



Microcosms of power dynamics: The hidden world of pharmaceutical testing

Review by Ellen A. Ahlness

JILL A. FISHER, 2020, *Adverse Events: Race, Inequality, and the Testing of New Pharmaceuticals*, New York: New York University Press, 317 pp., ISBN 978-1-4798-6216-0

Adverse Events is the product of over a decade of research, incorporating challenging ethnographic field work with theoretical considerations. At its core, it is a book about social inequality in a disconcerting place. The book is divided into nine chapters, an introduction, and a conclusion. Tables and figures are distributed through the book, though largely centered in two sections. Fisher does an excellent job of engaging the reader, and the book itself opens with a hypothetical thought process that an individual might go through as they as they consider whether to participate in the first phase of a clinical drug trial.

The introduction assumes that readers have little background knowledge about clinical trials, explaining the difference between various testing stages in the pharmaceuticals industry, and notes two critical features of the industry. First, that phase one trials disproportionately represent racial minorities and men, and second, that monetary compensation is the primary, if not only, motivation to enroll as a healthy volunteer.

The text is heavily centered on phenomenological research, interrogating how healthy volunteers experience their participation in phase one trials, especially compared to how the general public perceives their involvement. *Adverse Events*, therefore, tries to center the human experience in spaces where dehumanization is possible, as people increasingly lose agency over their bodies,

being told when they eat, if they can exercise, and how much blood will be drawn. Two themes are at the core of the entire book. First is the concept of imbricated stigma, the notion that people may have combined stigmas that affect the barriers they face. Second is the notion of the 'healthy volunteer' as a model individual. Together, these contribute to the social inequalities on which the research empire is built and even affect the agency of individuals who participate in research themselves. Individuals are rewarded for giving up their agency by submitting to controlled conditions.

Chapter 1 provides greater ethnographic detail about entering and staying in a clinic. It injects the reader into the environment by describing what it looks like, how it operates, and the general tone. This is also where Fisher inputs a great deal of reflexive research, setting up the methodological considerations of the project. Fisher is forthcoming about methodological difficulties. Despite this, there is an impressive amount of data for qualitative research: she interviewed 235 'healthy' volunteers for the project, lending credibility to her conversation on power dynamics and vulnerability.

Chapter 2 provides greater narrative on the economic motivations of volunteers, and how someone's background shapes their view and motivations for participating in phase one trials. Chapter 3 continues this theme to consider how variations in patterns of stigma and intersectionality influence perceptions of phase one trials. While Fisher does not explicitly use the phrase intersectionality in their introduction, their perspective on stigma and vulnerability is consistent with the idea of intersectionality

Chapter 4 examines a brief history of phase one trial clinics in the United States, which provides a foundation for a conversation on study protocols in Chapter 5, on how trial demands can lead to specific practices by research staff, which can affect validity concerns (analyzed in Chapter 6). While Chapter 7 does not draw on secondary data to articulate the risks of participating in phase one trials, the phenomenological and human centered themes are continued as Fisher investigates healthy volunteer perceptions of trials' safety and their self-categorization of some trials as more risky than others.

In Chapter 8, Fisher expands on this content, arguing that risk constructions are a kind of epistemology, representing the way that model volunteers make sense of knowledge from personal experiences, narratives of others, and the facts received from clinics. Chapter 9 concludes this conversation about risk by articulating a common and surprising narrative that Fisher found in their study: volunteers are very vocal about the economic risk of not qualifying for studies. *Adverse Event*'s conclusion brings everything together at a macro level, reflecting on the political and economic context of US phase one trials. Fisher asserts that a society characterized by stigmas, especially intersectional stigmas, means that there will always be healthy volunteers willing to undergo risks for financial compensation.

One of the text's greatest strengths is that it never presents an illusion of the author as being separate from their research. Moreover, it does this in a way that enhances its accessibility to the general public, as sections read like an autobiography. At the same time, there is a productive sense of discomfort throughout the book that individuals are 'selling themselves' because they have nothing else to sell. Fisher presents this perspective herself, but does give quotes that suggest that this is not an uncommon way of thinking among phase one trial participants.

In talking about the human experience, Fisher seems to be particularly conscientious about inferring participants' explicitly communicated motivations for participating in trials, cognizant to not ascribe secondary meanings. Culture itself is a major theme throughout the book. Even as trial communities develop their own cultures, the three regions in which phase one trials are conducted in the US each have their own unique clinical trial cultures.

Fisher concludes the book with a warning about the dangers of invisibility: the phase one world is fundamentally invisible. Even as it is robust and established in the US, along with other developed countries around the world, very few people are aware of it. That, more than anything else, gives these industries power. Their hidden nature adds to their stigma and further protects the interest of pharmaceutical industries while making volunteers more vulnerable.

Consequently, Fisher advocates for clinic and holistic industry practices that will reduce the stigma of participation.

This book is an excellent read both for those interested in the sociology and anthropology of healthcare and the medical environment, as well as for readers with interests in labor and Critical Race and Gender Studies; there is no denying the impact of race, gender, and class on phase one trials. Overall, this is a great read, particularly for graduate students and public readers who want to see how an environment traditionally imagined as ‘objective’ or ‘sterile’ is, in fact, affected by stigmas and bias. The effects—and events—are indeed adverse and serious.

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