

## ONE

### Introduction

#### *Knowing (in) This Place*

The Tu Du hospital in Ho Chi Minh City is Viet Nam's largest women's hospital. I went to Viet Nam in 2004, three years after the trade relations between the Vietnamese and U.S. governments were restored to "normal." Traveling with a group to study how the change to a market economy, Doi Moi, affected the Vietnamese, we were asked to visit the hospital and to tour its Peace Village. I knew little about Peace Villages, little about Agent Orange, and little about the destruction that I was about to see.<sup>1</sup>

As I walked out of the offices, a clinical space that revealed very little about what I was about to experience, I was troubled that two generations after the American war ended (what we in the United States call the Viet Nam war) children were being born with an alarming rate of congenital anomalies in the communities having the highest levels of exposure to Agent Orange. The director of the hospital said they suspect there are genetic changes occurring at the somatic level, in utero, as well as at the germ cell level, the level of the sperm and egg. What little I knew about research done on Agent Orange and U.S. Viet Nam veterans indicated that dioxin could not have genetic effects on these levels; dioxin was supposedly unable to bind with or alter

the structure of DNA.<sup>2</sup> Yet, I didn't know how else to explain the effects they were describing to me.

As I approached the Peace Village housed within the hospital I began to be challenged in a new way. I saw what was literally a village, set up with the goals of community interaction in mind, nothing like the sterility and false sense of safety generated in U.S. hospitals' common space. This was a space that reflected the needs of an impoverished community. Most of the patients housed in the Peace Village came from rural areas; many were from the Central Highlands and were poor. The village reflected energy and life, unlike U.S. hospitals that feel lifeless, literally and metaphorically.

As we walked through the village, we acquired an escort. He was a young man who several years earlier had been separated from his conjoined twin. He was dynamic, spoke to us in English, (typically American, none of us spoke Vietnamese) and did not seem overly hampered by the loss of the leg he shared with his twin. His vibrancy did not prepare me in any way for what I was about to experience as he escorted us up the elevator into the rooms that housed the other children in the Peace Village. What I saw can't be described well. The best I can say is that I saw bodies and lives destroyed in a way that was beyond my experience, beyond the experience of most westerners. This was a war zone, but 30 years after the American war ended. It hit me at a gut level that is hard to describe.

A Vietnamese-American woman came walking out of a room I was about to enter. She was carrying a child who suffered from hydrocephalus, a swelling of the brain and cranium caused by fluid build-up. The little girl also had no eyes, her eye sockets were fused shut, her mouth and palate were severely deformed, as were her arms and legs. The woman's name was Trinh Kokkoris. The name didn't mean much to me and it wouldn't have to most U.S. citizens, but it should have. However, the name Kokkoris meant a lot to the Vietnamese. In January of 2004 her husband Constantine Kokkoris had filed the first class action lawsuit against 37 chemical companies on behalf of the Vietnamese victims of Agent Orange. Though the children in this room were not named in this legal suit, these children and countless

children and adults like them would be beneficiaries if damages were awarded.

The physical evidence that I was seeing and the claims of the hospital's doctors didn't fit with the physical laboratory claims made by researchers who worked on the effects of dioxin. I want to emphasize that for both claims there was evidence, but they were different types of evidence, from different settings. One was in the clinical setting of the laboratory and one was here, in the living, situated environment of Viet Nam, a physical and social environment in which Agent Orange existed and has existed as part of daily life since it was first sprayed in 1961. Scientists tend to dismiss evidence from situated, complex, nonclinical settings because this evidence doesn't accord with predominant scientific methodologies, like toxic risk assessment or randomized control trials, which rely on isolating substances to understand their effects and studying individual diseases or isolating organisms to understand how they are affected. These methods are thought to ensure a more purely objective body of evidence because of their isolation from the complexity of the everyday world, which ironically is the setting in which life takes place and we actually experience things.<sup>3</sup> My visit to the Tu Du Hospital helped me to recognize a gap in what many scientists and laypeople want from science for it to generate knowledge to improve human living, and, in this case, its inability to do so. I began to question whether our current scientific methods could meet the needs of communities that are situated outside of dominant culture and experience multiple impacts, such as from poverty, poor access to medical care, environmental contaminants, stress, war, racism, colonialism, and sexism. From this experience I began to formulate the argument for a transactionally situated approach that I develop and argue for in this book.

#### KNOWING AND DOING

This experience also led me in another direction—what was my role, ability, and responsibility to act in this situation? I admire the work of early American pragmatists, such as John Dewey

and Jane Addams, because this question was at the forefront of all of their work. Furthermore, as was especially the case with John Dewey's work, the connection between epistemology and action, or as Dewey would say, "knowing and doing," were critical not only for the success of philosophy, but for the success of society. Thus, my epistemic intuition when I was in Viet Nam—that there was something missing from how researchers go about understanding Agent Orange in a living environment and my need to think about how I can engage this—was guided by the pragmatic motivation to connect knowing and doing to make change. One of the ways that philosophers make change is by providing theoretical pathways that can lead to methodological change in other fields. My project in *The Limits of Knowledge* is to take this up in relation to particular practices in science and medicine by developing extended case examples, such as race, gender, and class biases in the diagnosis and treatment of endometriosis and the health justice work of the Mothers Committee of Bayview Hunters Point in San Francisco. I use these to build on John Dewey's arguments for experimental inquiry and transaction and feminist arguments for situated knowledges. I pull these pieces together to develop the framework that I referred to earlier as a *transactionally situated approach*. This framework is used to provide an analysis of two predominate methodologies in medical and scientific research, evidence-based medicine and toxic risk assessment. My analysis is guided by a central framing question for this book that parallels John Dewey's thoughts in *The Public and Its Problems*: What are the conditions under which it is possible for science and medicine to meet the health needs of marginalized people and work with them to promote their flourishing, as individuals and as communities?<sup>4</sup>

What this book does not do is provide extended critiques of arguments for experimental inquiry or situated knowledges. My goal is to utilize these theories, or in William James's words, to see their "cash value."<sup>5</sup> I take this approach for two inter-related reasons: (1) In the United States philosophy as a discipline is rarely part of dialogue outside of academia. This is in many ways the result of the ways in which philosophers have shaped the trajectory of philosophy to be a discipline that internally hashes out theories, instead of a discipline that seeks to use

theories in a broader social context to help provide solutions to pressing issues or to develop frameworks through which to shape practice. Though the continual critique of various philosophical theories is an important and necessary part of philosophy, it, by and large, speaks only to philosophers. (2) Both feminism and pragmatism invite an approach that requires an engagement that goes beyond disciplinary boundaries and that takes us out into the world with tools to make change. Thus, my interests lie in what we can do with these theories. If these theories can help us restructure how we engage each other, then regardless whether each one presents a philosophically flawless argument, they present opportunities for engagement with the world and opportunities for restructuring the world and our transactions with it. This seems to me to be the heart of the philosophical enterprise and a way to make philosophy a socially relevant tool for change. In seeking to utilize these theoretical frameworks without substantial critique of them I don't intend to be dogmatic in my utilization of them, but instead to recognize, as Dewey puts it, the very point of developing theories and methodologies is that they are to be "tried" in order to understand their efficacy in everyday living.<sup>6</sup>

This book begins from what I take to be the commonsense claim that one of the jobs of science is to improve human living and that the best way for it to do so is by having methodological practices that gain useful and effective knowledge; that is, knowledge that we can do something with. There is no doubt that contemporary science and medicine are among the most successful pursuits in human history and that most of us are alive today because of the efficacy of their methods and practices. That said, some practices in science and medicine are not equipped well to handle the health needs of marginalized people, that is, groups that due to racism, sexism, classism, ablism, ageism, globalization, and other factors, lie outside of mainstream culture. Furthermore, the health needs of these communities are frequently greater than those of more mainstream and empowered communities precisely because marginalization leads to poorer health outcomes for these groups. Lead poisoning and its relationship to housing location, cyclical poverty, poor academic performance, and crime rates is a powerful example of the effects

of marginality on health and is developed as a case example in this book.

#### METHODS TO IMPROVE HUMAN LIVING

I also start this project from the commitment that philosophy should be a socially engaged and socially responsible practice that frames its work to meet the needs of the public. One of the reasons I adopt a Deweyian approach is that his work is grounded in this assumption and it shapes his activities as a member of an academic community and as a citizen, which he rightly views not as separate spheres but as shared circles of engagement. Furthermore, among the classical pragmatists, John Dewey's work has the deepest links to the sciences. His commitment to the promises of science and its methodologies drives his work more than any other pragmatist. Dewey adopts some of the language of the sciences, arguing that experimental inquiry, the methodology that was the foundation of the Scientific Revolution, was the most powerful practice to gain knowledge about the world and ourselves in this world. The goal of experimental inquiry, Dewey argued, was to generate knowledge to engage in "actions which change the face of the world."<sup>7</sup>

Feminist arguments regarding situated knowledges hold similar promise because of their desire to reorient and improve the epistemology and methodology of scientific practice. For example, the work of Chela Sandoval, Donna Haraway, Sandra Harding, Patricia Hill Collins, and Lorraine Code initiated conversations about the ways scientific and nonscientific knowledge is generated and assessed. In doing so they have argued that the social location of the epistemic agent is paramount in the development of knowledge. These two approaches complement each other well because although Dewey has tended to be more optimistic in his treatment of scientific methods, feminist epistemological approaches have been decidedly more critical. Yet both approaches seek transformative, critical dialogue and change to improve scientific practice with the goal of improving human living. Neither approach seeks to do away with science. They value science and work to improve it and use it for socially

transformative purposes. Some would describe this as liberatory epistemology.<sup>8</sup>

Like the situated knowledges positions and Deweyian pragmatism, the transactionally situated approach for which I advocate is a meliorist view and works to employ the transformative nature of scientific practice to improve human living. The methodologies of science frequently fail those who can least afford to be failed: women in all situations, poor of all colors, people of the two-thirds world, the socially, politically, and geographically marginalized and disenfranchised. Toxic risk assessment and clinical trials have been designed to limit the number of “inputs” in order to understand the effect of a particular chemical or a particular drug. Yet people who are socially and materially disadvantaged tend to live in environments with lots of “inputs.” They live in communities located in or near multiple types of toxic waste; they don’t have access to healthy or safe food or water; they don’t have access to adequate medical care; they don’t have easy access to information about their health and environment. This list can go on, but the point is that where we live is not a laboratory, nor is life a clinical trial, and those who are the least advantaged experience most strongly the effects of knowledge that is limited because it is not deep or wide enough. If we want to understand, for example, whether Agent Orange caused birth anomalies in Vietnamese children in the Central Highlands of Viet Nam, children whose parents and grandparents have lived in one of the most toxic environments in the world, then we need understand what it is like to be in these communities, living with a toxin, in a complex ecosystem, with the material conditions these communities are presented with, not just how dioxin does or doesn’t affect laboratory animals.

A transactionally situated approach brings together the insights from experimental inquiry and situated knowledges to argue that scientific research needs to be initiated from the complexities of the everyday world and the pertinent conditions and lives of those who are materially tied to the results of the research. Though laboratory research and clinical trials do yield knowledge, this knowledge is limited in that it does not reflect how disease and toxins function in the complexities of everyday lives. Chemicals may be benign in a laboratory setting, but when

they exist in a complex setting in transaction, in other words, in a “dynamic and co-constitutive relationship” with other environmental factors and in transaction with human bodies that are marked by race, gender, class, ability, age, and histories of marginalization, they may be toxic and may cause disease. Yet, we don’t have this information because we study chemicals and disease in settings “remote from any significant human concern.”<sup>10</sup>

Through a transactionally situated approach I emphasize the ways that communities whose illnesses are studied by scientists are physically, socially, and epistemically immersed and in transaction with their world—in other words situated—and make the claim that illness and toxins need to be studied in this complexity in the communities that may be affected by them. Furthermore, I argue that researchers need to recognize the experiential knowledge that community members develop by living in particular communities and with particular illnesses as well as the scientific knowledge that members of these communities frequently develop in order to be able to assess scientific claims about their lives.

## STRUCTURE

Each chapter in *The Limits of Knowledge* has an integrated extended case example that is used to not only develop and “test” the arguments in the book, but also to highlight pertinent social, medical, and scientific justice issues that tend to not receive front-page media coverage. In Chapter 2, “The Career Woman’s Disease: Endometriosis and Experimental Inquiry” I build on John Dewey’s work to develop a lens to study research on the disease endometriosis. Throughout the late 20th century and moving into the 21st century endometriosis has been cast as a disease that affects affluent, white, career-oriented women who choose to put off or to not have children. This chapter provides a Deweyian analysis of the biases that provide a foundation for the description, diagnosis, and framing of the disease. It intertwines research about endometriosis to create a case narrative that utilizes Dewey’s arguments for experimental inquiry and



transaction to both point out problems with research on endometriosis and provides a transactional framework for understanding the etiology of the disease. I conclude by considering how research on endometriosis affects the health of African American women.

In “Grounding Knowledge Through the Mothers Committee of Bayview Hunters Point,” the third chapter, by combining the insights of Chela Sandoval, Sandra Harding, Patricia Hill Collins, Lorraine Code, and current work on situated knowledges, I analyze the experiences and activism of the women of Bayview Hunters Point, San Francisco, focusing specifically on a community action group called the Mothers Committee. The women of the Mothers Committee of Bayview Hunters Point are certainly valuable strangers to the social order. It is hard to imagine a group whose members are more outside of science—they are female, African American, and living in one of the poorest, most toxic, and most violent communities in the United States. They self-consciously utilize this positioning to their advantage as part of their methodology as an oppressed group.

I study the physical and epistemological location of the Mothers Committee from the lens of situated knowledges to argue that this critically situated positioning of the Mothers Committee generated a methodology that they strategically employed to study their community, form coalitions with other groups, critique environmental racism, and physically transform their community. The Mothers Committee provides an apt example of the increasingly concrete engagements that situated knowledges arguments have moved toward. Furthermore, the lives of the people of Bayview Hunters Point and the work of the Mothers Committee are a critical example of environmental, health, and racial injustice and a powerful example of how communities resist injustice. Thus, the equally important goal of this chapter is to highlight how this community is subjected to, experiences, and resists injustice.

Building on the work in the previous two chapters, Chapter 4, “Transactionally Situated Frameworks, Gold Standards, and Silent Epidemics,” begins with a brief description of the problem of lead poisoning in Detroit, Michigan and then moves on

in the body of the chapter to lay out a framework that combines the insights from pragmatism with the insights from situated knowledge. I describe this approach as transactionally situated. A transactionally situated approach is one that:

1. Initiates its perspective by embracing critically formed marginalized views and marginalized knowledge at the same time that it employs experimental inquiry.
2. Not only views physical, economic, and social location as impacting knowledge of those in that situation, but recognizes that location, in a deeply transactional, embodied sense, must be part of how researchers frame questions and research about communities.
3. Following from #2, recognizes that short-term and long-term historical pathways shape health and reflect the proximate and distant experiences of communities and individuals.
4. Recognizes that there is agency and accountability in how researchers frame their questions, who and how they research, and how outcomes are interpreted.
5. Understands that given #2 to #4 marginalized populations, that is, groups that due to racism, sexism, classism, ableism, ageism, globalization, and so on lie outside of mainstream culture, have little influence on framing research questions and funding and participating in research.
6. Furthermore, given #2 to #5, a transactionally situated approach also recognizes that the health needs of these communities are frequently greater than those of more mainstream and empowered communities precisely because, as epidemiologist Nancy Krieger argues, marginalization leads to poorer health outcomes for these groups.<sup>11</sup>
7. Embraces the Deweyian commitment that the problems we are working with drive choices of methodologies rather than methodologies framing what sort of problems can be engaged.
8. Is reflexive in its approach because it is transformed by its own methodology while also critically transforming epistemology.

9. It has both descriptive and prescriptive import. In other words, the approach is not only able to provide an analysis of science and medicine, but also is able to provide direction for what these practices should do.

From this perspective I provide an analysis and critique of one of the most important and predominant practices that has arisen in the late 20th-, early-21st-century biomedicine, evidence-based medicine (EBM), arguing that EBM is not able to provide well for the medical needs of marginalized populations. From there I move on to argue that within biomedicine there is an approach, ecosocial epidemiology, which is transactionally situated and can meet the health needs of these populations who are not served well by EBM. I come back to lead poisoning in the United States as a case example to show the viability of transactionally situated approaches. Such an approach can help to understand the connections between our methodological choices and the outcome of these choices for people who are marginalized through class, race, and location.

Like the previous chapter, Chapter 5, “The Needs of Living: Agent Orange in the Central Highlands of Viet Nam,” studies a particular scientific methodology, toxic risk assessment, and its relationship to understanding dioxin levels in the Central Highlands of Viet Nam. I begin this chapter with an excerpt regarding the dismissal of the first class action lawsuit filed on behalf of Vietnamese victims of Agent Orange and connect it to the ways in which particular understandings of evidence have unexpected and far-reaching consequences. I tie the critique of EBM developed in the previous chapter and the arguments I made for a transactionally situated framework to understanding the methodology of toxic risk assessment. Next I lay out the history of Agent Orange in Viet Nam and then move on to discuss scientific and medical research on Agent Orange and dioxin. From there I look at a particular region in Viet Nam, the Aluoi Valley, to show how transactionally situated research on Agent Orange can yield different types of knowledge claims about its effects and can help us to understand how in this particular location Agent Orange can have the effects that the Vietnamese claim it does. I finish by showing the political and legal effects of nontransactionally situated research on the land and

people of Viet Nam by analyzing the U.S. diplomatic document on Agent Orange and its effects, as well as legal briefs from the U.S. appeals court in New York and the plaintiffs in the class action lawsuit against the 37 chemical companies that manufactured Agent Orange. My goal is to show the far-reaching consequences of a nontransactional, nonsituated approach to research.

In the sixth chapter of *The Limits of Knowledge* I consider the ethical implications of a transactionally situated approach. Chapter 6, "Rooted in a Community," studies the implications of and the insights provided by Dr. D. Holmes Morton's clinical work with Amish and Mennonite children at his Clinic for Special Children, located in the heart of Amish and Mennonite Pennsylvania, Lancaster County. Morton left his research position at University of Pennsylvania's Children's Hospital to immerse himself in this community to serve as a general pediatrician and to treat rare genetic metabolic disorders that affect Amish and Mennonite children at a higher rate than the general population. Morton put himself in this community, seeking to understand his patients not just as a research geneticist would, but as a pediatrician who treats the whole child. He seeks knowledge from members of the Amish and Mennonite community, primarily the parents of afflicted children, to understand the disorders that affect the whole community on different levels.

Morton's work with these communities provides an apt illustration of a transactionally situated approach to science and medicine. It also provides an opportunity for studying the ethical implications of this type of research. Working with marginalized communities, communities that are isolated physically and/or socially, presents ethical challenges that need careful consideration. If and how a researcher speaks for, about, or to a community is much more complicated than mainstream medicine and science have made them appear. Furthermore, questions of trust, listening, epistemic honesty, epistemic humility, knowledge-sharing practices, and epistemic injustice are equally as problematic. I begin by discussing not only how Morton situates himself in the community he is serving but also how he works to recognize, value, and employ the situated nature of the community. In the process of working through Morton's methodology, I take up the above ethical concerns by employing a number of

contemporary feminist and critical race theorists, such as José Medina, Lorraine Code, María Lugones, Heidi Grasswick, Mariana Ortega, and Miranda Fricker who have critically engaged these issues.

*The Limits of Knowledge* finishes by raising questions about the role and responsibility of philosophy to actively engage the everyday world. I argue that philosophy should not only make space for publicly engaged and publicly responsive philosophy, but also should value and make this type of work a priority. My hope with this book is that it contributes to the growing movement to make philosophy a publicly engaged, publicly responsive activity by viewing philosophy as practice that goes out into the world to improve human living.