themes emerge, the surfaces of which I shall attempt to scratch.

What?

The subjects covered in these patients' tales fall into a few well defined categories (table 1). The illnesses are serious, dramatic, or fashionable-mostly cancers and neurological problems. You won't find many personal accounts of the agonies of backache or ingrowing toenails. But it would be good to read patients' accounts of what it is like to experience, say, chronic bronchitis, renal dialysis, or thyrotoxicosis. Perhaps there is room for a book of short individual essays on these and other neglected topics.

Summary points The traditional case history stifles the patient's own narrative, but increasingly patients are

problems

Infirmary, Oxford OX2 6HE Jeffrey K Aronson dinical wader writing their own narratives (autopathographies or "patients' tales") An analysis of about 270 book length tales, most written in the past 20 years, shows that more men than women write about their illnesses and that

IM/ 2000;321:1599-602 they describe serious, dramatic, or fashionable illnesses-mostly cancers and neurological

Clinical Pharmacology,

University of Oxford, Raddiffe

They write out of a desire to help other patients to come to terms with their own illnesses, to obtain catharsis, to educate and criticise carers, and to make money

Almost all patients' tales contain denial: ignoring or misattributing symptoms, causes, or the effects of therapy; deliberately hiding the illness from others; and organic denial (anosognosia)

Fabrication is probably common, but obviously not quantifiable

Reading patients' tales can help doctors understand their patients better and teach them things they won't learn from textbooks

Who?

Most (54%) of the accounts are by men, and when the sex specific illnesses (cancer of the breast, endometrium, ovary, and prostate) are omitted, the proportion is even higher (63%). Some writers are doctors, but, not surprisingly, most authors of accounts make their living wholly or partly through writing academics, novelists, journalists; illness, after all, makes good copy. However, patients' tales need not be restricted to professional writers; indeed there are entertaining accounts by others, some ghosted. Doctors should be encouraging their patients to contribute in this way, if only because writing about one's illness can be therapeutic.4 And the web is a good place to post such material, even when it is not suitable for publication between covers."

The case history was invented by Hippocrates. Since then medical practice has been straitjacketed by its artificiality, to the detriment of the patient's own narrative. But patients have found ways of expressing themselves other than by talking to their doctors. Over the past two years I have been collecting a bibliography of book length autobiographical medical narratives, each completely or largely devoted to the writer's personal experience of drug use or illness. My growing list europhilist 1692 about 270 titles.

Search: patient biography OR pathography OR "nurse biography" OR "doctor biography" OR "physician biography" ***limited to English language

	Total Books	Total Relevant Books
2017	589	529
2016	768	437
2015	760	562
2014	768	567
2013	771	581
2012	<mark>8</mark> 29	710
2011	746	635
2010	732	600
2009	711	646
2008	<mark>6</mark> 29	528
2007	569	447
2006	512	402
2005	504	389
2004	426	347
2003	418	344
2002	396	325
2001	336	279
2000	407	338
	Total:	8666

"Books" include:
Print Books
eBooks
Large Print
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Braille Book

MYYEAR OFF

Recovering Life After a Stroke

ROBERT MCCRUM



Robert McCrum, My Year Off, Picador, 1998

MYYEAR OFF

Recovering Life After a Stroke

ROBERT McCRUM



Robert McCrum, My Year Off, Picador, 1998

When I was seriously ill in hospital, I longed to read a book that would tell me what I might expect in convalescence and also give me something to think about. There are many books about stroke in old age, but I was young and had been vigorous and there was nothing that spoke to me in my distress.

I have written this book to help those who have suffered as I did, and indeed for anyone recovering from what doctors call "an insult to the brain". I've also written for families and loved ones who, sucked into the vortex of catastrophic illness, find themselves searching for words of encouragement and explanation.

The other audience for this book is, of course, myself. The consequences of my stroke were simply too colossal to be ignored or shut away in some mental pigeonhole. Writing the book has been a way to make sense of an extraordinary personal upheaval, whose consequences will be with me until I died. Besides, I am a writer. Communicating experiences is what I do, and quite soon after I realized I was going to survive the initial crisis I also realized that I've been given



AN ILLNESS AND A HEALING

A A T I D H A L B E S T S E L L E R A N UNQUIET MIND A MEMOIR OF MOODS AND MADNESS

Kay Redfield Jamison

"An invaluable memoir of manie depression, at some medically knowledgeable, deeply human and beautifully written...at times poetic, at times straightforward, always unashamedly honest." - The New York Times Book Review



WHEN BREATH BECOMES

BAUL KALANITHI FOREWORD BY ABRAHAM VERGHESE

14		
		Product details
		Paperback: 258 pages
	A HOLE	Publisher: Philippa Thomson (May 26, 2016)
	IN MY LIFE	Language: English
		ISBN-10: 0993598900
		ISBN-13: 978-0993598906
. And	BATTLING	Product Dimensions: 5.5 x 0.6 x 8.5 inches
		Shipping Weight: 12.6 ounces (View shipping rates and policies)
	CHRONIC	Average Customer Review: $\uparrow \uparrow \uparrow \uparrow \uparrow \uparrow \uparrow \uparrow 28$ customer reviews
	DIZZINESS	Amazon Best Sellers Rank: #408,127 in Books (See Top 100 in Books)
		#448 in Nervous System Diseases (Books)
		#495 in Special Needs Biographies
	PHILIPPA	#1095 in Medical Professional Biographies
	THOMSON	

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AUTHOR'S NOTE

He who has health, has hope; and he who has hope, has everything. Thomas Carlyle, Scottish philosopher

This book is primarily about a relatively rare inner ear disorder, and how it has affected my life, but the scope is actually much broader than that. I set out to write the book that I wished had been available, when I needed it myself. It is aimed at everyone who may experience dizziness, in all its manifestations, and who needs a better understanding of what might be happening to them. It is also for those treating, or caring for, anxious and/or dizzy people. but he would have us remember most of all to be enthusiastic over the night, not only for the sense of wonder it alone has to offer, but also because it needs our love. With large sad eyes its delectable creatures look up and beg us dumbly to ask them to follow: they are exiles who long for the future that lives in our power...

In Memory of Sigmund Freud W H Auden Another Time Random House, 1940



1984

Medicine as a Human Experience

Copyrighter Charles

NARRATIVES

SUFFERING, HEALING

& THE

HUMAN CONDITION

ARTHUR KLEINMAN, M.D.

989

NARRATIVE

MEDICINE

Honoring the Stories of Illness



RITA CHARON

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The

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1995

The PRINCIPLES and PRACTICE of NARRATIVE MEDICINE

Conviction Material



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Narrative Based Medicine

Dialogue and discourse in clinical practice



Edited by Trisha Greenhalgh and Brian Hurwitz

Narrative Research in Health and Illness

Edited by Brian Hurwitz, Trisha Greenhalgh and Vieda Skultans



Maria Giulia Marini

Narrative Medicine

Bridging the Gap between Evidence-Based Care and Medical Humanities



OXFO8D:

Understanding and Using Health Experiences

Improving patient care



EDITED BY Sue Ziebland | Angela Coulter Joseph D. Calabrese | Louise Locock

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2013

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ON LIFE-WRITING

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EDITED BY ZACHARY LEADER

Oxford History of Life-Writing: 1940 to the Present Day,



Why This Website?

<u>Why this website?</u> Based on rates from 2004-2006, 15.9% of men born today (one out of every six men) will be diagnosed with cancer of the prostate at some time during their lifetime. In 2009, it is estimated that 192,280 men will be diagnosed with and 27,360 men will die of prostate cancer according to the National Cancer Institute (NCI).

A few years ago, my urology surgeon asked me to review a book written by a prostate cancer patient in which the author described his personal experiences and spiritual beliefs as they related to his disease. Upon reporting back about the book, my surgeon asked if I had kept a diary of my own cancer journey and if so, he suggested that I write such a book myself. Since books have endings, and since my story is on-going, I decided to share my experiences as a website. I will endeavor to tell my story in chronological order starting with my diagnosis in 1995. I will include medical references, Biblical references (which I will call "spiritual medicines") and a summary of lessons I have learned or am learning. There are also recurring themes which







GodandProstate.Net: Illness, Mortality, Faith, Evangelism and the Doctor-Patient Relationship in the Digital Age

Jacek Mostwin, M.D., Phil, Professor, Urology, Johns Hopkins Medical Institutions and Berman Institute of Bioethics, Johns Hopkins University Bjarne Gabrielsen, PhD., National Cancer Institute, Emeritus

In 1995, Dr. Gabrielsen, an organic chemist and formerly Senior Advisor for Drug Discovery/Development at the National Cancer Institute discovered he had prostate cancer. That same year, Dr. Mostwin performed a radical prostatectomy with findings suggesting a 90% probability of cure, although ten years later the disease would recur. On the evening of his operation, the doctor visited the patient and found him reading from the Bible in his hospital bed. So began a relationship that has so far endured 22 years.

On his website, GodandProstate.net Dr. Gabrielsen writes: "A few years ago, my urology surgeon asked me to review a book written by a prostate cancer patient in which the author described his personal experiences and spiritual beliefs as they related to his disease. Upon reporting back about the book, my surgeon asked if I had kept a diary of my own cancer journey and if so, he suggested that I write such a book myself. Since books have endings, and since my story is on-going, I decided to share my experiences as a website. I will endeavor to tell my story in chronological order starting with my diagnosis in 1995. I will include medical references, Biblical references (which I will call "spiritual medicines") and a summary of lessons I have learned or am learning (Lessons Learned | God and Prostate). There are also recurring themes which God seems to bring to my attention either from His Word (the Bible), from several devotional books or other sources. My hope is that the information and principles expressed herein will be used by any man in any condition since we all share similar physical bodies and spiritual natures."

ΗΟΜΕ

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ABOUT THE AUTHOR

Jan Rosenbaum



I have lung cancer. Upper right lobe, as big as a baseball. I am not "fighting it valiantly", the usual phrase in obituaries. I take my meds, do what the doctors tell me to do, and observe the process with great curiosity. I am lazy about getting rid of the stuff that gathers, I never became famous or tall. I take great pleasure in having come of age in Detroit during the Vietnam war protests, the sexual revolution, the era of nice drugs, wet darkrooms, and especially the music from Buddy and Jerry Lee through our own Marvin, Smokey, and Aretha; Joplin, Dylan, Garcia, and Hendrix.

At this point a resume no longer seems appropriate. Obituary, for release when needed

http://thelastproject.org/nature-of-the-last-project/#atwater

At Water





http://thelastproject.org/nature-of-the-last-project/#atwater

