

2017

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Recommended Citation

Ryder, Jonathan H., "Without the White Coat: An Analysis of Pathographies by Physicians with Cancer" (2017). *EMET Posters*. 2.
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Without the White Coat: An Analysis of Pathographies by Physicians with Cancer

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Special thanks to Rebecca Anderson, JD, MS, and John Schleicher, MA

Background

Pathography is a genre of literature defined as “a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death.”¹ Jeffrey Aronson’s analysis of 270 autopathographies found 54% were written by men, most authors were professional writers, a majority were published between 1980-2000, and most covered cancer, neurologic/psychiatric diseases, HIV/infections, and heart problems.² Anne Hawkins’s influential *Reconstructing Illness* analyzed the purposes and myths of this genre. Hawkins found four primary purposes of the authors: testimonial/didactic, angry, alternative medicine, and ecopathography.^{1,3} The mythic themes present were the myths of rebirth, battle, journey, healthy-mindedness, gaia, and narrativity. Of note Hawkins mentioned that physician pathographies were not analyzed separately, but may provide an interesting perspective. While there have been three compilations of doctor-as-patient stories, there is no known literature exploring the book-length pathography genre written by physicians.^{4,5,6} Because cancer is the most common disease in pathographies, we analyzed four books written by physicians in two separate eras (1980s and 2000s) with two specific cancer types (head and neck cancer and non-Hodgkins lymphoma) to explore themes, metaphors, myths, and purposes of this unique genre.

Themes

Author Characteristics

- All Jewish and male, most previously served in military
- All are specialists, most are academic clinicians
- All experienced significant disruptions in work
- Two had a wife who also had cancer

Metaphors and Similes

- Patient as Infant or Child: “I felt as nude as a newborn baby and suddenly as helpless.”⁷
- Patient as Object or Number
- Medicine as Business or Machine
- Illness, Hospital, and Treatment as Prison, Death Sentence, Slavery, or Torture
- Illness as a Battle

Head and Neck Cancer

A Taste of My Own Medicine

By Edward Rosenbaum, 1988⁷

Rosenbaum (1915-2009), an Omaha, NE native who attended Creighton University for undergraduate and University of Nebraska Medical Center for medical school, founded the Rheumatology Division in 1950 at Oregon Health Sciences University after serving in World War II in a mobile surgical hospital.

In 1985 at age 70, he was diagnosed with throat cancer near his vocal cords after nearly a year of hoarseness and misdiagnoses. He received 33 radiation treatments and chronicled in journal-like fashion the process of his diagnosis and each day of treatment. His book was made into a film, titled *The Doctor* starring William Hurt.

Key Themes: Didactic/Testimonial Purpose, Myths of Battle and Rebirth (as empathetic doctor and speaker)



My Voice

By Itzhak Brook, 2009⁸

Brook (1941-Present) is a pediatric infectious disease specialist at Georgetown University who served in the U.S. Navy from 1980-2006 including a stint in the Yom Kippur War. He is a well published academic professor in anaerobic and ENT infections.

In 2006 at age 65, he had a persistently sore throat and was diagnosed with a hypopharyngeal squamous cell carcinoma that was treated with surgical resection and radiation. Twenty months later he had a recurrence in his right pyriform sinus treated first with three endoscopic laser surgeries then definitive complete pharyngolaryngectomy. This surgery left him unable to speak without the use of a tracheo-esophageal prosthesis. Complications, side effects, and medical errors predominate his story.

Key Themes: Didactic/Testimonial Purpose, Myths of Battle and Rebirth (as laryngectomee speaker)



Non-Hodgkin Lymphoma

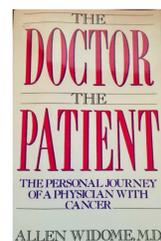
The Doctor/The Patient

By Allen Widome, 1989⁹

Widome (1915-1992) served as the founder and Chief of the Anesthesia Department at Columbia Hospital for Women in Washington D.C until 1983. He joined the Army in 1941 during World War II.

In 1983 at age 67, he experienced fatigue, abdominal pain, and nausea, and he knew he had cancer. After several misdiagnoses and a 42 day hospitalization, he was diagnosed with diffuse histiocytic lymphoma of the bowel, diaphragm, spleen, and kidney. He was treated with the CHOP chemotherapy regimen and entered remission. Support by his wife Fay was key to his recovery.

Key Themes: Testimonial/Didactic purpose, Myths of Journey and Battle



Even Doctors Cry

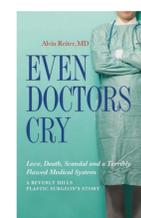
By Alvin Reiter, 2009¹⁰

Reiter (1945-Present) is an ENT facial plastic surgeon in private practice in Beverly Hills who is famous for reconstructing Rodney King’s face after the LA riot.

In 1994 at age 44, he was diagnosed with stage IV indolent follicular lymphoma after having a skin rash biopsy. In 1996 the lymphoma became aggressive, and he began fludarabine chemotherapy.

His book also details his run-in with the FBI for being involved in insurance fraud, for which he pled guilty to four counts of mail fraud in 1999 and was sentenced to 3 years probation. He also describes his wife Karen’s diagnosis of breast cancer in 1999 and her subsequent death in 2003. He references *The Doctor* movie in his book.

Key Themes: Angry Purpose, Myth of Rebirth (return to career)



The Doctor-as-Patient

Loss of Power, Control, and Dignity

- Gowns and private rooms: “a skimpy piece of cloth...it wasn’t long enough to cover the important parts.”⁷
- Consent forms: “absolved the physician of most, if not all, responsibilities...nothing in the form was directed toward *my* protection.”⁹
- Dependency on medical system, cannot resist or criticize
- Role reversal
- Attempts to re-gain control: making treatment decisions

Entitlement and Privilege

- Expectation of better care: only the best doctors; should not have to wait or go through standard procedures
- Patient, not doctor: called Mister instead of Doctor; prior positions of power unrecognized
- Medical knowledge, professional connections, and access to care: reading the literature; reviewing own pathology and imaging; preventing errors
- Self-awareness that doctors are not exceptional

Denial

- Knowledge of medicine and severity: more knowledge not always beneficial; self-diagnosis
- Lack of time
- Favorable prognosis of initial misdiagnosis lulls into complacency
- Avoidance of doctors: “whenever I got sick, I treated myself. Doctors were not for me.”⁷
- Refusal to be a patient, immunity as a doctor: “Doctors are the handmaidens of God. They earn their immunity from the ordinary problems of life.”⁷

Criticisms

- Lack of empathy from physicians
- Waiting and the waiting room
- Lack of urgency of cancer care: no treatment on weekends; delays in treatment
- Medical, surgical, and nursing errors
- Poor physical exams and hurried physicians

Isolation and Cancer Stigma

- The C word: “Nobody likes being treated by a dying doctor. Cancer is like cooties. If I were able to keep working, I would have to keep this illness a dark secret.”¹⁰

Mental Health

- Importance of support from physician, family, work, and support group

Conclusion

The physician-with-cancer pathography provides a unique perspective of our medical system. Doctors experience numerous difficulties similar to other patients, but their position and knowledge add to their frustrations. Their critiques may be taken more seriously by the profession than those of non-doctors. Further exploration of doctor pathography may lead to a better understanding of the doctor-patient relationship and how to improve patient care.

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