

AUTOPATHOGRAPHIES:

HOW 'SICK LIT.' SHAPES KNOWLEDGE OF THE ILLNESS EXPERIENCE

RACHEL HALL-CLIFFORD

I had the honour of being a member of the first class of MSc students in Medical Anthropology in Oxford in 2001. During the MSc I became interested in the intersections of medical anthropology and public health, particularly in considering how medical anthropology theory can be operationalized to improve public health program evaluation. I went on to complete a PhD in Anthropology and a Master's of Public Health in International Health from Boston University, where my research focused on the long-term impacts of oral rehydration therapy campaigns in highland Guatemala. I then spent a year working with Arthur Kleinman at Harvard University and, drawing on the foundational knowledge I gained from the MSc, became further interested in illness narratives. I conducted post-doctoral research on illness narratives through the Oxford Autopathographies Project, described here. I continue to investigate primary health care delivery in Guatemala and co-direct the NAPA-OT Field School in medical anthropology. I am currently Assistant Professor of Anthropology and Public Health at Agnes Scott College in Atlanta, Georgia.

Introduction

Autopathographies, or illness autobiographies, offer detailed accounts of illness experiences, usually written retrospectively. They not only present information about diagnosis, treatment and outcome trajectories, but also share how the illness has affected the sufferer's wider life course, social network and views of health care institutions. Autopathographies, such as John Diamond's *C: Because Cowards Get Cancer Too* (1998) and Elizabeth Wurtzel's *Prozac Nation* (1995), often appear on best-seller lists and reach a general public readership. The popularity of such works indicates that they are powerful instruments for communicating about illness within our society, despite the rise of the internet as a more expedient medium for sharing personal experiences in the last twenty years. What is it about autopathographies that a popular readership finds compelling, and what does this communicate about our

normative ideas of the morals of pain and of a life well-lived? This paper frames autopathographies as the outcomes of artful, culturally accepted acts of self-determination. It also outlines the Oxford Autopathographies Project, an investigation into the sharing of illness experiences that focuses on public engagement with autopathographies.

This project stemmed from the Patients' Tales Collection, which began when Jeffrey Aronson, an Oxford-based clinical pharmacologist, went in search of a book to give him further insight into the experiences of a friend going through an illness. Beginning in the 1990s, Aronson's collection grew as he realized, as both an avid reader and a clinical scholar, that there was a burgeoning genre of illness autobiographies. After much scouring through second-hand bookshops and following up on leads from news articles and colleagues, Aronson's collection now consists of over 300 titles spread across a vast array of health conditions. The collection is limited to volumes in the English language available on the British and North American book markets. Aronson presented his collection in *The Lancet* (Aronson 2000), describing the categories of health conditions represented and raising questions about how the books might be useful to clinicians, fellow sufferers and the public. He also created an index of the autopathographies in his collection that has been online since 2000 and is currently hosted by the University of Oxford, Department of Primary Care Health Sciences. Years after the publication of his initial article, Aronson still receives many queries about his collection and suggestions for additions, providing a glimpse into the widespread interest and contemporary salience of autopathographies.

Though some earlier examples of autopathographies do exist, they can only be said to have emerged as a genre beginning in the 1950s (Hawkins 1993). There were significant increases in the numbers of autopathographies published in the 1950s and again in the 1980s, a trend that has continued, with an exponential rise in publication rates in the last twenty years (see Figure 1).

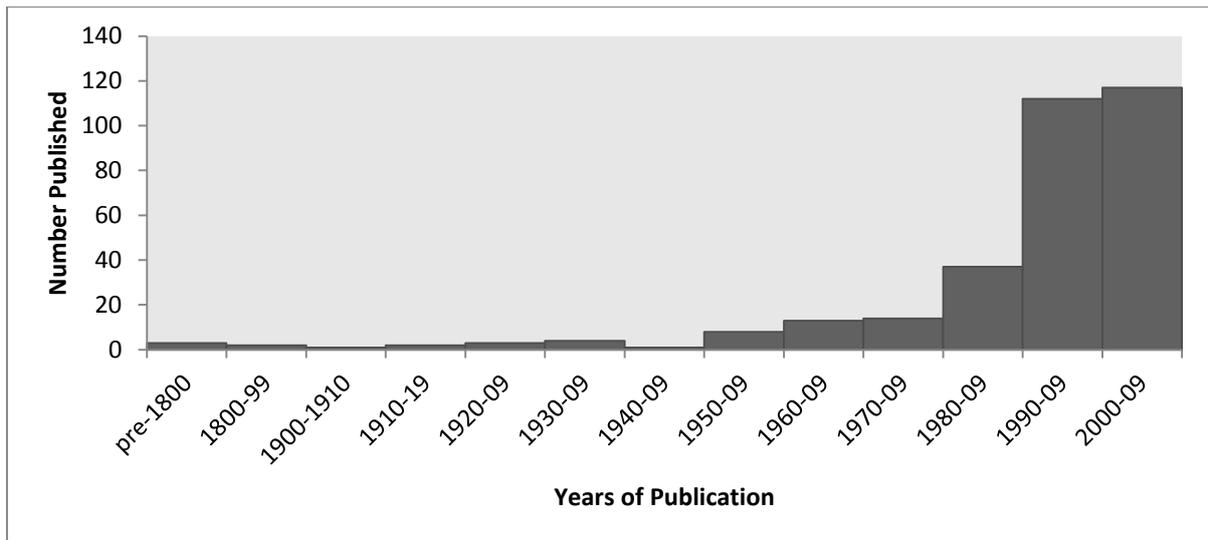


Figure 1. Publication Rates of Autopathographies from the Patients' Tales Collection (updated from Aronson 2001).

The timing of these jumps in publication rates is particularly interesting when considered within the wider context of trends in medicine and society. In the post-war 1950s, the vast advances in medical treatment and technology became available to the public mainstream, particularly in England, with the establishment of the National Health Service. These technological advances and the era of biomedical optimism that they ushered in may have prompted autopathography authors of the 1950s to share their new experiences. By the 1980s, the rise of new diseases, most notably AIDS, and the curative failures of the same technocratic medical system that sparked so much hope in the 1950s led the emergence of a different type of autopathography. As Susan Sontag famously illustrated, illness could be viewed as a metaphor of society and of individuals' positions within it (Sontag 1989). From this time, autopathographies began to explicitly address social ills and inequalities and to connect personal misfortune with societal malaise.

In considering the broad historical shifts that may have had an impact on the current popularity of autopathographies, we must, of course, include the concurrent rise of the internet since the 1980s. It perhaps seems contradictory upon initial inspection: there have

been continued increases in the publication of autopathographies, despite the rise of online health resources and instant web-based venues for the narrative sharing of health experiences through blogs, chat rooms and other online forums. We might expect quite the opposite: that those wishing to read about illness experiences would have been entirely appropriated by internet resources over the more traditional book format. However, autopathographies provide an important counterpoint to internet-based and other, more spontaneous way of sharing of patient experiences. Unlike most online illness narratives, which are often shared in brief articles or through posting updates, the accounts of illness presented in autopathographies are embedded in the wider life course of the author. Whereas internet resources tend to focus on the more immediate goals of sharing treatment information and experiences in dealing with specific stages or aspects of a condition, autopathographies uniformly take a step back and consider the deeper ways in which the illness has changed the author's life. In doing so, they provide not merely a window on to therapeutic pathways, but also an important locus of social commentary.

The Oxford Autopathographies Project

The Oxford Autopathographies Project is an effort to utilize the Patients' Tales Collection to conduct systematic analysis and research on autopathographies. The goal of this post-doctoral research project was to promote understanding of the pathways through which these texts communicate illness experiences to their readers and of how these have shifted over time, particularly with the increased availability of online health information. A coding schema was developed to allow for analysis both within and across disease categories (see Figure 2). The coding schema was developed based on previous work on the analysis of illness narratives, heavily influenced by the work of Arthur Kleinman (1980), with the aim of capturing the elements of the narratives that were most central to the patients' experience of

illness. The creation of the coding schema was an iterative process in which I developed broad categories of inquiry that were then refined and given detailed subcategories as I read approximately a hundred autopathographies, purposively sampled to represent a range of time period, disease category and authors. Unlike previous large-scale analyses of illness narratives (e.g. Stern and Kirmayer 2004), the objective of the coding schema was an effort not to present a monolithic structure for analyzing illness narratives, but rather to create an effective way of distilling the key features of autopathographies so that they might more readily be compared and further analysed on any one of these key features:

1. Publication Information
2. Narrative Analysis
3. Health-seeking behaviours/treatment process
4. Evaluation of treatment and institutions of health care
5. Techniques of transformation
6. Presentation of self
7. Responses from the social network
8. Use of metaphor

Figure 2: Outline of the Oxford Autopathographies Project coding schema

All books in the Patients' Tales Collection continue to be analysed using the coding schema. When complete, an online database repository of coded books will be made available to other researchers to enable autopathography research to extend beyond the volumes held by the Patients' Tales Collection and to promote secondary analysis. The project website (The Patients' Tales Collection 2011) hosts resources for illness narrative researchers, including an interactive catalogue of books by illness category and a form for submitting new entries to the catalogue and database. The Patients' Tales website helps to balance the prominence of web-based resources with the print modality, increasing access to contextualized illness narratives, and potentially reaching different segments of the patient and carer populations. In the longer term, the Oxford Autopathographies Project seeks to

increase the visibility and availability of autopathographies to the public and to measure their impact through the further analysis of coded material, publication rates and sales, and interviews with authors and readers.

Application of the coding schema

As discussed above, the purpose of the autopathographies coding schema was to enable comparative analysis amongst the salient features identified as central to all autopathographies. Here I illustrate how the coding schema might be applied through a brief comparison of two autopathographies of cancer: John Diamond's *C: Because cowards get cancer too...* (1998) and Elisa Segrave's *The Diary of a Breast* (1995). Both books were written in the same time period by UK authors who were already writers for a living, though Diamond was a more established journalist and public figure.

In terms of narrative analysis, Diamond and Segrave's works are about the same length at 256 and 287 pages, respectively. Both are written in a humorous tone, though Diamond's is more explicitly so, as he pokes fun of his own hypochondria and seemingly irrational responses to the treatment process, while Segrave focuses more on the humorous juxtaposition of the treatment process with the banality of the tasks of everyday life. Diamond's experiences are presented retrospectively, but Segrave's narrative is presented in the present tense in journal format. The experience of the diagnosis and treatment of their cancers forms the central focus of both books, though Segrave devotes more space (approximately 20% in comparison to Diamond's 10%) of her book to describing her family and social life apart from the illness. Both authors state that they want to present their pathway through illness to give others insight into the experience of cancer, without wanting to provide recommendations for treatments or other, more specific advice.

In evaluating the treatment and institutions of health care, Diamond focuses far more intently on scepticism of medical treatments, taking particular issue with alternative therapies. He writes emphatically, ‘where I stand on alternative medicine is roughly where the Pope stands on getting drunk on the communion wine and pulling a couple of nuns’ (1998: 98). However, Diamond also questions the biomedical treatments he receives, drawing on his own social network to assess medical literature and employing his skills as a journalist to investigate his options. For her part, Segrave focuses her evaluation of the health system and the treatment she receives on a more interpersonal level. She writes of one positive health care interaction: ‘I was delighted to see Dr W, whom I’d last seen just before Christmas. She looked pleased to see me too. She explained to me in detail what was happening and readily answered all my questions’ (1995: 150). She places faith in individual providers, but also voices fear of the overall treatment process: ‘Although I know that I’m supposed to think of the chemotherapy as an ally, “mopping up cells” and giving me a higher chance of survival, I can’t think of it as other than traumatic and frightening.’ Both authors give voice to their fears of the treatment process, as well as the possibility of death from their cancers.

Both of these ethnographies focus heavily upon the response to their illnesses from their social networks. Diamond pushes friends away, and retrospectively admits to doing so, but then resents their distance and their inability to interact in a way that he would find comforting – which, he confesses, alternates between wishing everyone would treat him normally, ignoring the cancer, and wishing that his friends would speak more directly about the illness. Diamond voices anger about his condition and recounts instances of lashing out at his wife and friends. Conversely, Segrave presents her process of dealing with her cancer as much more embedded in her preoccupation with caring for her two young children as a divorcee and navigating her social life given her sick role. She is very detailed regarding which friends help her with daily activities and her rationale behind whom she tells about her

illness and whom she does not. For the most part, Segrave is much more open with her social network about her condition and relies more heavily upon friendships to see her through the practicalities of treatment, as well as to buoy up her spirits.

Both of these autopathographies are compelling, humorous reads by authors of the same time period with cancers. However, they have very different approaches to finding the humour in their conditions and in navigating the treatment process and their altered social identities.

Research reflections

As an ethnographic enterprise, I found reading the autopathographies a compelling but difficult fieldwork experience. Accustomed to previous fieldwork on health-care delivery in Central America and Africa, I was surprised at how intimately personal fieldwork amongst piles of books could be. There are elements of autopathographies that hit the reader as ‘close to home’, as we all must face the transient nature of our lives and the uncertain nature of a certain end. Though I have deeply bonded with many research collaborators in my long-term field site in Guatemala, reading many of the works in the autopathographies collection generated a feeling of coherence with my own personal life that years of participant observation in ramshackle tin-roofed Maya villages have never evoked.

At the time I was working on the autopathographies project, I underwent genetic counselling for my own risk for cancer, having lost both of my grandmothers, an aunt and other relatives to a worrying range of breast, uterine and colorectal cancers. I found myself inextricably drawn to the narratives of cancer patients, and while reading them I often wondered whether the pain, fears, and perspectives articulated in them were those experienced by my loved ones, with whom I was never able to have open discussions of their illnesses. Retrospective insight into death is rarely cheering, and though many of the

autopathographies adopt a humorous tone, I often found them depressing. A section of my personal notes from the time reads:

Walked home again in the rain. It's cold, and I keep thinking it's evening and time to go when it's only mid-afternoon in the Oxford winter... Reading about other people's illnesses all day is making me depressed – which seems strange after watching children suffer hunger and diarrhea in Guatemala. This should be a cushy job by comparison! But I feel my grandmother sitting with me as I read, and I feel myself mourning her loss all over again. (17 January 2011)

In reading narratives of illness, particularly those on cancer, I also found it deflating to be left on a hopeful note by the author, only to learn through online research that they had in fact died from their illnesses.

Beyond the sad nature of the subject matter of autopathographies, many of them are written by charismatic authors, who write in such engaging styles that I found myself reaching for the next book immediately after closing the cover on the previous one. The authors are clearly interesting people; after all, not every ill person undertakes authorship of an autopathography. Ultimately, however, I found the static, one-way source of information to be the most frustrating aspect of working with the autopathographies collection as an anthropologist. Where I would have liked to create a dialogue with the authors, there was no opportunity to ask further questions or challenge their perspectives, as one might do in traditional ethnographic interviewing. Yet, a unique aspect of autopathographies is that the reader is left feeling that they know the author very well, despite having never met them.

Why write an autopathography?

Autopathographies are written by a self-selecting sample of patients, meaning that the choice to write a book about their illness experiences makes them not 'average' patients. There are varied motivations behind why an author might choose to write an autopathography, and many authors are up front about sharing those motivations, at least in part, in their texts. Authors often wish to share information about the health condition from

which they suffered and about the overall course of the treatment process. They may promote a specific political agenda (Egan 1999), typically by calling attention to deficiencies in health services, quality of care, or inequalities in access to health resources. They may also aim to raise awareness about their condition, to dispel myths about it and the nature of those who suffer from it, and to reduce any stigma attached to the condition. Authors address stigma by discussing the social and emotional impacts of their conditions, and they advocate removing secrecy or shame by being open about their own experiences.

Approximately sixty percent of the books held in the Patients' Tales Collection are written by celebrities, writers and academics. As people in the public eye or experienced authors, these groups are more likely to have the inclination, skills and professional access to be able to publish an autopathography. Autopathographies written by celebrities or experienced authors can bring greater attention to the book and to the particular health condition described. They also frequently have the ability to raise more proceeds for disease-specific research and charitable organizations than an unknown author, and many, such as the actor Michael J. Fox as an ambassador for Parkinson's disease, have utilized that power.

On a wider plane, authors can reclaim the story of their illness by writing autopathographies. They often discuss how their identity became uncertain during the course of their illness, centred on the illness itself and based upon the particulars in their medical charts. Authors regain power over their stories, choosing what to tell and what to omit, by writing autopathographies. Authors are free to cast themselves in identities of their own choosing. They can also attempt to influence others based on the authority of their experience of illness: 'In the reciprocity that is storytelling, the teller offers herself as guide to the other's self-formation... Telling stories in postmodern times, and perhaps in all times, attempts to change one's own life by affecting the lives of others' (Frank 1995: 17-18). Authors of

autopathographies have faced serious, often life-threatening conditions, and they write to share those experiences and the deeper meanings that they have ascribed to them with others.

Why has 'sick lit.' captured public attention?

My research suggests that autopathographies draw on narrative tropes, such as heroic battles and triumph-over-tragedy, that are familiar to contemporary readers from other popular literary forms, including novels, epic poetry and historical fiction. The structure of autopathographies often follows the formula of: 1) the author/protagonist is portrayed living life before or in ignorance of the health condition to come; 2) the first signs or symptoms appear, and a sense of foreboding develops; 3) the process of diagnosis takes place, where it becomes clear that the protagonist is in trouble; 4) the process of treatment unfolds, often resulting in a critical climax of poor health status, crippling fear, or existential angst for the protagonist; and finally, 5) the resolution of the condition or establishment of new norms and expectations for life are established. This narrative arch maps directly on to Freytag's (1908) classic paradigm of dramatic narrative structure: 1) exposition; 2) rising action; 3) climax; 4) falling action; 5) dénouement and resolution. This narrative structure is deeply embedded in Western cultural paradigms for the presentation of dramatic stories – and illnesses, where life hangs in the balance, are considered very dramatic.

Autopathographies, it follows, appeal to a wide readership because they are familiar in their dramatic narrative format, with the addition that they chart the course of real people and real experiences. Several classificatory systems for the type of narrative presented in illness narratives have been developed (Skultans 2000, Hawkins 1993, Frank 1995), yet the common thread of the dramatic narrative arch holds for each. It has been further suggested that illness autobiographies represent the contemporary, midlife version of the coming-of-age novel (Hunter 1991), which underscores the centrality of illness and healing experiences in

modern life. This comparison makes the implicit assertion that people want to read about illness because illness and interactions with health care are, just like coming of age, something experienced by and of interest to everyone. Moreover, publication may serve as a marker of authenticity and legitimacy that online illness narratives may not have. Autopathographies may in some way be viewed as more 'valid' simply through the process of being published, despite the fact that they are doubtless shaped in stylistic format and revised for content in relation to the author's original narrative by that process.

Through autopathographies, readers are able to view how individuals cope with unexpected and un-chosen life circumstances: narrative can restore equilibrium and restructure life expectations (Charon and Montello 2002). Though authors of autopathographies tend to follow the same dramatic arch in their storytelling, their tone and approach can vary widely from author to author. While some are serious and searching in their accounts, others adopt a humorous tone, poking fun at both practitioners and themselves as they come to grips with their changed situations and new identities. Likewise, authors differ in their attitudes and outlooks in re-achieving a sense of balance and identity, struggles that are central to autopathographies. Illness is a 'biographical disruption' that leads to self-examination and introspection that would otherwise be unlikely to occur (Bury 2001: 271). The quest for comfortable self-identity and life balance is a struggle familiar to many in contemporary Euro-American society, but illness forces action and sometimes places a more pressing timeline on resolution. Readers of autopathographies may hope to learn something from the experience of those who have faced the front lines of an existential battlefield and returned at least long enough to report what they have seen.

Contributions of autopathographies to understanding the patient experience

‘Not knowing’ can be institutionalized in medical systems (Littlewood 2007). As Douglas Ritchie writes in his autopathography of stroke: ‘There is a mystery about books on illness. Many doctors refuse to let their patients read them. They say that the more ignorant among them are bewildered by the medical terms, and feel that they are worse than is the case...But knowledge is nearly always better than ignorance, for anyone, for patients as for doctors.’ (1961: 142-3). Autopathographies can be used by patients and carers as a springboard for reflecting on their own experiences, both individually and through reading groups and other support networks. They can gain knowledge and be empowered through learning of others’ experiences of illness and how they negotiated the systems of health care.

Autopathographies can also be a tool for health-care providers to gain insight into patient experiences. Kathryn Montgomery Hunter contends that the plot structures of medical narratives (as opposed to illness narratives) are centred on the goal or endpoint of medical diagnosis: ‘Illness is a subjective experience, and the examining physician faces the task of translating it, locating the malady in the medical universe and conveying its characteristics and their meaning to others who know the medical language well but this particular patient not at all’ (1991: 52). The emerging emphasis on narrative in medicine has validated patient experiences; yet, ‘there is an irreducible layer of fact at the root – biological processes’ (Gunaratnam and Oliviere 2009: 7), that continues to dominate practitioners’ understandings of their patients.

Narrative can be used to bridge the universal and the particular (Skultans 2000). It is the patients and their particular experiences that are the focus of autopathographies rather than a universalizeable disease entity. As such, they have the power to reintegrate medical and (inter)personal aspects of illness by promoting understanding of the patient experience. The popular trend towards a wide readership of autopathographies should be built upon to

engage the public, patients and practitioners in explorations of the far-reaching impacts and meanings of illness for individuals, social networks and society.

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