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Exacerbations

Breathtaking: Asthma Care in a Time of Climate Change, by Alison Kenner.

Reviewed by Arthur Rose

In February 2013, nine-year-old Ella Kissi-Debrah suffered a fatal asthma attack in her home, twenty-five metres from the South Circular Road in London.¹ In the previous three years, Ella had been admitted to hospital twenty-seven times for exacerbations of her asthma.² These occasions often coincided with record levels of air pollution near her home, evidencing the presence of a poorly regulated environmental trigger. Nonetheless, an inquest into her death found asthma – in other words: not air pollution – to be the cause of death. In July 2018, her mother, Rosamund Adoo-Kissi-Debrah, petitioned the UK courts to quash this decision in favour of establishing air pollution as the cause. In May 2019, permission to reopen the inquest was granted. If the revised cause of death is accepted, Ella will have been the first person in the UK to die, officially, from air pollution.

The dreadful and tragic story of Ella Kissi-Debrah will be familiar to many UK-based academics, as will be her mother's battle to revise her daughter's cause of death.³ A personal tragedy with significant policy implications, the story of Ella's death demands a response as attentive to her family's private loss as well as to the more public consequences that underpinned most of the press attention it received. The story highlights the need for more nuanced approaches to the social understanding of asthma, both in its personal and political dimensions, than that permitted by the original inquest. Adoo-Kissi-Debrah might be spared the pain of reliving the details of her daughter's death for the court, if air pollution induced asthma had legal consequences for the polluters or their regulators. Indeed, the tension around Ella's cause of death replays, in tragic terms, a tension inherent in asthma discourse, of whether asthma should be understood as a matter of individual responsibility or a site for collective action.

Alison Kenner's *Breathtaking: Asthma Care in a Time of Climate Change* (2018) draws out the socio-political consequences of precisely this continued emphasis on individual responsibility in asthma care. *Breathtaking* sums up eight years of extensive ethnographic fieldwork (2009-2017) in seven US cities (although based mainly in Philadelphia), comprising eighty-one interviews with people living with asthma, including college students (22), practitioners of a specific breathing technique called Buteyko (21) and 38 others, met through social contacts, as well as two dozen interviews with care workers at social justice organizations and fifteen interviews with university-based scientists. It also includes assessments of Buteyko breathing training workshops, over 300 asthma support apps and

nine climate change workshops for activists working in Philadelphia. On the basis of this impressive multi-site assessment, *Breathtaking* makes three arguments: 1) asthma care practices must be understood in the contexts they occur 2) the contexts in which asthma occurs impact the ways in which asthma's increased biomedicalization has been taken up by stakeholders in the arena of asthma care, but also, and perhaps most importantly for Kissi-Debrah's case, 3) how the emphasis in asthma care has largely emphasized individual responsibility over collective action. Perhaps most interestingly, though, Kenner's study demonstrates how asthma care presents a concatenation of deleterious effects for individual and collective entities. Since asthma is a heterogeneous umbrella term for various causes of disordered breathing, it can, in that heterogeneity, serve as a conceptually approachable metonym for other, more disparate social or climatic phenomena that are more difficult to grasp. The spatial and temporal features of climate change or deep time may elude even the most patient of explanations, but breathlessness is intuitively a matter easy to grasp. Taking as a starting point the disordered breathing that grounds the various understandings of asthma provides a rich ground for thinking about some of the conflicting versions of time, place and care that subtend current work on the Anthropocene.

Kenner's study builds over five chapters. The first two consider the modes of asthma care, whether through the sufferers' attuning to time and place (i.e. how they register the effects place and season will have on one's breath) or through control, namely breath control, environmental control and asthma control. Subsequent chapters consider specific sites of care: training sessions for the Buteyko breathing technique (the breathing practice designed to alleviate asthma and other health problems, and named for its creator, Konstantin Buteyko, phone apps that monitor and maintain care practices, and public health workshops on the impact of climate change on public and home environments in Philadelphia. While the opening chapters present categories and conflicts in asthma care that intuitively fit with the concerns of stakeholders, whether asthma sufferers and their carers, health care providers, or institutions, the chapters on breathing techniques, datafication and the workshops show how asthma care is changing in the present, to accommodate alternative therapeutics, digital analytics and changes in climate.

The first chapter presents asthma as an epistemological challenge. Adapting Kathleen Stewart's concept of atmospheric attunement, or the focus of our attention on the "qualities, rhythms, forces, relations, and movements" of our situation in place and time,⁴ Kenner notes the complex understanding that experienced asthma sufferers bring to bear on their condition in sensing particular triggers and places: "an emplaced knowledge of the contexts and conditions that trigger asthma" on the basis of "changes in breath and a feeling in [the] lungs" (36). Through the sensory differences between, say, tightness, wheeze, or breathlessness, which may, in turn, be associated

with different triggers (whether exercise or allergies), sufferers develop a heightened understanding of asthma's heterogeneity, a felt correlative to the biomedical befuddlement that has emphasised the condition's variations in the medical literature. Kenner folds these two divergent forms of knowing together through their common difficulty in actually naming asthma, "a proliferation of disease dimensions anchored by affect, time and place" (33). Where there is continued uncertainty in consensus statements on defining asthma in the medical literature (i.e. the Global Initiative for Asthma's 2018 report, *Global Strategy for Asthma Management*), Kenner's participants identify some, but not other, manifestations of their asthma *as asthma* (because they feel they have "outgrown" their asthma, or that their experience does not match their understanding of what asthma is. Attunement, valuable as it is for assessing the immediate risk of an attack or exacerbation and for determining a gradual deterioration of health over hours, is less likely to signal the long term loss of lung function. At the same time, the changing nature of asthma between different persons, or even in the same person in different places over the life course, "frustrates biomedical paradigms designed for comparability across subjects" (58).

The challenges to knowing asthma cascade into challenges to controlling asthma. Control is a term whose use varies between asthma sufferers and healthcare providers. It takes three forms, or modes, which clarifies the conflicts that emerge in asthma care across different "timescapes" - Barbara Adam's term for the "multiple intersections of the times of culture and the socio-physical environments" (Qtd Kenner 18). Breath control, for example, speaks to the various methods experienced asthma sufferers learn or develop to manage attacks and exacerbations, either as they happen or as they are anticipated: the "temporal rhythms and placed-based knowledge [sufferers use] to care for disordered breathing (Qtd Kenner 18). Environmental control, on the other hand, considers the strategies used to mitigate the effects of environmental triggers, by moving one's self out of a potentially triggering environment or by regulating one's presence in particular homes, offices or sites of transportation. Kenner opposes these two forms of control to diagnostic models of asthma control, which the Global Initiative for Asthma's report gives as "the control over symptoms as well as over 'future risk of adverse outcomes'" (Qtd. in Kenner 60). In the latter case, control is understood as a biomedicalized measure that covers "asthma attacks, symptom frequency and severity, limitations to activities and how often a rescue inhaler is used" (61). But it is also an assessment of future risk, based on long term lung function, history of exacerbations, and other complicating factors. Asthma control necessarily involves sustained assessments over time, together with an evidence base that shows how regular use of control medication can forestall future exacerbations. This biomedical narrative often comes into conflict with the emplaced experiences of asthma sufferers themselves, who are generally more attuned to exacerbations (perhaps, at the

expense of less perceptible long term deterioration), while also being resistant to long term dependency on medication (whether for anxieties about money, worries about short- or long-term effects, or simple suspicion of big pharma), as well as more concerned with the immediate timescape of breathing control than the more protracted timescape of asthma control.

Later portions of the book consider how the sensory activity of attunement and the resulting direction, regulation or mitigation of activity, plays out in three different sites that appear only glancingly in biomedicalized asthma care: the Buteyko Breathing Education community, which habituates asthma sufferers to particular breathing practices that help them to control their condition; the online communities facilitated by the explosion of asthma tracking apps, which generally provided data sharing about local environmental concerns, standardized tracking categories, and associated data visualizations for sufferers to chart their symptoms over time; and the workshop community, which reported back on the environmental conditions associated with housing in Philadelphia. These fora provided different chronic care infrastructures, Henriette Langstrup's term for "the sociotechnical systems that enable treatment beyond the clinic" (19). So sufferers could make time for "care time" (in Puig de la Bellacasa's terms) by submitting to the lengthy process of learning BBT, render themselves as data to be analysed by a range of asthma tracking apps, and embed themselves in "caringscapes" and "carescapes", Sophie Bowlby's terms describing, respectively, "how care is enacted in different temporalities and terrains over the life course" and "the broader 'resource and service context' that shapes people's ability to care" (158). Each site challenges the individualism that underwrites most asthma care by presenting different forms of interpersonal or community level response. They subvert the dominance of biomedicalized asthma care by showing how it might be complemented by therapeutic practice, frustrated by uncertain or inconsistent data gathering practices, or superseded by scalar concerns about climate, housing or pollution.

Insofar as *Breathtaking* cuts across scales of time and space, and across the heterogeneous categories of ethnographic interview, medical report, theoretical anthropology and science and technology studies, it is committed to a productive conceptual violence. By wrenching us across different sites and circumstances, Kenner tries, and for the most part succeeds, in showing us that the experiences of individual sufferers, the biomedical models used by their carers, and the larger systemic changes (whether systems of health, housing or climate) are not, as we might imagine, in conflict. Rather, they miss each other completely, engaged as they are in different scales of time and space. Such problems of scale variance demand a language that operates awkwardly, which perhaps explains the book's unfortunate reliance on theoretical neologisms, like carescapes and timescapes. Asthma, a condition whose variations make it an illness "out of joint", demands a language that

splices different “scapes”, a suffix, we might recall, related to quiddity or essence. For all the theoretical verve of this language, Kenner concludes her study with four recommendations that are admirably clear. People should be provided routine access to high-quality medical care. Pharmaceutical interventions should be accompanied by breathing skills training. All levels of government need to invest in care for the built environment. Nations (the USA specifically) need to take climate change seriously, not simply as a matter for long term health or for planetary conservation, but for its clear and present influence on the global asthma epidemic. Here, Kenner’s study will be most useful for those who find themselves little interested in the vagaries of asthma care: how the problems of presenting the scalar concerns of the Anthropocene might be averted by rerouting the debate through what Juliana Spahr has called “this connection of everyone with lungs”. Asthma, in its relative ubiquity, can provide a shared staging ground for developing consensus around the health consequences of climate change.

But we must be wary of the erasure, the slow violence, that such consensus risks, most notably for vulnerable groups. For, as Kenner notes, the language of “triggers” “renders invisible the structural inequalities and contexts of environmental racism, which have been linked to higher asthma prevalence rates and worse treatment outcomes” (161). For this reason, I was as disappointed as she that her interviewees weren’t more representative of the class and race slanting of the asthma epidemic. The relative paucity of such stories, not just in Kenner’s study, but in the anthropological literature as a whole, makes her decision to end her final chapter with the story of 12 year old Laporshia Massey’s death the more poignant. Like Ella Kissi-Debrah, Laporshia Massey died of an asthma attack that might have been controlled, were a more care-filled infrastructure in place. Like Ella Kissi-Debrah, Laporshia Massey’s death needs to be understood as a personal tragedy that emerges within the context of structural racism, slow violence and conflicting timescapes. Perhaps then we might begin the difficult work of averting the deaths of children like Ella Kissi-Debrah and Laporshia Massey.

Arthur Rose

¹ <https://www.theguardian.com/uk-news/2019/may/02/ella-kissi-debrah-new-inquest-granted-into-air-pollution-death>

² Exacerbation refers to an acute increase in the severity of a medical illness, like asthma. I use it throughout not merely because it incorporates degrees of severity not necessarily understood as an “attack”, but also because, as Kenner notes, “while asthma attacks highlight the life-threatening potential of disorder breathing [...] these events also render invisible the accumulations, the chronicity, the mundane, low-grade, normalized dynamics of environmental health” (5).

³ <https://www.theguardian.com/uk-news/2019/may/02/ella-kissi-debrah-new-inquest-granted-into-air-pollution-death>

⁴ Stewart, Kathleen. “Atmospheric Attunements.” *Environment and Planning D: Society and Space*. Vol. 29, No. 3 (2011): 445-53, 445.