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THE FLUID BOUNDARIES OF NONCOMMUNICABLE DISEASE

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Introduction

One day, around his fiftieth birthday, my father stopped talking. It wasn't a complete silence, but seemingly overnight he struggled to voice more than a few words at a time. A couple of weeks later, he quit the career he'd held for twenty years and began sleeping most of the day. Not long after, he lost his way to the bathroom. Then he lost the kitchen. He lost how to empty the dishwasher and cut the ends off asparagus and tell which door is the refrigerator. He lost how to put together puzzles and form cohesive sentences and tell you how many kids he has. If you sent him to the grocery store for toilet paper and bread, he came back with unripe mangoes and brown sugar.

After a couple years, he started seeing people who weren't there. *Murderers* he would call them. *Bad men over there*. He would stare, clench his fists, and start yelling at the crown molding or at a bush outside the window. He mistook my youngest brother for one such person, which is how my brother ended up shoved in the mud one day while they were walking in the park. After four neurologists, multiple psychiatrists, psychologists, MRIs, PET scans, a CT scan, an EEG, and multiple rounds of medications, we finally got a diagnosis. Years after

he first stopped talking, a lumbar puncture came back suggesting early-onset Alzheimer's—likely developing when he was in his forties. By then, our conversations began involving discussions of towering medical bills, bankruptcy, and eviction. Without health insurance and with one parent providing full-time care to the other parent so nobody was working, there wasn't much left.

My father did not die for nearly six years.

The first time my youngest brother told me that he too had Alzheimer's, he was fifteen years old. We were on the phone—there were thousands of miles spread between the two of us, but the connection was a good one. When he spoke those words, I was surprised at just how unsurprising that statement was. How easy the words *I have Alzheimer's* sounded in his fifteen-year-old tenor. Perhaps it was because I had heard those same words uttered by my mother—still in her forties—just a week before. *My mind is slipping*, she had said. My youngest brother was *losing things*. *Just like Dad*. He couldn't remember what was said in school; he was forgetting how to spell, how to recall basic information. *I'm serious*, he told me. My mother had said the same nearly verbatim. I had brushed it off at the time; I echoed the doctors, telling them that it was just stress, that of course a fifteen-year-old did not have Alzheimer's disease. Which is true, of course. The disease that ultimately killed my father was not diagnostically what my brother was suffering from. And yet today, just a couple years after my father's death, I'm still stuck on the words my brother uttered to me at age fifteen, the certainty in his voice. I'm less inclined to brush it off now. In fact, it is this moment, this phone call with my brother so many years ago, that is the driving force behind this essay.

Much of the literature surrounding an Alzheimer's diagnosis attends to the mechanics of the *disease* itself—the physical “unspooling” of a diseased brain via neuritic amyloid plaques, neurofibrillary tangles, and the shrinking of brain tissue (Lock 2013, 52). It's a disease that is often framed by the parameters of a singular individual, by the limits of a singular brain. However, recent literature shows that Alzheimer's, much like obesity and many other chronic, noncommunicable diseases (NCDs), is a multi-pronged disease: an interconnected and interlocking web of both individual and sociopolitical factors deeply rooted in complex cultural, economic, and political systems. In fact, current research suggests that some noncommunicable diseases are partly or even wholly *communicable*, spread through social networks, cultural conditions, and intergenerational transmission (Allen and Feigl 2017, 129). This is an essay about what it could mean to reframe noncommunicable diseases like Alzheimer's, to resist reducing them to singular individual afflictions, and instead recognize that they are complex webs of interconnected illnesses that reach far beyond the boundaries of a singular body (Ito 2017).

Spillover

“I place a fork in her right hand and guide it to the poached egg in the deep bowl. I have already cut up the toast, so that I can help her spear pieces of bread and soak up the yolk. She can't find the teacup in front of her, so I move her hand next to its handle,” writes Arthur Kleinman (2009, 292). Kleinman's writing is meticulous; it is ordinary. Grounded in the everyday minutia of a dementia caregiver, it tells of loss, pain, and attention. “Caregiving is not easy,” he writes. “It consumes

time, energy, and financial resources. It sucks out strength and determination” (ibid., 293).

Kleinman’s words are important to pay attention to here, not only because he’s a physician and medical anthropologist, but because his narrative eloquently articulates some of the most enduring and pervasive tensions inherent in the life of a caregiver for someone with dementia. He locates his world within hers, within the navigation of silverware and amplification of his desperation, he too inhabits a space touched by the disease. “She is happy much of the time,” he writes of his wife. “It is me, the caregiver, who, more often, is sad and despairing” (Kleinman 2009, 293) He calls his role of care a new life of “solidarity” and “enduring the unendurable” (ibid., 292–293). His exposition articulates a world where a disease of an unspooling brain—his wife’s Alzheimer’s—saturates and affects his life narrative in turn (Burke 2014, 30).

This process by which Kleinman’s world is “saturated” by the disease of his wife is what is referred to in the literature as the *caregiver burden*—a “multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience” (Vellone et al. 2008, 423–424). Among other health risks, “caregivers have higher rates of insomnia and depression, are at risk of serious illness, and are less likely to engage in preventative health measures” even though one half of all caregivers have at least one chronic condition (Collins and Swartz 2011, 1310). In one study, 17 percent believe that their health has deteriorated as a result of providing care, and spousal caregivers reporting high levels of strain have a 23 percent higher Framingham Stroke Risk than their non-caregiver counterparts, as well as increased all-cause mortality (as high as 63 percent in four years) (ibid.). Often, many caregivers “take on the role while healthy, but

subsequently become ill” (Mittelman 2005, 634). This burden is also compounded by gender; the majority of dementia caregivers are women (Collins and Swartz 2011, 1309).

This barrage of health risks has led some researchers to note that “it might be useful to start viewing caregiving as, in itself, a health hazard” (Fonareva and Oken 2014, 725). Indeed, “one of the greatest risks for caregivers is becoming ill themselves” (Collins and Swartz 2011, 1309). The phenomenon by which a caregiver, faced with the unyielding sickness of often a spouse or a parent, *also* incurs health risks is known as the “spillover effect” (Wittenberg and Prosser 2013, 490). The person affected by spillover “may be providing care to the ill individual or may be related to the individual who is ill or both” (ibid.). The effects of spillover are broad—including somatic and psychological health, emotional health, quality of life and well-being, finances, relationship stability, and work (ibid.). Not only does the caregiver’s health suffer, but the effects of this disease spill over into economics as well. Alzheimer’s is among the most expensive of diseases—in 2000, the average out-of-pocket expenses for caregivers was “approximately 10 percent of the caregiver’s annual income” (Collins and Swartz 2011, 1310).

While Alzheimer’s is not a communicable disease in the traditional sense of disease vectors and infection, the cascading health effects of Alzheimer’s upon those surrounding that individual suggest that simply framing this problem as a singular disease of a malfunctioning brain might be misleading. Using the specific language of “social networks” and “contagion effects,” researchers Wittenberg and Prosser contextualize the “well-documented burden of caregiving” in the same frame as obesity and smoking, which, they note, have effects that *extend* to family members and others (Wittenberg and

Prosser 2013, 490). This language, that of extension, contagion effects, and social network systems, is important in creating a landscape of health in which caregiving and care-receiving are tightly interwoven phenomena. Overall, “research has established that health effects extend beyond one individual to include those surrounding them, including those physically present and those emotionally connected. The landscape of health decision making is altered by the conceptualization of health as a family affair” (ibid.). By invoking the “landscape of health decision making,” there is some implication of context, of connection, of tightly knit social networks that together impact the health and well-being of both caregivers and receivers. Further, while “the importance of including those spillover effects has been noted by many,” creating empirical estimates of spillover is challenging because the very premise of “spillover” resists compartmentalization and reductionism. It, in fact, does the opposite, creating networks of overlapping effects—social, emotional, physiological, and somatic (ibid., 498).

Perhaps one of the better demonstrations of the spillover effects of these intertwining illnesses is in the cognitive and psychological effects of caregiving. In one study detailing effects of caregiving on a spouse’s cognition, researchers found that “spousal caregivers of dementia patients have on average lower levels of cognitive functioning than age, sex, and education matched controls. Caregivers performed significantly worse on measures of general cognitive functioning, speed of information processing and verbal memory” (de Vugt et al. 2006, 164; Correa et al. 2015, 371). Even further, the study found that “low performance on verbal memory was related to a decrease in caregiver competence and an increase in patient behavioral symptoms” (de Vugt et al. 2006, 164). It’s important to note the ways in which cognitive impairment of

the dementia patient provides a context in which the general cognitive functioning, verbal memory, and information processing of the caregivers is *in turn* impacted.

This is worth spending time on. Among a whole slew of health risks, caregivers for dementia patients are at a higher risk for *developing dementia* (Fonareva and Oken 2014, 744). In the literature of spillover, one of the more insidious problems for caregivers comes via a feedback loop whereby the effects of dementia are reflected and amplified back and forth from the dementia patient to the caregiver. “Caregiving is relational and reciprocal,” writes Kleinman (2015, 240). Part of this relational and reciprocal relationship is undoubtedly the ways in which these diseases of care have spillover and “contagion-like” effects on those surrounding the disease.

Noncommunicability?

“A name that is a long-winded non-definition, and that only tells us what this group of diseases is not, is not befitting of a group of diseases that now constitutes the world’s largest killer,” write Allen and Feigl in a 2017 *Lancet* article discussing the utility of framing and reframing noncommunicable disease labels (Allen and Feigl 2017, 129). They begin by first describing the way diseases are traditionally divided into three groups. The first group is made up of infectious diseases like HIV, malaria, and tuberculosis. The second consists of NCDs like Alzheimer’s, obesity, and cancer. The third is a category of injuries (*ibid.*). Calling these three divisions “outdated” and “counterproductive,” they attempt to bring attention to the problematic noncommunicable disease category. They note that noncommunicable diseases “share all of the ideological and social justice issues of HIV but cause 30 times more

deaths and receive 17 times less funding” (ibid). Further, even though the category begins with “non,” these noncommunicable diseases “will cost the global economy US\$47 trillion over the next two decades,” they will “continue to push millions of people into poverty,” they and will continue to be “the leading cause of death worldwide” (ibid., 129). It’s not simply a matter of semantics or pedantry, they argue, because “anything that begins with ‘non’ must be considered a ‘non-issue’ or a ‘non-starter’” (ibid.).

The issue here is one of framing. “The disproportionately low levels of national and international attention paid to NCDs in terms of action plans, funding, and global institutions might be partly attributable to the framing of these conditions” (Allen and Feigl 2017, 129). They recognize that “calling the world’s biggest killer ‘non-communicable’ propagates confusion, undermines efforts to spur a sense of urgency, and deflects attention from effective and system-wide interventions” (ibid.).

Beyond linguistic semantics, they also argue that the medicalized distinctions themselves need rethinking. This well-entrenched medical binary of communicable and non-communicable is a distinction that, in light of modern medical anthropological discussions, might be very tenuous. Noting that this division between communicable and noncommunicable is anything but firm, they argue that “evidence is mounting that some NCDs are partly or wholly communicable” (Allen and Feigl 2017, 129). “They can be spread through social networks, viruses such as hepatitis, cultural and economic conditions, food deserts (i.e., areas short on fresh fruit, vegetables, and other healthy foods), and intergenerational transmission (i.e., diabetes and obesity)” (ibid.). Even further, they write, “The present misnomer implies that the causes are individual rather than societal. This implication is simply not the case: NCDs

have largely sociogenetic antecedents, and efforts focused on individual behaviour have little overall effect if the social and policy environments do not change in parallel” (ibid.).

Despite their clear and persuasive language, Allen and Feigl (2017, 129) spend little time fleshing out what they mean when they say that “evidence is mounting that some NCDs are partly or wholly communicable.” Obesity, as they mention, is one NCD that has the potential to complicate the binary of communicable and noncommunicable diseases. I contend that Alzheimer’s is another such disease that resists the reductive framing of the noncommunicable label. To more fully understand how Alzheimer’s fits this description, it’s helpful to look at the recent research surrounding obesity as a means of seeing how an NCD might be reframed.

The move from framing obesity as a failure of individual willpower is an important shift in medical anthropology. Though there is a debate as to whether or not obesity is a disease in the first place, Annemarie Jutel specifically addresses this question, noting that where being overweight once was merely a descriptor of corpulence, it has undergone the “transition to a disease entity” (Jutel 2006, 2269). Sociologist Karen Throsby notes that often, in the contemporary rhetoric surrounding obesity, “the fat body is easily labeled as lazy, self-indulgent and lacking in discipline” (Throsby 2007, 1561). Further, “those who become fat often find themselves needing to account for their size in order to refute the suggestion of moral failure that attaches itself easily to the fat body” (ibid.). Much of the dialogue surrounding obesity reinforces this notion of an *individualized* problem and a failure of willpower. Recent obesity research, however, has begun to challenge this view of obesity, recognizing that this noncommunicable disease occurs in a sociopolitical and environmental *context*, and that there are

explanations for obesity that are not reduced to the failures of individuals.

In “The Global Obesity Pandemic: Shaped by Global Drivers and Local Environments,” Swinburn et al. discuss the concept of an “obesogenic environment”: “The simultaneous increases in obesity in almost all countries seem to be driven mainly by changes in the global food system, which is producing more processed, affordable, and effectively marketed food than ever before” (2011, 804). Swinburn shows that the drivers of the obesity “epidemic” are inherent in the globalized food system itself. For Swinburn, obesity as disease is actually the result of people “responding *normally* to the obesogenic environments they find themselves in” (ibid.; emphasis mine). And while “support for individuals to counteract obesogenic environments will continue to be important, the priority should be for policies to reverse the obesogenic nature of these environments” (ibid, 807). Through the lens of obesogenic environments, Swinburn is able to complicate this individualized model, emphasizing that a focus on encouraging consumers to make better food choices fails to fully grasp one of the large-scale drivers of obesity: context and global markets. In a similar vein, the report “Wider Income Gaps, Wider Waistbands? An Ecological Study of Obesity and Income Equality” (Pickett et al. 2005, 670) also directs the conversation away from an individualized notion of obesity and instead focuses on the effects of poverty and income inequality on obesity. Among developed countries, “income inequality was significantly related to obesity among men and women, diabetes mortality, and average calorie intake” (ibid., 672).

Research into obesogenic environments and the impact of socioeconomic status upon obesity is important in this

discussion as it relates to noncommunicable diseases, including Alzheimer's. Although it by no means shows that this is a communicable disease in the traditional sense of disease vectors, this research does complicate the boundary between communicable and noncommunicable by showing that obesity is not just an individual problem, but an interconnected and interlocking web of both individual and social factors. Obesity is not solely the result of poor individual choice, it's a multipronged disease: political, socioeconomic, and personal at the same time.

"There is an ongoing and largely unhelpful emphasis on individual healthy choices" that "hamper a shift towards more effective and equitable population-level policies such as tighter tobacco control and measures to address obesogenic environments" (Allen and Feigl 2017, 129). Allen and Feigl argue that this tendency to align noncommunicable diseases within the realm of individual bodies, such as the tendency to blame obesity on the moral failings of the individual rather than looking at larger scale factors such as obesogenic environments, obscures a more complex, nuanced understanding of the causes of disease and in turn prevents "systems-level interventions" (ibid.). Obesity, like Alzheimer's and other noncommunicable diseases, are made up of many complex and interconnected systems that contribute to the disease.

Further refuting the idea of obesity as an individualized disease, researchers have linked the spread of obesity through social networks. One study considered the extent to which weight gain in one person is associated with weight gain in friends, siblings, and spouses. Framed with the aim of looking into networks and connections as a means of studying the extent to which obesity is "spread through social ties," their findings suggest that "obesity may spread in social networks

in a quantifiable and discernable pattern that depends on the nature of social ties” (Christakis and Fowler 2007, 370, 377). Their results indicate that a person’s chance of becoming obese increased by 57 percent if he or she had a friend who became obese in a given interval. If one spouse became obese, the likelihood that the other spouse would become obese increased by 37 percent (*ibid.*, 370). What’s important about this study is the recognition that social networks, human interactions, and the complex web of interpersonal dynamics is now a component of obesity research much like spillover is in caregiving. As the study shows, “the spread of obesity in social networks appears to be a factor in the obesity epidemic” (*ibid.*, 378).

These are just a few examples of the avenues in which current obesity research is finding ways to contextualize obesity and extend the etiology to social, political, and interpersonal spaces. Obesity is a complex web of relationships, and recent research suggests that trying to fit obesity into a framework that doesn’t account for this nuance and complexity is problematic.

Which brings us back to Allen and Feigl’s call to question the NCD category. Much of the strength of their article lies in its willingness to push against these seemingly ingrained medicalized distinctions such as communicable vs. noncommunicable and individual vs. societal. And although there is not a specific mention of Alzheimer’s disease or caregiving in their article, I contend that just as obesity resists these reductionist frameworks of singular disease, so does caregiving. Alzheimer’s is a disease of many interlocking problems. Like obesity, it’s a disease at the nexus of political, social, economic, and interpersonal issues especially when it comes to the well-documented health risks of the caregivers, yet often the diagnosis is a highly individualized one, emphasizing the tangles and plaques of a single malfunctioning brain. Increasingly,

however, the vocabulary of caregiving literature is beginning to push against the individuality. Like Allen and Feigl, I argue that the traditional framing of NCDs is problematic in the ways it decontextualizes and individualizes diseases like Alzheimer's. Further, given the literature of caregiving, I want to suggest that aspects of Alzheimer's disease resist the binary disease label that separates the communicable from the noncommunicable in the way that the diagnosis affects not only the diseased brain in question but also the health of the caregivers and the surrounding family. How does Alzheimer's stay within the noncommunicable disease boundary when the literature of caregiving uses phrases like "contagion effect" and "spillover" to describe the health effects of caregiving? (Wittenberg and Prosser 2013, 490). Indeed, Kleinman notes that the pathology of the *disease* may be limited to a single brain, but Alzheimer's clearly breaks those boundaries by making those *surrounding* the disease ill (Klienman 1980, 73).

To be clear: the argument here is not that obesity or Alzheimer's is an infectious disease or that it presents the kinds of problems that a disease like Ebola virus can engender. Insofar as I push against these communicable vs. noncommunicable labels, it is not to equate the two, as the challenges of tuberculosis are indeed very different from those of Alzheimer's. This debate is not about the utility in continuing or not continuing to use "infectious" as a way of describing particular kinds of diseases. This debate is about whether or not the reductionist language of noncommunicability, with its built-in binary, is the problem. I want to suggest that the language of infection has use, but the binary might not. Regardless, NCD is a category that is not only problematic, but might be anathema to the goals of attending to the interactional and interpersonal nature of certain diseases like Alzheimer's and obesity.

Allen and Feigl (2017, 129) note that they are not the first to call for a reevaluation of the noncommunicable and infectious disease binary, and they certainly aren't the last. Just five months after their article, two more articles were featured in *The Lancet*, one calling this reframing a “welcome” change (Rigby 2017, 653). Instead of noncommunicable, anthropologists Kozelka and Jenkins suggest renaming NCDs “interactional diseases” (Kozelka and Jenkins 2017, 655). And while the authors recognize that there is conceptual danger in conflating this notion of biological contagion with social or political contagion, Kozelka and Jenkins note that “all diseases are interactional in some sense; infectious diseases are also contracted and treated in particular social worlds” (ibid.). The “interactional nature of diseases formerly clustered as NCDs must be considered for researchers, clinicians, and policy makers to understand the complex content of interactional disease course and outcome” (ibid.). In lieu of NCDs, Allen and Feigl use the term “ecological” as a means of overcoming the binary of communicable and noncommunicable diseases (Allen and Feigl 2017, 129). By ecological they merely mean “the relation of living organisms to one another and to their physical surroundings” (ibid.). This definition, coupled with the “interactional” conception of diseases, has the potential to overcome some of the barriers inherent in the binary and, through a more ecological, relational lens, potentially reveal greater insight into how connected and complex NCDs are.

This discussion is more than just language and semantics. Given the burden of caregiving and the ways in which the disease infiltrates the social networks surrounding the person with the diseased brain, the categorizations of noncommunicability fall short. It's not just a minor issue of wording, it's a systematic

failure. The framework itself is failing to account for the literature showing that to be a caregiver is to also to be at risk.

Fluid Boundaries

Anthropologist Stanley Ulijaszek uses images of water and fluidity as a guiding visualization articulating the complexities of obesity. “There are leaks and flows between bodies and the environments that surround them, as there are between disciplines that study obesity,” he writes (Ulijaszek 2014, 3). “Obesity has been studied using genetic, physiological, psychological, epidemiological, cultural, environmental, political, and economic frameworks, among others” (ibid.). He notes how, increasingly, systems thinking has been applied to the study of obesity, which involves “attempts at understanding how things influence one another within a whole” (ibid.). Ulijaszek recognizes that this kind of thinking is anything but new, “since the study of ecosystems, which involves relationships among physical and biological elements within the environment, including water, goes back to the 1930s” (ibid.). Indeed, Ulijaszek writes that for obesity, conceptual frameworks that can recognize “how things influence one another within a whole” is hugely important, given that a phenomenon like obesity is “ecological, transdisciplinary, and complex” (ibid.). “Boundaries between fields of knowledge are important for their integrity (a body without boundaries would not be a body), but it is equally important that they should be leaky,” he writes. “Leaky” is the word he uses to describe how one might approach such a complex issue like obesity. This language of water and fluidity, he writes, is important in that it draws attention to how scientists “should approach their pool of study: with open hands,

with fluid boundaries and technologies of mind and body to try and catch the uncatchable” (ibid.).

These images of water, fluidity, permeating boundaries, and complexity can frame not only obesity but also, I argue, Alzheimer’s. This notion of “spillover” has already led research in this direction—recognizing that Alzheimer’s occurs in a context, and that to conceptualize the health effects of those surrounding the disease, one must consider a web of interconnected systems of social, economic, relational, and biomedical factors. And that, even then, the boundaries between those are fluid and “leaky.” Margaret Lock recognizes the need to broaden the framework of Alzheimer’s beyond the biomedical. She writes, “To date, relatively few researchers have paid attention to the relationship among AD incidence and poverty, social inequalities, and family histories, but this situation is beginning to change, spurred on by findings in epigenetics” (Lock 2013, 7). Medical anthropology can provide this complex framework, allowing Alzheimer’s to be placed in the context of systemic poverty, social inequality, and family histories, showing how the boundaries of this disease are leaky.

The importance of contextualizing Alzheimer’s patients and recognizing that their health is linked to the caregivers is clear in Collins and Swartz’s “Caregiver Care.” In their article, the authors lay out the health risks of the caregiver burden and talk about the potential for caregiving “interventions,” which are individualized assessments where a physician simultaneously treats the caregiver and the patient with Alzheimer’s (Collins and Swartz 2011, 1312). An NYU caregiver intervention program includes “individual and family counseling sessions tailored to each caregiver’s specific situation, followed by weekly support group participation and ad hoc telephone

counseling at the request of spouse-caregivers and other family members for the entire duration of the disease” (Mittleman 2005, 637). Collins and Swartz note that “when patients and caregivers are treated as a dyad, outcomes for both are improved” (Collins and Swartz 2011, 1312). While it may seem like a subtle distinction, the word *dyad* holds huge importance here. When patients and caregivers are treated *together*—as a group of two people—the outcomes improve. Again, it seems subtle, but in treating this disease as a dyad, there is some recognition of the interactional nature of this complex issue.

It’s not a tidy argument. The arc of this research is rooted in leaky boundaries and invocations of complexity—but that is the point. Even now, the driving force behind this essay boils down to the day my fifteen-year-old brother told me that he too had Alzheimer’s, which is, of course, not strictly *true* from the biomedical lens of disease. However, if Alzheimer’s can instead be seen as a web of interlocking and interpersonal illnesses, if it isn’t reduced to the boundaries of a singular body, then perhaps this can account for a fifteen-year old who is worried that he too, has caught a disease he knows is “uncatchable.” I draw similarities between obesity and Alzheimer’s caregiving not because the research is necessarily similar, but because Alzheimer’s, like obesity, requires understanding “how things influence one another within a whole” (Ulijaszek 2014, 3). They are two diseases that cannot be reduced to the problems of individualized bodies—they simply *resist that reduction*. They are interpersonal and *interconnecting* medical issues that defy linear causation and instead must be approached through the lens of fluid systems, leaky boundaries, and open hands to “catch the uncatchable” (*ibid*).

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Against Reduction

Designing a Human Future with Machines

By: Noelani Arista, Sasha Costanza-Chock, Vafa Ghazavi, Suzanne Kite, Cathryn Klusmeier, Jason Edward Lewis, Archer Pechawis, Jaclyn Sawyer, Gary Zhexi Zhang, Snoweria Zhang

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