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Not Breathing Easy: "Disarticulated Homework" in Asthma Management

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Recent health policy in the United States encourages an outsourcing of labor from professional practice into domestic spaces, where in theory, medical professionals supply the training, technologies, and guidance needed to discharge responsibility for care to patients or caregivers. Mattingly et al. (2011) term this labor "chronic homework," describing the relationship between the assigning and undertaking of medical care at the borders of professional and domestic domains. This is a system predicated on relationships between professional and caregiver. However, in our research with families and providers in two U.S. sites, we observed a "disarticulation" of asthma care from professional medicine. Caregivers may undertake routine asthma management with little physician oversight, transforming chronic homework into what we term "disarticulated homework." We argue that expanding the concept of chronic homework to theorize disarticulation processes can help elucidate how health disparities are reproduced in the gap between medical systems and domestic life. *[asthma, self-management, caregiving pharmaceuticalization, health disparities]*

Introduction

In January 2018, four-year-old Jackson's asthma got really bad. On the first day, he struggled to breathe, his mother Shonda, a Black woman living in St. Louis, took him to urgent care. The urgent care doctors put Jackson on a "breathing machine," or nebulizer that aerosolizes albuterol, a short-acting rescue medicine. Jackson had his own nebulizer at home, but the next day he was still wheezing, so Shonda took him to the pediatrician. To Shonda's dismay, the pediatrician again treated Jackson with the same nebulized albuterol they had at home and told Shonda to continue monitoring his symptoms and administer treatments every four hours. "I could've did that at home," she lamented. On the third day, Shonda went to the hospital, and finally, Jackson received a steroid shot and the nebulizer. "So all three days," she reflected, "they kept giving him that same medicine." The treatments administered by the urgent care doctors would only "work temporary"; within a day, Jackson would be struggling to breathe again.

Jackson's case meets many of the Global Initiative for Asthma (GINA) criteria for risk of poor asthma outcomes: multiple prior exacerbations; high albuterol use;

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family history of asthma; living in a low socioeconomic context. But only one of the urgent care physicians mentioned that Jackson might need to be on daily controller medication and told Shonda to follow up with her doctor. “And I did follow up,” Shonda said—the following month when Jackson had yet another exacerbation. But this time, she didn’t see the doctor, only the nurse, and she was not sure if she remembered to mention preventative medication. Because the urgent care clinic, the hospital, and Shonda’s doctor operate in three different health care systems, there was never any inter-provider communication about Jackson’s repeated exacerbations or the potential need for daily controller inhalers. Jackson missed multiple school days each year because of wheezing, but Shonda would not normally ask the doctor about asthma, because she had many other problems she needed addressing, and she forgot about asthma until she got home. From Shonda’s perspective, it would help if the doctors could give her “that steroid shot” to keep, because then, when Jackson’s asthma flared up, she could give him the injection herself, along with the nebulizer four hours later, and then she could manage at home, rather than having to go to the hospital.

Shonda’s vision of herself managing Jackson’s exacerbations from home mirrors decades of health policy in the United States that encourages an outsourcing of medical care labor, particularly for chronic conditions, from the professional sector into domestic realms (Mattingly et al. 2011). Under such policies, medical professionals are to “empower” self-care by supplying the training, technologies, and guidance needed to discharge responsibility for care to patients or caregivers. Mattingly and colleagues (2011) term this labor “chronic homework” to represent the accumulation of medical responsibilities increasingly assigned as to students by teachers. Homework, in this conception, is produced through practices and processes that are generated and transformed in the blurry zones between clinic and household, negotiated between the individual and larger institutional or political entities through uneven relationships of power, authority, compliance, and resistance.

Asthma is a notable example of this shift, particularly in the United States. While in the earlier decades of the 20th century asthma treatment in the United States commonly involved residential care (Keirns 2004), since the 1990s new ideologies of self-management emerged, which saw much of the executive decision-making and work of asthma management reassigned to households—generally to mothers. This “domestication” of asthma has been accomplished, as for other illnesses such as TB (Hunleth 2013), through a pharmaceuticalization of public health, whereby self-managed adherence to physician-prescribed pharmaceutical regimes have become central to household illness management (Biehl 2007). In the case of childhood asthma, “homework” is, according to U.S. guidelines (NAEPP 2007), expected to involve routinized intake of daily controller medications to address chronic inflammation, with a primary measure of success being low frequency use of the rescue albuterol that treats immediate symptoms. Even acute crisis care in the United States has become domesticated through the wide distribution of personal nebulizers in households; such home nebulizers are not recommended by the GINA guidelines and not commonly used in other countries. In the United States, however, these machines encourage families to manage acute exacerbations themselves, meaning that children like Jackson are less likely to receive the recommended oral steroid course and follow-up review of preventative pharmaceuticals.

This is a system predicated on close relationships between professional and caregiver. Yet, in our study of caregivers' management of pediatric asthma, we frequently observed an absence of such relationships, meaning that the daily homework for asthma control has never even been assigned. In the United States, a constellation of structural inequities, systemic racism, and racial and economic disparities, along with the complexities of insurance, decentralized medical systems, and privatized emergency medicine, have resulted in what we term a "disarticulation" of asthma care from professional medicine, pushing the responsibility for health care even further onto patients and caregivers. For caregivers such as Shonda in socioeconomically and/or racially disadvantaged circumstances, access to medical professionals and the pharmaceuticals to carry out prescribed homework may be sporadic, and practices variably disarticulated from professional guidance. For these caregivers, what Mattingly et al. (2011) describe as the "borderland" between professional and domestic health care starts to look more like a crevasse. When routine maintenance is supplanted with emergency care, as in Shonda's case, the training and resource provision assumed in clinical models of care may be largely nonexistent, and self-management may be undertaken without any physician oversight at all—an outcome of systemic neglect.

Despite this crevasse, caregivers in adverse circumstances acquire expertise and engage in complex regimes of medical care that extend far beyond the homework that doctors prescribe. Caregivers we met were not so much improvising on physician training as they were generating a curriculum of their own, assembling a deep and individualized expertise on their child's body and a set of practices to cope with symptoms in the moment. What, then, does chronic homework become when generated through disarticulated care?

We use "disarticulated" to describe relationships with medical professionals that are distant, discontinuous, strained, or misaligned, for example, where the primary contact for asthma care occurs within emergency medical contexts. Though families were rarely completely disconnected from professional medicine, their articulations with the kind of professional care required for chronic homework were dislocated by systemic gaps, which further widened for vulnerable groups. Overcoming these gaps required caregivers to create new ways of managing asthma: what we call "disarticulated homework." In this article, we elaborate two forms of disarticulated homework that we observed among asthma caregivers in two U.S. sites: case management and caregivers' protocols. We suggest that these forms of homework unequally distribute care labor and health outcomes across social groups, contributing to asthma disparities for low-income and Black children.

Narrating Disarticulated Homework in the United States

We draw data from an ongoing (2018–2022) mixed-method, interdisciplinary study that examines caregivers' management of pediatric asthma in settings of substantial economic and racial disparities in St. Louis, Missouri, and Gainesville, Florida. Several study components inform this article. We carried out narrative interviews of caregivers of children (under 18) with asthma, using an adapted McGill Illness Narrative Interview (Groleau et al. 2006). We sought to learn from caregivers about how they managed asthma in their households in conjunction with their children, other family members, and health care providers. We interviewed 25 caregivers in St. Louis and 16 in Gainesville. Most caregivers were parents to the children with asthma, except two who were grandparents. The interviewees identified as Black (30), White (11), American Indian/Alaska Native (AI/AN) (three), and Asian (one).[1] Based on reported financial status and/or ability to pay an unexpected $500 medical bill not covered by insurance, we classified 32 caregivers as being of low economic status. Of these, 27 caregivers identified as Black, two identified as AI/AN and White, one identified as AI/AN and Black, and three identified as White, a distribution mirroring the overlap between racial and economic disparities in the cities.

The narrative interviews with caregivers led us to identify the disarticulation between home and clinic. Through clinical contacts in our university medical schools, we recruited and interviewed 11 health care providers who treat children with asthma in St. Louis and Gainesville, including pediatricians, pulmonologists, school nurses, a pharmacist, and an asthma coach. To further understand how families manage asthma, the lead author engaged in participant–observation in the households of nine caregivers, working with 14 children with asthma and five siblings. These household visits allowed us to clarify the patterns we were drawing from the interviews.

The Disarticulating of Asthma Homework

Asthma, typically characterized as a chronic disease involving airway inflammation, affects around 6.2 million children in the United States. Morbidity, however, is not evenly distributed. Asthma disparities are growing particularly for non-White and Hispanic children (Akinbami et al. 2014; Gold and Wright 2005; Oraka et al. 2013); the rates of asthma are more than twice as high among Black children (15.7) than White children (7.1%) (Zahran 2018). Living in poor urban areas is also associated with higher asthma morbidity and more frequent asthma-related emergency department (ED) visits and hospitalizations, independent of race or ethnicity (Keet et al. 2017; Sullivan et al. 2019).

While these disparities are linked to racial, economic, and structural inequities in environmental conditions, including unequal exposure to poor housing conditions (Keet et al. 2017; Sullivan et al. 2019), pollution (Guarnieri and Balmes 2014; Maantay 2007), and stress (Chen et al. 2010), public health perspectives generally frame the consequences of uncontrolled asthma in terms of economic burden to emergency services, cost of hospitalization, or missed school days (Bender and Rand 2004; Colice et al. 2012; Sullivan et al. 2018). The finding that high numbers of ED visits result from issues that could be treated or prevented through primary care is frequently misinterpreted by policymakers who assume that ED visits for asthma are the result of poor judgment on the part of patients, not that primary care may not be accessible (Kellermann and Weinick 2012). These economic burdens, and the behavioral problems presumed to cause them, are then addressed through behavioral and capitalistic solutions: out-sourcing labor for health care to families through self-management with pharmaceuticals—what anthropologists have termed the "pharmaceuticalization" of public health (Biehl 2007; Nichter 1989).

According to U.S. clinical guidelines, physicians should, in "partnership" with asthma patients or caregivers, develop management plans with the goal of long-term asthma control (NAEPP 2012). "Control," from clinical perspectives, is achieved when symptoms and exacerbations are prevented without overuse of quick-relief inhalers, and lung function and activity are maintained at normal levels. The primary, physician-mandated avenue to asthma control is through the use of daily controller medications, most commonly inhaled corticosteroids (ICS). When pharmaceuticals are the center of chronic disease management, most care can be shifted away from physicians in clinics and onto caregivers at home, a perspective one St. Louis pediatrician reflected: "The whole goal, really, with asthma is for you to manage it at home and not have to come to the doctor or go to the hospital. I mean, that's what we want, right?"[2]

Aside from a divestment of focus on the inequitable environmental conditions contributing to asthma disparities, pharmaceutical management of asthma requires substantial patient counseling, technical and health education, and regular reassessment by medical professionals. This is complex care work, challenging even when well supported with close patient–professional "partnerships," yet scholars have noted these relationships receding, leaving only self-management. For example, Susanna Trnka (2017) observes an absence of close relationships between caregivers and primary care physicians in New Zealand, where decades of "responsibilizing" neoliberal policies hold patients responsible for their own self-care, while the costs of primary care drive many to use free emergency services for noncritical care needs.

We observed further disarticulations occurring in U.S. contexts, where a raft of policies work to systematically disrupt access to health care. Caregiver–professional partnerships are expected to develop through a privatized, fragmented delivery health care system, requiring residents to hold health insurance for access to most services. Meanwhile, national and state policies have throttled Medicaid insurance for very low-income families, while a shortage of primary care physicians, especially for Medicaid patients, have left access to care precarious (Asplin et al. 2005; Cheung et al. 2012).

Moreover, a long history of racial and socioeconomic disenfranchisement and discrimination continues to disarticulate care for non-White residents. Generations of structural racism have constricted accessibility of health care, leaving Black caregivers more likely to be on Medicaid or uninsured (Buchmueller et al. 2016), and locating clinics outside of segregated Black areas (Harris 2019). Furthermore, racial discrimination in quality of care and interactions with physicians or medical systems has been documented for decades, undermining Black patient faith in the system (Boulware et al. 2003; Gamble 1997). Particularly relevant is a St. Louis focus-group study where Black participants reported a preponderance of negative experiences with physicians or the health-care system (Jupka et al. 2008). As a result of these experiences, including racism, inadequate communication and treatment, and feeling unsafe, some participants indicated they would not seek health care unless absolutely necessary. Specific to asthma, evidence suggests that physician prescribing practices are likely to be influenced by racial identities of patients; in one study, providers with higher numbers of Black patients were significantly less likely to report prescribing daily ICS for mild persistent asthma (Sawicki et al. 2008). Understandably, then, many caregivers' main contact with medical professionals occurs in an ED or urgent care context where they are dealing with an acute need.

As providers described to us, the gap in primary and emergency medical services has, over the last two decades, been filled by a proliferation of urgent care, or "retail-based" clinics (Weinick et al. 2009). Based on a "customer-centric, on-demand delivery" consumer model, these centers promote themselves as providing convenience, including the capacity for drop-in visits with short wait times, extended operating hours, proximal locations, and cheaper co-pays than EDs (Stoimenoff and Newman 2018). In St. Louis, for example, the Total Access chain of urgent care centers expanded from 15 to 26 clinics between 2015 and 2019. While the stated purpose is to provide "episodic" care, these centers have, like EDs, come to replace primary care of chronic conditions like asthma for many families. Because they operate within a closed network, there is no system for data sharing, no continuity of care with primary care providers, and consequently no follow up or ongoing chronic illness management (Bhuyan et al. 2016). Clinic staff may offer some basic information and techniques, but their priority is attending to the immediate situation and advising families to follow up with their primary care physician, instead of offering chronic illness education. Once the crisis is over and symptoms subside, however, families may find systems prohibitive to obtaining primary care follow up, especially when that visit is costly in time and financial resources, when caregivers may have experienced racism or discrimination from health care providers, and when the family may feel the child's asthma is being managed successfully between themselves and urgent care. This could explain how a St. Louis pulmonologist we spoke to recounted how she had just met a child with heavy symptoms who had "never seen a pulmonologist … an allergist, or anybody … never been on a daily inhaler." Like other providers we spoke with, she located the responsibility for identifying the need for asthma care with families rather than with physicians, framing the incidence as an issue of caregiver misrecognition, rather than disarticulation: "When you tease out some of the symptoms, [children] do have more symptoms than [families] think." Providers conceptualized caregivers' disarticulation in terms of "barriers," identifying transport or insurance, or, as Jeanette, an asthma coach in St. Louis described, "the parents not havin' the knowledge or the education of how to maneuver the system." Jeanette's role, a unique product of a St. Louis medical school initiative, was to help guide caregivers through the system—to articulate them—even attending appointments with doctors to help translate medical jargon. Despite her insight into the complexities of the health care system, Jeanette still tended to frame the issues in terms of individual behavioral changes and deficits in education, rather than systemic barriers that required an "asthma coach" to be accessible.

School nurses seemed best positioned to identify families who had been managing their child's asthma independently from primary care. Leah, a high school nurse we spoke to, offered an example of the disarticulations she observed: "there was a kid with asthma comin' in all the time, goin' to urgent care all the time. [I] finally called the primary care physician … who says, 'What? What are you talking about? I've never treated this kid for asthma.'"

Leah told us that the family was managing asthma with "a family inhaler," probably prescribed because the "grandmother has actually been to a physician." Often school nurses could identify these cases during school fieldtrips or camps when a child would arrive with a rescue inhaler prescribed for a different name. Proximity and frequent contact more closely articulated school nurses with families, allowing for a view of family pharmaceutical practices that had become normalized within disarticulated care. In their role, school nurses focused on acute care and education, attempting to reconnect families to primary care for their homework assignments, or in some cases, taking on the homework themselves, as doctors would arrange for schools to administer controller medications when families could not manage. Like most providers we spoke to, however, nurses also held limited perspectives as to the range of caregivers' asthma management practices.

Caregivers as Case Managers

Sara is a White, single mother of 14-year-old Sam, who has had asthma since age two. Speaking quickly and dropping acronyms with a fluency that intimated years of acquired expertise, Sara described how after three visits to the ER within the space of six months for exacerbations, Sara got Sam to a pulmonologist of her own volition. "That was all me. I don't think he was referred," she noted. Neither the ED nor her PCP had made the suggestion, rather, after seeing a flyer for an asthma caregivers' focus group, Sara began participating in studies, from which she sourced information to obtain the care she needed. Sara later took a nonmedical job in pulmonary research, where she learned even more about asthma.

Sara informed us that PCPs don't like to refer out, they "over-treat with albuterol," and they under-prescribe corticosteroids, which she attributes to a for-profit medical system. Sara therefore no longer consults her child's PCP for asthma, simply advising him that *she* has put Sam on corticosteroids when she brings him to the clinic for viruses. She described how, at the pulmonologist's office, she would ask providers to do pulmonary function testing (spirometry) even though she knew that they didn't recommend it, adding: "It does help to train [the providers]. So they're real good on 'em now." And, after working on a clinical trial on the link between Vitamin D and asthma, Sara decided to begin giving Sam large doses of vitamin D. She did this, she said, until the blood tests she requested that her doctor order indicated his vitamin D level was "like, 107 nanomoles" and her doctor said "that I needed to take him off it immediately." But six weeks later, Sara started Sam back on the vitamin D, after his asthma was "triggered again" and "he was back on his albuterol."

Sara represents an example of what Trnka (2017), writing in a New Zealand context, describes as a "parent–expert," where, under policies that responsibilize patients, caregivers respond by asserting themselves as medical experts and taking command of their child's asthma management, including the management of physicians. Here, Sara's self-responsibilization for Sam's asthma management represents less a moral project of cultivating parent–expert status, and more the result of a dysfunctional medical system that did not facilitate access to the care her son needed. Sara was left to educate herself in asthma management, which she accomplished by participating in asthma research, including our own study. Her son's untreated symptoms *required* her to bypass her PCP and refer herself to a pulmonology clinic, where she positioned herself as training *providers* to conduct spirometry tests. *She* informs her PCP of her son's pharmaceutical—and vitamin D—regimes, because in a decentralized system, her PCP is disconnected from her pulmonologist, and because in the absence of support, Sara had to become Sam's case manager.

This case management—where caregivers must take control of managing doctors and medical systems to get the care and treatment they require—is one form of homework that arises from a disarticulated medical system. A homework that is not physician-assigned, case management has become necessary as the outsourcing of medical labor now includes not only surveillance and administration of physician-prescribed treatment, but also health education, decision-making, health communication, and coordination of professional care that used to be the domain of professionals.

Case management has also become a requirement of fragmented health systems and privatized insurance. Kerri, a White social worker in St. Louis, found that her role in her children's care went beyond homework as an outcome of a three-way tension between employment, caregiving, and access to health care that is characteristic of U.S. policy. Kerri had to work to keep the family's health insurance, but to be able to attend doctor's appointments she had to take a new job working nights. The accompanying change in her insurance meant that the family had to shift medical systems and change all the physicians in her son Noah's complex medical team. The two different hospital systems created incompatibilities for the transfer of care, however, and Kerri became the case manager in charge of coordinating two teams of doctors, each of whom assumed the other was not cooperating. After taking Noah to each of their many ER visits, the ER would tell her to follow up with her doctor, which Kerri would do only to find that he did not have her discharge summary because the electronic updates were not delivered. "So what do you do?" her interviewer asked. "I just tell him what happened," she replied, as was required from her role of case manager, now responsible for communicating complex medical information between physicians.

Unlike Trnka's parent–experts, this is a situation where caregivers have to become doctors out of *necessity*, because they are working in a fractured system that requires caregivers to take the lead in asking providers for help and expects caregivers to know what constitutes a need and how to communicate those needs in physician-speak. Stephanie, a Black mother of two children with asthma, summarized this onus on caregivers to do the work of physicians: "Sometimes, us, we—we is a doctor. We have to tell the doctors what's goin' on." What's going on, however, can depend on which of multiple needs are most salient at the moment of the clinical encounter. Hence, Shonda takes Jackson to emergency care three days in a row, but does not bring up asthma again when she finally sees a primary care nurse a month later, because by then asthma was not a pressing priority to address in the short time available. Meanwhile, caregivers are not equally equipped to accomplish the work of managing physicians. Kerri herself recognizes that her privileged background and occupation as a clinical social worker gives her the education and cultural capital to navigate complex medical systems, meaning she has the social, economic, and time resources to do this case management work on behalf of physicians. By "blow[ing] up the phone 24/7," she attempts to articulate herself with a system that is not articulating with her. If this is what it takes to keep connected to the health system, though, what happens to caregivers who do not have these advantages?

Ambivalent Articulations

When Marcus was born, the doctors “tried to say” he had a little hole in his heart, a heart murmur. His mother Amber, a Black woman living in Ocala, Florida, thought he must have gotten over that one, but she didn’t really know. “I kept askin’ the doctor about it, but he brush me off,” she said. When Marcus was eight, doctors “tried” to diagnose him with obesity and “give him diabetes,” but they said he was “growin’ out his asthma.”

“But to me,” Amber says, “when we’re at home, and at night, he still coughin’.” Sometimes Marcus would cough until he vomited.

From Amber’s descriptions, Marcus, now 11, experiences “coughin’ throughout the whole night,” or in clinical terms “uncontrolled asthma,” with exacerbations about every year. Marcus’s asthma appears to be aggravated by chronically poor housing conditions; their previous apartment had “mold in the wall, mold in the corner,” and the walls had holes in them. “And so, when he kept sleepin’ in that environment, like my baby was suffocatin’ every time he walked through the door,” Amber explained; his asthma was triggered by the mold, the dust, and the mice. Escaping that apartment was hard, because Amber worked a pizza job, and “other expenses was tumblin’ in on me” so that she couldn’t even afford to replace the old bed that seemed to further worsen Marcus’s asthma.

Amber didn’t have a nebulizer anymore to give Marcus albuterol, because the doctor “took his nebulizer away from him, his albuterol,” though Amber wasn’t sure why. When Marcus had trouble breathing, Amber’s mother would call the doctor or take him to the ED, while Amber preferred to give him garlic. When we asked her about medicines, she explained to us:

> When it comes down to me, I’m a mother nature myself. If I need to go to the hospital, I will and make sure I don’t have anything that I can’t take care of or cure on my own. But, when it comes down to them, if it’s somethin’ like that, I can kinda maintain them back to health without the doctor.

Sometimes, Amber recognized, she had to take Marcus to the doctor when his asthma worsened and his inhaler no longer worked. But mostly, she said, “I don’t need a doctor,” because Marcus hated doctors, and he didn’t like going to the hospital. Marcus was staying with her mother while he finished up the school year, but Amber hoped he would join her soon, and she would change his doctor, “cuz my baby got to have a doctor. I cannot live without a doctor.” She hopes that when Marcus arrives, “he can get some really good care.” At the time of our interview, however, she did not have insurance.

Amber’s ambivalence toward doctors may reflect any number of things, including a sense that she needs to present herself as a good parent who finds her son medical care. It is *Marcus* who hates the doctor, and so she used home remedies to avoid going for *him*. However, her doctor stories also tell a history of feeling dismissed and uncared for: the specter of a hole in Marcus’ heart; the nebulizer that was taken away; the unwanted obesity and diabetes diagnoses. Whatever contact she has had with Marcus’s doctor, his asthma was undertreated; the frequency of his symptoms and exacerbations exceeds the clinical criteria for persistent uncontrolled asthma that indicate the need for daily corticosteroids. Instead, Marcus was prescribed a ProAir quick relief inhaler that he took "every day." While he had some "chewing tablets" at one point (likely Singulair for allergies), Amber said "they've" stopped giving him those too, and the ones she had were expired. Whether this under-treatment was the result of Amber's previous negative experiences, physician neglect, or a combination of both, Marcus's under-medication pointed to a disarticulated doctor–patient relationship.

Disconnected from medical oversight, then, Amber cultivated a medical practice of her own that included pharmaceuticals when she had them, but mostly featured a *decentering* of pharmaceuticals in asthma management. When she had the prescription for the "chewing tablets," Amber gave them to Marcus "just to do the extra step" and "just because they prescribed it to him." She let him take them three days out of the week, but no more, because she didn't want him to "overdose" on medicine. Instead, her preventative care work involved cleaning the apartment for dust, adding more grains and vegetables to Marcus' diet, and keeping him hydrated with water, Gatorade, or juice. Marcus hated grapefruit juice, but Amber would make him drink a whole glass to help open up his throat.

For acute symptoms, Amber improvised a set of experimental techniques, combining the pharmaceuticals she had on hand with home remedies from the Internet and her own experience. She used hot sauce to treat her young daughter's congestion, along with the corticosteroid Nasonex. She sought alternatives where she could; from a YouTube video of "healthy hacks" where they teach "all the healthy things you need just to survive without medication," she learned a technique of breathing through a cloth with honey and lemon. When he had an asthma attack Amber worked on getting Marcus to relax, holding and rubbing his chest until he breathed enough that she could find him treatments from the kitchen. Amber would fix him ice-cold water, or hot tea with ginger, lemon and honey, and a peppermint and Vicks. These remedies worked, according to Amber, because Marcus had only needed to go to the hospital three times in his life.

In clinical parlance, Amber's pharmaceutical regime would be considered "nonadherence" due to lack of knowledge or barriers to be solved by education around asthma control, pharmaceutical function and technique, and navigating obstacles toward adherence. This focus on the individual as the problem overlooks the ways that Marcus's asthma status is an outcome of political and racialized structures. When doctors and their pharmaceuticals are necessary but unreliable resources, they reinforce power structures that trap some people in environments that make them sick, and deposit society's resources for wellness with physician gatekeepers. Amber's lack of power to access physician expertise and tools may underpin her ambivalence toward doctors and pharmaceuticals, reinforcing her disconnection from resources she needs but does not trust and cannot depend on. Amber's conception of herself as an "earth mother type" may or may not have preceded her distressing experiences with physicians, but this identity now frames her health practices, further rupturing her relationship with a medical system that was not designed to care for her.

Amber's health care practices represent responses to a structural context that placed her and her children in transient and unhealthy environments, alienating them from medical care. Marcus's preventative treatment was not pharmaceutical based, in the first instance because he had not been prescribed corticosteroids, and his prescription for pills had lapsed. Little of Amber's homework was physician assigned or legitimized. Instead, many caregivers established programs of care that incorporated a range of strategies beyond pharmaceuticals, although albuterol in particular remained central.[3] These regimes were mostly unseen by the providers we spoke to, who usually viewed ICS as the primary and often only form of asthma management.[4] When pressed, some providers identified quitting smoking or removing carpets as additional things caregivers could do to manage their child's asthma at home. Providers indicated little awareness of any other caregiver strategies except albuterol, rendering the range of practices caregivers described—the home remedies, the cleaning, and the behavioral management—an invisible and illegitimate domestic load; what we have termed the caregivers' protocol.

The Caregiver's Protocol

Tasha, a Black and Native American mother, first acquired her homework when baby Kayleigh was hospitalized for pneumonia: instructions to administer nebulized albuterol to Kayleigh twice a day. This is an assignment that Tasha appeared to have adhered to, describing a routine that the family had "down pat," beginning with a breathing treatment of albuterol at 5:30 am, before Kayleigh, now age 14, got up for school. Kayleigh's asthma was "a little more critical than everybody else's," according to Tasha. Her asthma attacks were sudden and unpredictable, the causes uncertain because "you'll never know what's hidin' in a old house," like lead paint. Tasha's home is an older house with unknown dangers; the family moved in recently after returning to St. Louis following a house fire 1.5 years ago, when they lost their apartment and all its contents. Last month, in this new old home, Tasha awoke to her husband bellowing "Call 911!" While he was watching TV, Kayleigh had collapsed without warning; that ambulance trip to the ED was one of about three that year.

Along with the large daily quantities of albuterol, at some point during her childhood Kayleigh had begun taking Flovent, a common brand of ICS, but only two puffs a day before bed, as Tasha understood it, "so it can settle when she sleep." Even at its lowest dosage Flovent necessitates administration twice daily (NAEPP 2007), so Kayleigh is clinically undertreated, as evidenced by her frequent symptoms and exacerbations. Tasha seemed uncertain about the preventative function of Flovent, and implied she expected it to work as a slow-acting relief medication, commenting "the Flovent takes its time" and that she could still hear Kayleigh's wheezing. Tasha took Kayleigh to her pediatrician for an asthma check-up every six months, but wondered, "why it take so long?" reflecting, "anything can happen in that six-month stretch." When she suggested to the doctor that the Flovent might not be working well enough, the pediatrician suggested strengthening the dose, but he did not help Tasha understand why this might work, nor did he refer Kayleigh to a specialist.

In the absence of effective clinical support and pharmaceutical management, then, Tasha constructed her own protocol. Kayleigh's asthma strikes suddenly, so Tasha refined an intimate and highly individualized process of "reading" her child's body to predict the unpredictable.[5] Tasha listened for what she calls the three coughs: the "hard" cough that meant Kayleigh was "gonna be sick," the "medium cough" that meant "she's clearin' her throat," and the last cough that meant "the sickness is really, really gonna come on." Although doctors or nurses could sometimes offer basic instruction on surveillance techniques, for example, how to recognize the intercostal retractions or "pulling" between the ribs when breathing, for many caregivers we spoke to across both sites, this expertise in reading a child's body for asthma was more detailed and more central to asthma management than in clinical guidelines.

For example, Tuana, a Black mother of five in Gainesville, described "the three spots you look" on five-year-old Connor's body—flaring nostrils, sinking in his neck and his ribs—that told her when he was in respiratory distress and needed to be started on the Prednisone stock she had at home. "Once I hear the cough or even a slight cough, I know what's goin' on," Tuana said, and would use the stethoscopes she had "started takin'" home from the hospital to listen to his lungs and hear the wheezing. "I shoulda been a nurse," she mused, describing in detail the different kinds of crackling she might hear in Connor's lungs. The "reading process" could differ across children. Another caregiver, Christina, described how she listens for "the death rattle" in her younger daughter Vanessa, while for her older daughter Marissa, she listens for the wheeze when she inhales, where "it sounds like something in there is tight." Such specialized knowledge takes time to acquire and is not easily imparted to others such as co-parents, teachers, or sports coaches.

Tasha also developed a range of non-pharmaceutical treatment strategies. She would have Kayleigh breathe into a brown paper bag, a technique she learned from a nurse once, "and sometimes it works." Other caregivers developed their own alternatives: Rebecca used steam and a can of caffeinated soda; Monique learned from her mother to boil peppers in water and then apply them to her daughter's face with a rag. Though many caregivers described such home remedies, they could also appropriate other medical devices for asthma treatment. Erin "know[s] all the tricks of it" because at times when they did not have insurance coverage and her daughter Janelle "coulda went to the hospital to done a treatment," Erin managed the exacerbation at home by herself, sleeping on a chair in Janelle's room, and using the CPAP Erin had for sleep apnea to push oxygen into Janelle's lungs.

Finally, caregivers devised their own protocols for asthma prevention, which often involved environmental management. Tasha's asthma protocol featured prevention not through pharmaceuticals, but through vigilant attempts to regulate the air, perhaps accentuated by residual trauma from that day of the house fire when she found smoke coming from her daughter's bedroom. She kept the house temperature at a constant 60 degrees, kept smokers out, boiled "sage, onion, and garlic," her Cherokee grandmother's recipe, to clean the air, and used humidifiers. She opened windows so Kayleigh could benefit from the fresh oxygen. "Anywhere that my daughter need to go, those two spaces gonna have air on. The car and the house. All the time," she explained. Kayleigh's school presented a challenge as it was not possible for Tasha to manage the classroom's air.

These air management practices may have offered Tasha what her home and her doctor did not—a sense of something she could do to control the uncontrollable—but they also came at social and financial costs. There were many places Tasha wouldn't let Kayleigh go because of worry about air quality or germs: Walmart, the ice-skating rink, the zoo. Regulating air temperature was expensive, and family members would not visit their cooled home in winter. Nor could Tasha bring Kayleigh to visit family; there were smokers in the house, and so the pair stood outside on the porch and finished conversations quickly. Although family accused Tasha of alienating Kayleigh, Tasha commented to us, "Well, I have to alienate my child for her to breathe."

The caregiver protocols we observed in St. Louis and Gainesville were pluralistic[6]: domesticated versions of "chronic homework" that combined acute pharmaceutical treatment with popular folk medicine, but derived out of the fissures of disarticulated relationships with professional medical systems. Here, systemic neglect and racism has abandoned caregivers to cope through improvised or inherited strategies for preventing symptoms. Her physician-assigned homework having failed her, Tasha is adherent to her own management regime aimed at controlling domestic environments that mysteriously trigger Kayleigh's breathlessness. She attempts to compensate for her disarticulation with an enormous burden of additional labor that is unseen and undervalued by a professional sector focused on pharmaceuticals. Caregiver protocols, however, manage symptoms; they treat coughing and wheezing with albuterol, garlic, and liquids, and mitigate perceived triggers with dusting, air regulation, or restrictions on activity. These tactics keep children breathing, but they do not address the underlying causes of asthma symptoms; without controller medication, children's invisible airway inflammation persists in conditions of inadequate housing or pollution that require substantially more resources to modify. Addressing this chronic inflammation can only be achieved through policy change and more attuned physician–caregiver relationships. Caregivers' protocols, therefore, represent a desperate response to a public health system that has failed them.

Toward Coauthored Homework

Our study shows that the homework of self-management for asthma in this U.S. context is left tenuous in situations where borders have cracked open and relationships fissured. Disarticulations are produced from the confluence of policy, inequality, and systemic dysfunction, straining the ability of physicians to even assign homework, let alone support caregivers in its undertaking, and of caregivers to obtain appropriate medical care. Mattingly and colleagues' (2011) concept of chronic homework therefore only partially explains contemporary relationships between physicians and patients in the distribution of care work; physician-provided training and homework assignments represent just one of the dynamic ways care work is generated across professional and domestic spaces. Beyond chronic homework, the disarticulated homework we have described may resemble case management, where caregivers manage physicians to extract the care they need, or domestic protocols, where caregivers replace provider care with their own regimes in which physician prescriptions or advice may be absent or minimal.

These strategies are not exclusive, but in our sample we observed that few caregivers had the resources to engage in case management, which required considerable savvy with systems, time, cultural capital, and biomedical knowledge to overcome powerful physicians and opaque medical systems. White caregivers of higher socioeconomic status were more likely to have access to these skills and resources, and, accordingly, were more likely to describe interaction with health professionals and to make the system work for them. Caregivers of lower socioeconomic status who utilized the case management strategy were often health care workers themselves, so they were familiar with medical systems and biomedical thinking and parlance and could hold different expectations of what asthma treatment should entail. After navigating systemic gaps in medical care, these caregivers tended to maintain vigilant adherence to the pharmaceutical regimes they negotiated with physicians. Meanwhile, racially and economically marginalized caregivers like Amber and Tasha, who, due to systemic racism were more likely to be Black, tended toward developing caregiver protocols. These protocols could function as expressions of resistance or cultural identity, but were often innovation born of necessity, keeping children alive with stolen stethoscopes, requisitioned CPAP machines, and concoctions of garlic, sage, and onion.

The effects of disarticulation on asthma homework are therefore mediated by class, race, and gender. While both case management and caregiver protocols are resource-intensive, the labor costs of compensating for gaps in professional care are far greater for some. Caregivers facing racial, environmental, and economic injustice described protocols that attempted to overcome unequal exposure to poor housing, stress, pollution, disparate clinical treatment and unequal access to transport and quality health care (Hunleth and Spray et al. In press). The relative simplicity of daily ICS regimes was replaced with protocols of attention that required intimate and individualized forms of expertise that were not easily transferable across caregivers, compounding the often-gendered burdens caregivers held.[7] As these forms of homework unequally distribute care, labor, and health outcomes across diverse social groups, they contribute to asthma disparities for low-income and Black children.

The intimacy of these protocols—the deep, specialized knowledge of and attention to individual children's bodies, and the physical and emotional labor of care—are partly why disarticulated homework still keeps children breathing most of the time. Yet these self-designated homework assignments are not typically "turned in" to doctors, who do not ask for nor recognize this expertise. A structural and discursive division between medicine and caregiving in biomedical models (Kleinman 2008) means that much of the care work and knowledge that directly influences asthma management is invisible in clinical spaces, creating an appearance that caregivers are undertaking little asthma management work at home. These protocols then engender further disarticulation as the overlap between physician and caregiver regimes recedes, dislocating those practicing in the biomedical world of corticosteroids from those who practice in the strained and unpredictable domestic world of caring for a child with asthma.

In her critique of New Zealand's application of asthma management policy, Trnka (2017) argues that refashioning self-management into a form that guides and supports patients would require, among other elements, increasing interaction between patients and medical professionals and involving patients as coauthors in the shape of their care by centering their perspectives in the clinical discussion. A policy that encourages homework to be coauthored, rather than physician-assigned or caregiver-derived, would require rearticulating caregivers and patients with professional medical care. Though the factors disarticulating care are multidimensional, and addressing these in the United States especially would require dramatic restructuring of medical systems, physicians can start by recognizing the varied forms of homework that caregivers engage in—even when that care falls outside of conventional medicine. Dismantling the distinction between care and medicine can help legitimize caregivers’ labor in the health care partnership—a step toward transforming disarticulated homework into coauthored homework.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval was obtained from the Washington University School of Medicine and University of Florida Institutional Review Boards.

Notes

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1. Some participants identified with more than one category. One caregiver also identified as ethnically Hispanic.

2. What this home management looks like from a clinical perspective is often decontextualized and based on assumptions about home, rather than on the more dynamic process of therapy management identified by medical anthropologists, whereby a range of social actors influence therapeutic access and decisions within broader social relations of power and political economic contexts (Janzen 1978; Nichter 2002).

3. Though albuterol was often not used as prescribed and could be used prophylactically in lieu of ICS.

4. In many cases, families actively rejected corticosteroids for various reasons, including concerns about growth inhibition, dependency, or distrust of medical systems. One family actively sought to reduce albuterol use through breathing techniques.

5. Trnka (2017) also describes caregivers’ intimate expertise of their asthmatic children’s bodies.

6. Anthropologists have shown that medical and healing systems can coexist, referring to such coexistence as therapeutic pluralism, but also demonstrate that pluralistic processes are contextually and historically contingent. (see Crandon-Malamud 1991; Janzen 1978).

7. Anthropologists have used the concept of the “therapy management group” as a methodological and theoretical approach to identify the range of clinical and lay actors involved in diagnostic and treatment decisions (see Janzen 1978). They have also shown that, in some cases, there are marked absences of involvement by lay or clinical actors, such as in cases where widowed women are sick or are attempting to care for sick children (Feierman 1985; Hunleth 2017). We build on this work in our focus on the absences of diagnostic and treatment interactions between providers and caregivers and in the ways that some women we interviewed (e.g., Shonda) viewed themselves as taking up care for the children largely on their own.

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