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Social Context: A Review of Autobiography of a Disease

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Abstract

Autobiography of Disease by Patrick Anderson thoroughly examines the author's life threatening experience with *Staphylococcus aureus* (MRSA) osteomyelitis. Through notes kept by the author and caregiver/mother Anderson tells an evocative ethnography as told from the perspective of MRSA itself. This complex weaving of narratives highlights how multiple social and environmental considerations interact to impact Anderson's experience with illness. This book may be of interest to anyone seeking to learn more about the social context of illness.

Keywords

Ethnography, Social Ecology, Social Relationships

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Social Context: A Review of Autobiography of a Disease

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Autobiography of Disease by Patrick Anderson thoroughly examines the author's life-threatening experience with *Staphylococcus aureus* (MRSA) osteomyelitis. Through notes kept by the author and caregiver/mother Anderson tells an evocative ethnography as told from the perspective of MRSA itself. This complex weaving of narratives highlights how multiple social and environmental considerations interact to impact Anderson's experience with illness. This book may be of interest to anyone seeking to learn more about the social context of illness. Keywords: Ethnography, Social Ecology, Social Relationships

Imagine an orchestra of musicians thrown together seemingly haphazardly; the particular musicians do not matter; it is the combination and the music they produce that matter. The rise and falls of bows to strings, lips to brass can either result in perfect, blissful music under the conductor's watch or, if an appropriate combination of musicians is not present, cacophony. Now substitute the musicians for microbes, trillions of microbes existing in symbiotic harmony on and in the human body, this is the human microbiome (Turnbaugh et al., 2007). In this case, the conductor represents the human body. Every person's microbiome is unique, with diverse coexisting ecological communities carefully balanced to maintain health (Huttenhower et al., 2012). Under the right circumstances, an unbalanced orchestra or microbial community can make the conductor or patient susceptible to a serious illness, such as in Patrick Anderson's experience with Methicillin-resistant *Staphylococcus aureus* (MRSA) osteomyelitis (infection or inflammation of the bone or bone marrow) presented in his book *Autobiography of a Disease* (2017).

The microbiome, and its impact on a patient's health, is ubiquitous in research and popular literature. Less often considered is the impact of social support networks on a patient's health. Now consider the musicians themselves as a social conglomerate of varying experiences and talents meant to create a composition of harmony and melody to support the conductor. One musician might have just had a fight with their partner and now bears down on their instrument too hard; another might be preoccupied with the excitement of reconnecting with a college roommate and now fleetingly forgets a few notes. The result is a poor performance.

It is this social context where *Autobiography of a Disease* shines. The social context of disease is something that we are generally unaware of—a seemingly trifling detail necessary for the delivery of treatment for an infectious disease. Anderson elevates the psychological and social labyrinth that encases disease treatment as critical for determining the efficacy of that treatment. Through a potent retelling of the author's intensive struggle with MRSA osteomyelitis, Anderson details the relationships surrounding his care: a psychologically disconnected and geographically removed family that now engages with his care, a close-knit network of friends, and a bee-hive of clinicians each making an indelible and unique impact on his prognosis.

Central to *Autobiography of Disease* are the communication strategies used within and between the groups interacting with Anderson. Whether it is clinicians who communicate with one another; for example, the diametric power struggle between a nurse and physician or an indifferent paramedic. They communicate to Anderson through a range of disconnected language, hostile narcissism, and gentle caring. A simple offhanded remark questioning

another physician's decision to try to save his patient's leg can have reverberating consequences for the patient. Through lyrical gesturing, the presumptive heroic qualities of clinicians are peeled back to reveal a complex social-ecosystem; the clinician is neither hero nor villain, but a person. The task of humanizing clinicians is challenging considering the limited viewpoint of one patient, but Anderson does this masterfully.

Similarly, reflections on the author's family and friends, and their experience and reactions with each other have important impact on Anderson's recovery far beyond his activities of daily living. Family and friends make varying levels of sacrifice in an attempt to improve Anderson's dire condition. An absent preacher of a father tries to make amends through prayer; a group of friends organizes a mailing list to ensure everyone is up to date on Anderson's progress. Importantly, Anderson also reflects on internal states of mind, not just of his own, but of others—most notably his mother during an extended walk through a park and her emotional pull to be near her ailing son. Anderson breathes life into the importance of these relationships and the weight they had on his recovery. He demonstrates that each personality does not exist independent of others, rather they are an ensemble, a *social-biome*.

Social ecology contains institutional-, community-, and policy-level conditions that each impact the efficacy and delivery of medical treatment and exist outside of the above-mentioned individual and interpersonal realms (Bronfenbrenner, 1977). Carrying on with the orchestra theme, this would be the building where the performance is seen, the audience members, and the policies that regulate ticket prices. These other components of healthcare culture are particularly important, but do not seem to meld with the narrative of the book as easily as the social components. Where the book does succeed is through a description of the complicated web of healthcare systems through which Anderson has to navigate. For example, concern over the availability of a hospital bed creates both psychological tension and physical consequences for the ailing patient. Additionally, an ever-present concern over paying for his treatments lurks in the background throughout the story. Reviewing bills and haggling with insurance companies does not make for an engaging read; still a more inclusive account of these struggles may have provided the reader with a fuller understanding of the competing priorities Anderson had to navigate.

A fascinating and critical aspect to the success of *Autobiography of Disease* are the data collection techniques used to weave the narrative. Anderson had a background in anthropology and communications studies, and during the time of his illness was a graduate student of performance studies at University of California, Berkley. He presumably uses this background and his detailed notetaking, particularly during the times when he was feeling better to reflect on his experience. Other times his mother, Diedre, meticulously documented dates names and treatments in a notebook, acting as a scribe throughout Anderson's journey. These data are presented as a story of a lived experience using evocative autoethnography (Bochner & Ellis, 2016), and told through the voice of MRSA itself as the narrator. MRSA as a narrator succeeds from time to time, but other times feels forced.

The main challenge to the reader is understanding what the cluster of bacteria is and from what angle it is telling the story. Anderson attempts multiple techniques for giving MRSA voice, oscillating between telling the history of MRSA, MRSA as a living organism trying to survive, describing Anderson's ongoing health challenges, and reflecting on the author's personal history and experienced emotional state. The description of MRSA as a living thing seeking to survive is poignant and thought provoking, but the other methods of storytelling fall flat. How is the reader supposed to believe that MRSA understands the emotional struggle that Diedre is experiencing? How is MRSA supposed to describe the delicate dance of tugboats around San Francisco Bay?

The telling of Anderson's health struggles is a complicated affair and the author tells the story with just enough drama to keep the reader engaged. *Autobiography of Disease* never

quite reaches a crescendo, but this is okay; true life rarely does. The book is only 222 pages and sections are chopped into short, easy to read passages of text making the book easy to put down and come back to if the reader is so inclined. While tempting to read in short bouts, I found Anderson's prose to be engaging enough that I wanted to continue reading and discover what the next section had in store. The experience of illness is complex with multiple moving pieces each having varying impacts on the efficacy of treatment. Anderson offers up a fascinating ethnography highlighting an accompaniment of performers, each playing a part in his recovery.

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