

Breathtaking: Contemporary Figures of U.S. Asthma Care

by

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ABSTRACT

Breathtaking is a study of the contemporary asthma epidemic, focusing on several disciplinary and geographical communities in the U.S. It highlights problems posed by the epidemic and describes the various ways communities approach these problems. *Breathtaking* argues that approaches to asthma are marked by ‘care’ – practices that respond to problems with more questions than answers; practices necessarily characterized by experimentation, openness, and muddling through (Fortun and Bernstein 1998). Caring practices are a necessary approach to asthma given the variability, uncertainty, and questions surrounding the disease. Many of the problems outlined in *Breathtaking* stem from relationships and conventions found in the contemporary health assemblage – which includes scientific studies and research programs, clinics, pharmaceutical companies and regulatory agencies, patient advocacy groups, alternative health communities, patients and caregivers. Most prominently, the contemporary health assemblage fails to provide the tools and frameworks for addressing environmental health issues, such as asthma. The limitations and constraints of the contemporary health assemblage force asthma researchers, health professionals, asthmatics and asthma caregivers to muddle through information and techniques, all in an effort to figure out and manage the asthmatic condition.

Research for *Breathtaking* was conducted over a two-year period, at multiple sites. Data was collected through participant observation, ethnographic interviews, and analysis of scientific and associated literatures. Participant observation took place at scientific conferences, in communities with air quality problems, in conversation with asthmatics, and at a Buteyko clinic in Woodstock, New York. Ethnographic interviews were conducted with asthmatics in Upstate New York, as well as with scientists, community organizers, and advocacy workers at multiple locations. Document analysis included histories of asthma and memoirs of asthmatics, peer-reviewed articles focused on asthma research, government reports on the asthma epidemic, and the publications of nonprofit organizations, including newsletters, research reports, and press releases.

Research for *Breathtaking* was informed by *The Asthma Files*, a collaborative social science project that aims to produce and circulate ethnographic knowledge about asthma in new ways. Designed by a collective of social scientists and humanities

scholars, *The Asthma Files* is a digital archive of images, text, and videos that have been curated through a number of themes and questions posed by *Asthma File* researchers. Participation in *The Asthma Files* took a number of forms – through digital scholarship and course seminars at Rensselaer Polytechnic Institute, through regular planning meetings with other *Asthma File* collaborators, and as a representative of the project, which involved giving presentations and talking with various publics and academics about the project.

Breathtaking focuses on four problems that riddle the contemporary asthma epidemic: 1) the problem of definition: how to define ‘asthma’ given its diverse and variable manifestations; 2) the problem of air quality: how to account for air quality in asthma research; 3) the problem of individualization: how to address the asthma epidemic without making disease management an individual responsibility; and 4) the problem of failed treatments: how to manage the asthmatic condition when biomedicine fails to provide effective remedies.

Breathtaking’s empirical chapters are organized around these four problems. Chapter two highlights the process through which national guidelines for asthma diagnosis and management were created. Chapter three focuses on the ways in which scientists account for air quality in asthma research. Chapter four analyzes the work conducted at Columbia’s Center for Children’s Environmental Health, an interdisciplinary research center which pioneered a study on prenatal exposure to environmental toxins. Chapter five looks at the Buteyko community, a community where severe asthmatics learn alternative health techniques to manage symptoms.

In each of these chapters, experts and researchers, asthmatics and their caregivers, respond to the asthmatic condition in ways characterized by care. The idea of caring practices derives from earlier work by feminist scholars. Feminist ethics emerged in the 1980s and 1990s, and argued for ethical frameworks that, not only took stock of the gendered structure of contemporary ethics, but that acknowledged and moved forward from women’s work conditions and the dynamics of domestic space. Care was cast as the means through which women approached domestic responsibilities.

Moving beyond the earlier tradition of feminist care ethics, *Breathtaking* argues that the work undertaken by those concerned with and impacted by the contemporary

asthma epidemic is caring, approaches characterized by a muddling through unknowns and uncertainties; experiments that kludge together what is known and what tools are available; and openness to new theories and strategies for figuring out the asthmatic condition.

In addition to advancing conceptualization of care – which contributes to feminist literatures on caring as well as understandings of knowledge production in science and technology studies – *Breathtaking* describes and analyzes how asthma care unfolds at different scales: nationally through clinical practice guidelines, in cities through air quality research, in local communities and neighborhoods particularly hard hit by the epidemic, and in families and home spaces where the asthmatic condition is managed daily. By tracing and comparing caring practices across scale, *Breathtaking* furthers understanding of the ubiquitous reach of environmental health problems (such as asthma), the multiple levels of impact and problem-solving, and conceptualizes the strategic practices that emerge when dealing with public health problem.

