

## Chapter 20

# Asthma, Culture, and Cultural Analysis: Continuing Challenges

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**Abstract** Recent research indicates that asthma is more complicated than already recognized, requiring a multilateral approach of study in order to better understand its many facets. Apart from being a health problem, asthma is seen as a knowledge problem, and as we argue here, a cultural problem. Employing cultural analysis we outline ways to challenge conventional ideas and practices about asthma by considering how culture shapes asthma experience, diagnosis, management, research, and politics. Finally, we discuss the value of viewing asthma through multiple lenses, and how such “explanatory pluralism” advances transdisciplinary approaches to asthma.

**Keywords** Environmental health • Transdisciplinarity • Explanatory pluralism • Anthropology of science • Cultural frames • Qualitative methods • Compliance and cultural competency

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## 20.1 Introduction

Asthma is at once (1) a heterogeneous chronic disease experienced by hundreds of millions of people around the world, living in very different settings; (2) a standardized (although variable in practice) diagnostic category deployed by health care professionals to direct disease management and enable disease surveillance; (3) a research focus of scientists employing a wide array of methods in fields as varied as pulmonology, genetics, epidemiology, immunology, air chemistry, and cultural anthropology; and (4) a sentinel condition that motivates environmental research, activism, and regulation. In short, asthma is a complex condition, with multiple dimensions, prompting diverse efforts to understand and manage it. All of these efforts need further development and refinement, even after decades of research and concerted effort. Asthma has resisted our most dedicated efforts to understand and care for it.

Furthermore, recent research developments call attention to the possibility that asthma is even more complicated than has already been recognized. An editorial in *The Lancet* in 2008, for example, noted that the “notion of asthma as one unifying disease concept is disappearing further into the realm of historical over simplification” (Lancet editorial 2008). A 2011 article by veteran asthma researcher Stephen Holgate and coauthors (Holmes et al. 2011) also points to over simplification in asthma research to date: “No single method is sufficient to model a syndrome as complex as asthma accurately,” they write (Holmes et al. 2011). Their critical review was directed primarily at the limitations of animal models of asthma, which “use the concept that allergen-driven Th2-type inflammation is the underlying abnormality in asthma” (Holmes et al. 2011). In the view of Holgate and coauthors, animal models “have failed to recapitulate important features of the disease,” especially those more closely connected to “infection (viral and bacterial), air pollution, diet, environmental tobacco smoke, drugs and other chemicals, and their interplay with genetic factors.” What is called for, in their view, is the development of a “tool-kit” of multiple approaches and methods that “when combined, build a holistic picture of the disease.”

Statements such as those made by Holgate and coauthors indicate that asthma is not only a health problem but also a knowledge problem, calling for new knowledge practices and forms. Asthma is also, we argue here, a cultural problem. The complex multidimensionality of asthma makes it difficult to deal with clinically and scientifically, and also culturally—because it challenges us to create new modes of thought and practice that differ from those behind conventional ways of thinking about health, research, and politics.

Modern health care and research aim to identify the cause and mechanism of disease, progressively ruling out what is not determinative. The logic is binary: Is it X, or not? If not X, is it then Y, and not Z? Modern health care and research are also organized into disciplinary specializations, allowing for impressive depth of knowledge and analysis, but making it difficult to see “the whole (bodily, much less environmental) system.” And modern health care and research privilege “in-body”

constructs of disease; air chemists and exposure scientists are usually not housed within Schools of Medicine; few medical training programs cover environmental health stressors; the U.S. National Institute of Environmental Health Sciences enjoys only 2 % of the overall budget for the National Institutes of Health; social scientists—especially the qualitative kind—are not seen as deeply relevant to understanding and care of disease.

Intense focus on bodily mechanisms and singular causation has enabled amazing advances in medicine over the last century. It has also fueled what anthropologist Mary Jo Good (2007) has termed a “medical imaginary” that fosters belief that modern medicine can provide both explanation and cures for any range of ills. Even in the most difficult cancer cases, Good argues, there is often great expectation that biomedicine will come through—with clear explanations and solutions to the problem of illness. This drives people in varied positions—patients, family members, doctors, researchers, the media—to conceive, represent, and deal with disease in a particular manner: one which is straightforward and clearly actionable. We all want to know what, *exactly*, to do when someone is sick. And we count on health care experts, institutions, and research to tell us this.

But asthma is much more complex. And the acknowledgment of asthma’s complexity by researchers like Holgate and his coauthors indicates a potential convergence, we also argue, between biomedical researchers’ recognized need for more holistic perspectives and anthropologists’ long-standing goal of systemic, holistic understanding of culture. That convergence in turn creates new opportunities for genuine “transdisciplinary” work involving not only diverse biomedical researchers but also cultural analysts as well.

Complex conditions such as asthma cannot be adequately explained or cared for within current cultural frames. Cultural innovation is therefore required. Cultural analysis can document and enhance understanding of how established health institutions and research programs work, drawing out the assumptions that undergird them. Cultural analysis can also draw out the explanatory limits of biomedicine—what it cannot address because of habitual, often discipline-specific modes of thought and practice that efforts at “transdisciplinarity” are intended to overcome.

As Harvard physician–anthropologist Paul Farmer (renowned for his work in Haiti and Africa with Partners for Health) has emphasized: a critical epistemology of disease is needed that addresses the multifactorial nature of disease emergence. This kind of innovation starts, Farmer argues, through examination of existing conceptual frameworks, asking: “What is obscured in this way of conceptualizing disease? What is brought into relief?” (Farmer 1996). Cultural analysis, carried out in dialog with biomedical researchers, physicians, and all other involved in asthma care and knowledge production, can advance this kind of conceptual examination. Cultural analysis can highlight cultural innovation, the development of new modes of thought and practice in all areas of the “asthma complex system”—from researchers like Holgate, to clinicians, to asthma sufferers themselves.

Below we describe how asthma can be understood as a cultural phenomena and problem. In the first section, we describe how the theories, methods, and techniques of contemporary cultural analysis have been updated for study of complex societies,

dealing with complex problems. We then describe how cultural analysts have examined asthma experiences, diagnosis and management, research, and politics—collectively drawing out the many ways that asthma is a cultural phenomena. The final section discusses the cultural challenge and value of multifactorial, pluralistic ways of understanding asthma systemically, “holistically,” or “transdisciplinarily.”

## 20.2 Theories, Methods, and Techniques of Cultural Analysis

Cultural analysis not only strives to document all that is going on in a “system” but also seeks to explain how and why things occur. It maps the many influences that shape human perceptions and actions, and the forms and patterns of language, thought, behavior, and social interaction that characterize a particular context. In cultural anthropology, the ambition is holistic. Cultural anthropologists strive to explain the parts, relationships, and dynamics of whole sociocultural systems—their structure, functioning, and context, and how they change (or resist change). They do this through observation of systems at work, through research that draws out historical and external forces on a system and through sustained dialogue with human actors within the system.

In early anthropological research, the system studied was often a village or particular language or ethnic community, seeking to explain how religious and economic practices, family and political structures, and aesthetic and narrative forms synchronized to produce the particular system at hand. An array of ways to study whole systems emerged. Researchers learned, for example that focusing on women’s roles, practices, and perceptions was a reliable way to understand how a system was held together (Weiner 1976).

In the last few decades, cultural anthropologists have studied increasingly complex societies and phenomena, where the “system” studied could be a residential or scientific community, a particular hospital or urban space, an organization like Doctors Without Borders that works across geographic locations, and large-scale phenomena such as globalization and neoliberalism (see e.g., Fischer 2003). This has entailed a need to “study up” (Nader 1972), focusing on the cultures and practices of elites and professionals, including health professionals. The anthropology of science has also developed as a cutting-edge subfield, with work focused on how scientists think, work, and are organized and on ways science is understood by citizens, patients, lawmakers, and other stakeholders (see Fischer 2007 for a summary). A pulmonologist with supplementary training in allergies and immunology, anxiously trying to meet three grant application deadlines to keep his laboratory at a major university medical center active and productive—driven by a complex mixture of curiosity, socioeconomic need, and desire to heal—is thus treated as much as a cultural actor as a Mexican-American mother of three, who is an evangelical Catholic, with

limited English, and resides in Los Angeles County, California, while managing both her own relatively mild asthma and the more severe asthma of two of her children. Organizations are also analyzed as cultural actors. Bureaucracies formed in different historical and geographic contexts, for example, delineate and address complex problems like asthma in different ways and thus need to be analyzed and understood as cultural actors and producers.

“Culture,” in this way of doing cultural analysis, has a dynamic character. Culture is not so much a stable and consistent “worldview,” conceived largely as a set of beliefs, as it is habitual modes of perception, action, and articulation—patterned ways of seeing and conceptualizing problems, and figuring out how to respond. Culture provides terms and techniques for making sense of things (Fischer 2003) and is thus both a resource and a limitation.

### 20.3 Culture and the Experience of Asthma

How asthma is experienced differently according to historical, geographical, and cultural context has been studied by cultural analysts using a range of approaches and methods, including interviews, ethnographic fieldwork, videography, and participant observation—although much work remains to be done (Adams et al. 1997; Chalfen and Rich 2004, 2007; Gabe et al. 2002; Rudestam et al. 2004; Williams 2000; Wind et al. 2004). Some cultural anthropologists also analyze literary texts to illuminate how asthmatic experience is shaped by culture; as an example of this approach, we consider here journalist Tim Brookes’ (1994) autobiographical account *Catching My Breath: An Asthmatic Explores His Illness*.

As an adult, Brookes was nearly killed by an asthma attack, which set in motion a remarkable process of exploration to figure out *the* cause. Brookes consulted specialists in numerous medical fields, experimented (unsuccessfully) with homeopathy, and learned about the wide array of alternative treatments asthmatics have tried, including yoga, acupuncture, hypnotism, and cockroach tea. He wrangled with insurance companies and rode with a mobile health unit in New York City serving poor communities—all aiming to understand the spectrum of factors that shape asthma experience and outcomes. At the end of his book, Brookes decides that the “culprit” behind his life-threatening asthma attack was an antacid tablet containing yellow dye. To test his theory, he contacted his pulmonologist and again ingested a yellow-dyed antacid tablet in the controlled environment of the Pulmonology Function Lab. But there was no emergency. In this instance at least, the yellow-dyed antacid did not trigger a life-threatening asthma attack.

Brookes did not thus conclude that he was safe with yellow dye. Instead, he recognized that his own response was shaped by what we have referred to here as the “modern” culture of explanatory simplicity: a habit of working to identify *the* cause behind any effect—be it an asthma attack, another disease outcome, or some other complex problem. “Even after all this time,” Brookes reflected, and all his effort to explore the multiple complexities of asthma, “I was still looking for the single

causes, simple cures." Brookes desperately wanted to know *the* cause of his asthma attacks and felt that this was what was needed to care for, if not cure, himself. Brookes thus provides a powerful example of how a "medical imaginary" can powerfully shape asthma experience.

And that cultural effect is not limited to asthma sufferers but is a systemic effect that works on multiple levels of the asthmatic condition including on biomedical researchers. Reflecting on the long history of asthma research in which he has played a prominent role, Fernando Martinez likens research on asthma to kindred research on rheumatoid arthritis, for which scientists "yearn[ed] for a theory that would fit it all together, under one formula, one idea, one mechanism" (Martinez 2007, quoting Weyand and Goronzy 2006). Such ideas would have to be relinquished, Martinez argues, and researchers must, "with apologies to William of Ockham," learn to tolerate "less parsimonious" explanations that do not rely on any simple cause or mechanism, biological or environmental, but grapple instead with "weak linkages" and "indirect, undemanding, and low-information regulatory connections" that are "highly flexible" and thoroughly heterogeneous. We return to these cultural analyses and their implications for future asthma research in the conclusion.

## 20.4 Culture in the Diagnosis and Management of Asthma

Culture also shapes asthma diagnoses and management by health professionals. As medical anthropologist David Van Sickle (2005, 2009) has documented, for example, biomedical professionals in Chennai, India do not see and diagnose asthma in the way prescribed by the ISAAC (International Study of Allergy and Asthma in Children) protocol for the study of asthma incidence across nations. In part, this is because of the stigma attached to asthma, and resulting hesitation to confirm an asthma diagnosis. Van Sickle argues that because patients and their families do not want to be diagnosed with asthma, doctors (who are trying to make their patients happy in a very competitive medical market place) tend not to diagnose asthma in these individuals. This means that asthma goes untreated, is not controlled, and comes to adversely shape life trajectories in significant ways. A culture which frames asthma as stigma thus unleashes a cascade of effects on patients and shapes what physicians see and do.

Van Sickle concludes that "many practicing clinicians in India differ in the perception and interpretation of common asthma symptoms depicted in the ISAAC video," and that the cumulative effect of these many cultural differences "may account for the low rates of reported asthma observed in epidemiological studies conducted in Chennai and other parts of India, and suggests that rates of diagnosed asthma among these populations underestimate the true burden of disease" (Van Sickle 2005). The ISAAC protocols and research effort have been crucial to our understanding of asthma internationally. But Van Sickle's research also suggests that Chennai physicians have ways of understanding respiratory illness outside

expected frames. A key challenge for cultural analysis and global public health is to leverage the difference in perspectives—not seeing the perspective of Chennai physicians as a better one than that embedded in the ISAAC study, but as a different one, and thus a means to critically reflect on different ways of conceptualizing and managing asthma. Again following Paul Farmer, such differing perspectives shaped by culture become an opportunity to ask, of ISAAC protocols and Indian physicians alike: “What is obscured in this way of conceptualizing disease? What is brought into relief?” (Farmer 1996).

## 20.5 Culture in Asthma Science

In his history of asthma and allergy in the USA, historian of medicine Greg Mitman tells the story of Oren Durham, a photographer and amateur “pollen collector” of the early 1920s who supplied his uncle—one of the first physicians in the USA to practice immunotherapy on his hay fever patients—with pollen samples for his immunization treatments. He quickly turned professional and developed the first detailed pollen maps of Kansas City and Chicago, linking pollen levels to urban neglect in the process. Durham went on to build a collaboration with the US Weather Bureau, using its networks to coordinate and standardize a system of pollen collection and analysis that led to the first national pollen maps. Durham was later hired as chief botanist by Abbot Laboratories to develop a market for pollen extracts (1930), foreshadowing the huge role the pharmaceutical industry would come to play in asthma knowledge and care. Mitman goes on to describe intricate links between the pharmaceutical industry and professional societies, questioning how commercial interests have shaped how we approach asthma. Part of the story is about increasing standardization in the way asthma has been conceptualized, regardless of context. Mitman’s overarching message is that we should “widen our focus on the causes and prevention of [asthma] and invest more in research that takes into account the ecological relationships between illness and place” (Mitman 2007).

Mitman lays empirical and analytic ground for understanding the wide array of sciences that contribute to asthma knowledge. There is an intriguing array of actors just in the story he tells, and there are even more in the contemporary asthma picture. Cultural analysts need to map their connections, as Mitman did for Durham, questioning how these connections have staged and influenced their work on asthma. Cultural analysts can also work to understand how the disciplinary frames that scientists and health professionals from different fields bring to their work. These disciplinary frames provide important analytic purchase, yet can also make it difficult for people from different fields to work together.

The atomistic way that both medical fields and scientific disciplines are configured in modern societies illustrates a cultural tendency to deal with problems by breaking them apart to explore different possible mechanisms—assumed to be isolatable. This way of organizing knowledge production and translation both embodies and reinforces assumptions that causality is singular, usually linear, and, once

delineated, can be “fixed.” Cross-systems cascades and cumulative effects are hard to get at within such a regime. And it is hard for individual researchers to rise above it. This is not because individual researchers do not recognize the need for systems approaches and interdisciplinarity. Many researchers do. But a researcher trained in a particular discipline is deeply encultured to see in a particular way and to have a particular “thought style.” Indeed, this is what it means to be disciplined.

Working across disciplines—creating what historian of science Peter Galison has called “trading zones” can thus be enabled by cultural analysis that draws out the thought styles of different fields, increasing the visibility of their assumptions and logics. Cross-disciplinary understanding is a form of cross-cultural understanding; it does not solve the problem of cultural differences within the sciences and among medical fields, but it can animate methodological reflexivity and the kind of creativity crucial in transdisciplinary effort.

## 20.6 Culture in Asthma Politics

Numerous cultural analyses of biomedicine have documented its tendency to “individualize” disease (Good 1994, 2007; Frankenberg 1980). The difficult paradox involved becomes all too clear in the case of asthma; clinicians and researchers alike must attend to the heterogeneous specifics of an individual’s respiratory distress, yet doing so can occlude the social, cultural, economic, and political determinants of illness. Cultural analysts can help reach the goal of a more systemic understanding of asthma, bringing its political dimensions back into view.

Sociologist Phil Brown and colleagues, for example, have studied “not how the illness shapes the individual experience,” but how community organizations can “create a collective identity around the experience of asthma” that “links social and physical realities” that can “transform the personal experience” into collective effort and environmental advocacy (Brown et al. 2003). The Brown group analyzed how Alternatives for Community and Environment (ACE), in the Boston neighborhood of Roxbury, built new scientific collaborations with researchers at the Schools of Public Health at Harvard and at Boston University, developing the AirBeat project to install neighborhood air monitors, collect air quality data, and analyze the relationship between air quality data and doctor and hospital visits. A similar group, West Harlem Environmental Action (WE ACT), partnered with researchers at Columbia School of Public Health to develop an even more extensive research program. These collective efforts resulted in a way of thinking about asthma that was overtly political. As one community leader put it, “it’s the underlying conditions of poverty and social injustice that are contributing to all these things...[Y]ou just can’t get rid of cockroaches and expect asthma to go away. For that matter, you can’t just put in better buses and expect asthma to go away. It’s all got to be approached in a social justice framework” (Brown et al. 2003). Foregrounding the social and political dimensions of asthma in these cases led to more, and better, biomedical research.



In other cases, biomedical researchers more focused on the systemic forces shaping asthma lead to recognition of its political dimensions through the lens of health disparities research. Pulmonologist Rosalind Wright and Diane Gold have been active in the Asthma Coalition on Community, Environment, and Social Stress (ACCESS), a long-term prospective cohort study noteworthy for its multilevel approaches including gene–environment interaction studies, molecular profiling, socioeconomic analysis, indoor and outdoor exposure monitoring, behavioral factors, and numerous other measures of differential social support or violence, all modeled in an effort to better understand how psychosocial stress may shape the health disparities visible in asthma. They conclude that “in the United States, effective reduction in disparities in asthma morbidity will be dependent only in part on specific measures like establishment of smoking cessation programs, home allergen reduction in sensitized asthmatic children, physician feedback, and/or health education. The long-term success of any of these specific measures is likely to depend, in great part, on more general improvements in living conditions and life opportunities” (Gold and Wright 2005).

Health disparities in asthma incidence and severity exist beyond US borders, of course. Cultural analysis is important at the global level as well, again bringing out the more systemic political and cultural forces that shape asthma. The Global Alliance for Clean Cookstoves (<http://www.cleancookstoves.org>), for example, is a private–public coalition of academic organizations like Columbia University, multilateral organizations like the World Health Organization, and numerous corporations working collectively to produce the cultural, technological, and political changes necessary to reduce the global burden of respiratory diseases, including asthma, resulting from traditional cookstove use that disproportionately affects low-income women and children.

## 20.7 Toward a Culture of Explanatory Pluralism

Today’s global asthma epidemic exemplifies the kind of complex problems that involve interlinked systems of different kinds—biological, ecological, social, economic, and technical. Responding to complex problems requires extraordinary levels of coordination in research and practice, a capacity to work beyond established paradigms, and the drive for “holistic,” systemic understandings shared by both cultural analysts and asthma researchers. The complex dynamics of asthma thus present an opportunity where conversation and collaboration can occur between cultural anthropologists and biomedical researchers and clinicians focused on asthma.

Section 20.2 analyzed biomedicine’s tendencies toward simplification and unification, and their effects on asthma sufferers and researchers alike. Anthropologist Ian Whitmarsh sees this tendency at work in the long history of efforts to deal with asthma. Since the end of the nineteenth century, Whitmarsh (2008) points out, “asthma has been viewed as neurosis or physiological predisposition; caused by dust, pollution,

heredity, parental emotions, the unclean modern home (carpets harbouring dust mites), or the continually cleaned modern home (underexposure to infections); and treated with stimulants and depressants, dieting, steroids, and various tonics." Asthma researcher Fernando Martinez (2007) reinforces the cultural anthropologist's analysis, noting how understanding of asthma has constantly shifted from one "unifying explanation" to another, while never successfully unifying. Whitmarsh notes that what is most remarkable in this history, however, "is not the plurality of definitions, causes, and diagnostic techniques" in its own right, "but rather the attempt to reduce this plurality". The plurality of definitions, practices, and etiologies has been framed as something to be resolved rather than something to be actively leveraged.

We emphasize again: this is a cultural phenomena and problem. Modern biomedical culture expects pluralities to be reduced, "mysteries" to be cleared up, with straightforward and preferably singular explanations, after sufficient rational effort has been expended.

Here is where cultural analysis can suggest a different frame. Rather than be frustrated or mystified by asthma's resistance to singular explanation, we can cultivate what historian of science Evelyn Keller calls a culture of "explanatory pluralism"—the idea that science, rather than seeking or needing one definitive answer, in fact thrives best on multiple interpretations that do not try to reduce or eliminate each other. Keller argues that throughout history, the culture of the life sciences has been one of "de facto multiplicity of explanatory styles in scientific practice, reflecting the manifest diversity of epistemological goals which researchers bring to their task. Explanatory pluralism, I suggest, is now not simply a reflection of differences in epistemological cultures but a positive virtue in itself, representing our best chance of coming to terms with the world around us...[T]he investigation of processes as inherently complex as biological development may in fact require such diversity" (Keller 2002).

Valuing and cultivating explanatory pluralism in asthma research and care will be a cultural challenge. But here is where the reframing that cultural analysis can offer joins with biomedical researchers' own efforts to reframe scientific practice, thinking, and organization to better understand and cope with complexity. Attempts to create "transdisciplinary" approaches to complex conditions like cancer and asthma are recognition, in our view, that biomedical research faces the challenge of transforming its own culture from one geared toward unifying explanations to one that values explanatory pluralism. But as Colditz et al. (2012) discuss in the context of cancer research, although the "benefits of transdisciplinary teams...have been touted for decades...few such teams have been successfully assembled." They argue that "operating in this collaborative way is not intuitive," so "investigators...regress toward the mean of siloed research, which is familiar and routine." The mutual recognition by researchers and anthropologists alike that biomedical research culture needs to change if we are to effectively deal with asthma presents an opportunity for more dialog. Perhaps cultural analysis, with its ability to comprehend and reframe "familiar and routine" understandings and elicit alternatives, can help biomedical researchers meet the challenges of transdisciplinarity and, in turn, the global challenges of asthma.

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# Heterogeneity in Asthma

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