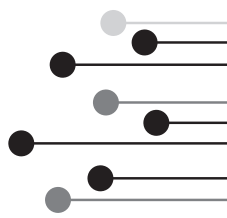


The Ethics of Working with Human Participants



Orientation

In this chapter, we'll dive into the considerations social science researchers must make when working with human subjects, the folks we variously call our respondents, participants, informants, and collaborators. These considerations arise from a long history of developing ethical codes for our disciplines, some of which were the result of debates in cases where researchers may have conducted unethical research—research that harmed the people whom it was studying. As a result, there are standards and processes to better ensure that we do not harm the people we are studying. Our ethical decisions may be the single most important choices we make as researchers and should be carefully considered.

Ethics in Conducting Research with Human Subjects

What do we mean by *ethics*, and why are ethical codes so important when conducting research with human subjects? **Ethics** are standards of what we ought to do in terms of right and wrong: our subjects' (participants') rights, our responsibilities to various others (including our participants), the way our research ought to benefit the people whom we study and society as a whole, and issues of fairness and virtue while conducting research. *Ethics* also means the study and development of ethical standards—that is, the field of research on how to do research ethically. Generally speaking, the purpose of ethics is to provide broad guidelines on how to think through the effects our research has on our participants, and more broadly on the world, and to minimize harm while maximizing positive effects.

Chapter Learning Objectives

Students will be able to do the following:

- 2.1 Explain what ethics are and why they are important, as well as provide examples of ethical codes
- 2.2 Describe the responsibilities a researcher has to the people we study
- 2.3 Describe the responsibilities a researcher has to scholarship and science and to the public at large
- 2.4 Explain how ethical dilemmas occur despite ethical codes and think through complex ethical dilemmas
- 2.5 Understand how to identify and problem solve for potential problems concerning population

- 2.6 Understand how to identify and problem solve for potential problems concerning positionality
- 2.7 Describe the institutional review board (IRB) process and explain how to work with an IRB to assess and manage risk

Disciplinary associations write **ethical codes**, or documents that are meant to clarify the issues that have been carefully considered by professionals in the field and guidelines for researchers and practitioners. These codes outline the reason why they were written as well as *professional standards* for conducting research or practice—that is, standards that are broadly agreed on by professionals in a field as good practices and considerations to ensure that participants and society at large receive maximum positive effects and minimal negative effects from the research that is conducted. The American Association of Physical Anthropologists (AAPA) *Code of Ethics* (2003), for example, reads:

No code or set of guidelines can anticipate unique circumstances or direct actions in specific situations. The individual physical anthropologist must be willing to make carefully considered ethical choices and be prepared to make clear the assumptions, facts and issues on which those choices are based. These guidelines therefore address *general* contexts, priorities and relationships which should be considered in ethical decision making in physical anthropological work.

Most professional codes of ethics work this way, in that they cannot anticipate all specific circumstances in which researchers will work, but rather seek to guide a process by which professionals can think about their research and encourage professionals to hold themselves accountable to their professional associations and their participants (and communities or populations they study).

Because of this, professional standards tend to be broadly applicable to a wide range of contexts, highlighting significant considerations across many different places, peoples, and situations. For example, the American Anthropological Association (AAA) *Statement on Ethics* states:

Anthropologists should be clear and open regarding the purpose, methods, outcomes, and sponsors of their work. Anthropologists must also be prepared to acknowledge and disclose to participants and collaborators all tangible and intangible interests that have, or may be perceived to have, an impact on their work. . . . Anthropologists have an ethical obligation to consider the potential impact of both their research and the communication or dissemination of the results of their research.

In its code of ethics, the AAA outlines a number of considerations for researchers, particularly those of openness and honesty with a number of entities and the importance of using findings in appropriate and timely ways. These professional standards arose both from broadly agreed-on practices that encourage positive and lasting relationships with all groups involved in research (participants, colleagues, and funding organizations) and from responding to ethical problems that have occurred in the past. For example, during some of the wars in the twentieth century, anthropologists were employed or

Ethics Standards of what we ought to do in terms of right and wrong actions.

Ethical codes Documents that provide agreed-on guidelines and standards for a profession in order to consistently minimize harm and maximize benefits during the course of the professional's work.

funded by the US military or Department of Defense to conduct research that was not forthright in its purposes with its informants. This was later considered problematic and unethical by other professionals, because it violates the rights of participants to understand what they have agreed to participate in and how the results of their participation will be used. The importance of appropriate and timely dissemination of findings is also important, because when doing research with human subjects, we ask a lot of time from our participants—often without pay. If we don't draft appropriate and timely presentations, manuscripts, films, or other media to share our findings, we have essentially co-opted research and our participants' time and effort for our own enjoyment and amusement—and that isn't social science research.

Discussion

When you consider the professional standards outlined in the AAA code of ethics, you'll note that they don't define certain terms, such as what is *appropriate* or *timely*. Why do you think this is the case, and how might this be both helpful and problematic? Can you think of two or three different dissemination outcomes of a research project that could be appropriate but have entirely different purposes and/or audiences? What factors might affect the timeline to dissemination and make timeliness challenging? How might you communicate or collaborate with participants to ensure that their ideas of what is appropriate and timely are taken into consideration in your plans for dissemination and that their expectations are realistic given factors over which you lack control (such as review timelines for publication)?

The Researcher's Responsibilities to the People We Study

Arguably, the most important responsibilities we must consider in research are those to the people we study—to our participants. **Human subjects** is the term most frequently employed by institutions such as universities and funding agencies when they refer to the people whom we study, who provide us with data through interviews, surveys, or other methods. However, the term *subjects* is framed by a colonialist background, when research often occurred on behalf of (and/or funded by) a colonial government on isolated, "primitive" peoples. As a consequence, it often is unfortunately a put-off to contemporary groups of people, who don't want to be viewed as subjects of the researcher's gaze. While we often have to use the term *human subjects* on forms for universities or funding agencies, it can be helpful to consider other ways to describe the people who are the focus of our study. Some of the popular ways to refer to these folks are aligned with particular methods: Researchers often say they have *informants* for interviews and

Human subjects
A common formal term that means the people whom you study (your participants).

respondents for surveys (though *informant* can also sound a bit like a spy or a snitch in some contexts!).

A neutral term that implies greater equality between the researcher and those who are studied is *participants*. Some researchers who are dedicated to **participatory research** or *collaborative research*—research in which the researcher and the community or population being studied work more intensely and equally together to define the purpose, methods, and outcomes of the research—prefer the term *collaborators*. This is also a particularly good way to refer to key participants who are more heavily involved in one's research and devote a lot of time and effort to it. Unlike in the early days of ethnography, such collaborators are increasingly given not only more power over defining the research project and its outcomes but also more credit, including becoming coauthors with researchers to acknowledge the significant contributions of their intellectual property to the project. In this textbook, we'll use *participant* to refer to people whom we study and who are participating in our project, *key informant* only in cases where we are narrowly referring to specific individuals who are heavily utilized for interview research, and *collaborator* to mean persons who (whether academics or not) are involved in research design and/or dissemination of results.

The responsibilities we have to our participants, and more broadly to the community or population we study, are the most important ones we have as social science researchers. Why? There are ethical and practical reasons for this. Ethically, we arguably have a social (and some would even say moral) obligation to reciprocate in kind the gifts of trust, time and effort, and openness our participants give us (and, more broadly, the information they provide arising from their cultural knowledge). In a practical sense, if we behave badly and break down trust in a community or population, people are likely to paint all of us—all the researchers in your discipline (and sometimes even in other disciplines)—as untrustworthy, rude, or careless people. This makes it much more difficult for future researchers to effectively work with those communities or populations. The ways you interact with your participants now have a ripple effect far beyond yourself and even your lifetime. Remember that you're working on behalf of not only your own project but also your institution, your discipline, and researchers everywhere.

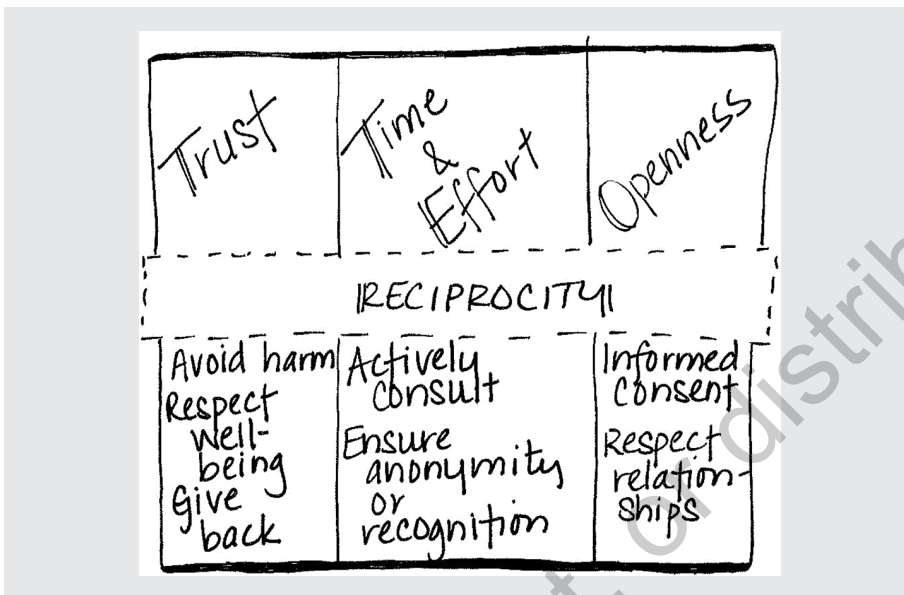
There are a number of responsibilities that, when met, help ensure we are adequately reciprocating our participants' generous gifts of trust, time and effort, and openness (see Figure 2.1). We reciprocate trust by *avoiding harm*, *respecting well-being*, and *giving back*.

In order to return the trust our participants give us, we keep their needs and safety first in our minds. This is why research design begins with assessing risk to our participants and going through an institutional review board (IRB) process (which we'll cover later in this chapter), which allows fellow researchers to review our purposes, methods, and projected outcomes to double-check our minimization of harm.

Beyond avoiding harm, we need to respect our participants' well-being. This means that we not only minimize risk but try to maximize the positive effects of our research on our participants and their communities. For example, we try to anticipate how compensating participants may be perceived as unfair by the broader community and limit any negative social effects that may occur from participation. We treat our participants as we'd treat colleagues or friends—we make sure that we are sensitive to overstaying our welcome, being too intrusive, and showing our participants that we value their time.

Participatory research Research in which the researcher and the community or population being studied work more intensely and equally together to define the purpose, methods, and outcomes of the research.

Figure 2.1 Reciprocity with Participants



Finally, we try to avoid exploiting our participants by finding culturally appropriate ways of giving back. This can take many different forms, from gift cards or raffles for iPads in research conducted across a US county to volunteering to teach English at a rural school for a community in Guatemala. Sometimes giving back involves direct payment or compensation to participants who devote many hours (even years!) to our research as key informants (informants who usually have specialized knowledge and whom we rely on heavily)—this is especially the case if those informants are considered experts in their communities and are sharing uncommon knowledge with us. Other times, giving back—especially in cases where we are studying commonly held cultural beliefs, knowledge, or behaviors—may take the form of broadly useful or welcomed community-based assistance, such as providing supplies or human resources at schools, medical clinics, or community centers. It can be helpful to take a collaborative approach to the question of how to give back in these cases and incorporate culturally appropriate activities that allow the community to decide what it would like in return (but within a range of services or activities you can actually provide!).

A special consideration, especially if you are collecting specialized knowledge or information about cultural heritage, is to consider the issues around intellectual property. **Intellectual property** consists of creations of the mind, such as art, literature, inventions, and uses of things (such as cures derived from plants). Legally and ethically, people have a right to their intellectual property and fair compensation when it is used. We should engage in protecting our participants' intellectual property rights and give back to them in reciprocity for sharing it with us, but how? We have to consider the questions of

Intellectual property Creations of the mind, which may be held individually or collectively.

whom we choose as key informants and fieldworkers and how these jobs given to certain members of a community—especially if they are individually compensated—will affect how the person is perceived by others in their community. We also have to ask ourselves how widely such intellectual property is shared. Expert knowledge, such as what we might receive from a *curandero* (folk healer) on herbal remedies, may be appropriately compensated at the individual level in some cases. Broader aspects of culture, such as an annual performance that is part of a group's cultural heritage, may necessitate creative ways of giving back to entire communities or cultural groups.

We reciprocate time and effort by *actively consulting with participants* and *ensuring anonymity or recognition* (as participants wish). Aside from the question of giving back, we have to consider how we can return the time and effort participants give us in more intangible ways. We can honor their knowledge and willingness to participate by being more inclusive in our project design and implementation and in publicly giving them acknowledgment (or not, as they desire).

Active consultation with participants can, at its most inclusive and collaborative level, take a form of advocacy on behalf of communities in which the researcher designs their research project around purposes or goals that the community itself has established. In these cases, the researcher is more like a consultant to the community, and the ultimate goal is often to train community-based researchers so that they are eventually independent and self-sufficient in conducting their own research and advocating for themselves. Even in more standard, ordinary academic research (which is generated from the interests of the researcher, as we discussed in Chapter 1), there are ways in which we can consult with our participants throughout our research project. These can include honoring established community-based decision-making frameworks, such as going before the Tribal Council of a Native American tribe to request permission to conduct research in their community and to ask how you might ensure that your findings are returned to them in a meaningful way. It can also include (in bigger projects) hiring **fieldworkers** (paid workers who help collect data) from the community itself rather than from outside institutions or locations. We can also implement consultation on a micro scale in our research, such as periodically checking in with a participant during a long interview to ensure the person is comfortable and doesn't need a break. If we remember to consistently humanize our participants and treat them as we'd like to be treated, we'll find that we remember at all turns to consult them for their feelings, thoughts, and reflections on the research process.

Finally, in research in which people provide substantial time and effort, such as providing long interviews or sessions of participant observation, we should discuss with them their preferences on anonymity or acknowledgment in our manuscripts and other final products. In some cases, our research topic may be tied to conflict, or a participant may not wish to be identified by name for some other reason, and it is best to provide acknowledgment in anonymous, general ways, such as by thanking "all the participants who made this research possible." In other cases, participants may wish to be acknowledged by name, such as when an expert on healing is repeatedly consulted over the course of a year as a key informant.

Finally, we reciprocate openness by securing *advance informed consent* and *respecting close and enduring relationships*. We ask our participants to open up about their lives, often rather deeply and sometimes even painfully or intrusively. Imagine if a researcher

Fieldworkers Paid
workers who help
collect data.

showed up on your doorstep, asking if they could hang out with you for five hours a day and observe your life! Would you let them in? Letting people into our lives and being open and honest with them is challenging and often socially uncomfortable. Surprisingly, participants all over the world agree to donate significant time, effort, and discomfort to qualitative studies. We need to show gratitude by reciprocating with our own openness and by respecting the relationships we forge with our closest participants.

We primarily model openness from the beginning of our researcher–participant relationship through obtaining advance **informed consent**. We'll talk about this in detail later in this chapter, but this is a process that informs potential participants *before they begin participating* about our project's purpose, what it entails, and what risks they might face. It's our way of building trust, and while most new researchers find it awkward at first to obtain advance informed consent, it's a key part of being open and forthright with our participants.

Once we build those relationships, we need to remember that if we work with our participants deeply and repeatedly over time, as is often the case in ethnographic research (where we often return to a location many times over the course of several years or even our entire research career), these relationships often become more than professional. These close and enduring relationships become friendships as our participants share in our joys of discovery, our frustrations, and sometimes (for both parties) our tragedies and challenges. In conventional ethnographic research in smaller-scale communities, this means that over time, there is often little privacy between the researcher and the participant—and we may be asked to interweave ourselves ever deeper into the lives of our participants and their community. Ethnographers have become godparents of participants' children, loaned participants money for medical bills, and even sponsored participants to become US citizens. It isn't unknown for ethnographers who return to communities for many years to be treated as both insiders and outsiders at once, or even to have romantic relationships with members of the community. It's important to critically reflect on your role as a researcher throughout your time spent in a community and with particular participants, establishing boundaries that honor your needs and concerns for meeting your research goals while also finding ways to respect your participants' close relationships with you.

Discussion

Reflect on the research topic you selected in Chapter 1 of the workbook. What do you anticipate using as your field site, and whom do you anticipate having as participants? How close do you think you'd get to your participants over the course of your research? Would you rather have a short-term project only or eventually return to the community or site again and again? What are some initial ways you think you could give back to your participants (and, more broadly, the community or population you're studying)? How could you consult with your participants? How could you find ways to respect relationships you build with them?

Informed consent
A process that informs potential participants about the project's purpose, what it entails, and any risks they might face before they begin participating in the project.

The Researcher's Responsibilities to Scholarship and the Public

While researchers' most significant responsibilities are to the people they study—and those responsibilities should be first and foremost—our responsibilities don't stop there! We're also responsible to scholarship and science and to the public as a whole. Our responsibilities to scholarship are sometimes framed as how we give back “to our field” or “to our discipline.” Basically, such responsibilities ensure that we facilitate rather than impede the advancement of social science as a whole, our discipline, and the work of our colleagues. Responsibilities to scholarship cover three focus areas: planning, sharing, and reputation.

Responsible scholarship in *planning* includes considering potential ethical dilemmas that may arise and planning for how to handle them, as well as including ethics in research proposals—both in terms of considerations of how to ensure that funding mechanisms support ethical standards and in terms of having proposals reviewed by an IRB whenever possible.

Responsible scholarship in *sharing* refers to the “appropriate and timely” dissemination of findings that the AAA code of ethics referred to earlier. Basically, researchers should use their results in meaningful ways, disseminate their findings so that other researchers (as well as policy makers and others) are informed by them, and share data after they're done using the information for new publications and presentations. By sharing data and findings with other researchers, we contribute to the advancement of entire fields and we capitalize on the time and effort our participants have already provided to research.

Finally, responsible scholarship is attentive to maintaining the *reputation* of the discipline (and science) as a whole. As we discussed in the section on our responsibilities to those whom we study, if we behave ethically, we preserve fieldwork opportunities for other researchers who come after us. By being honest and transparent, we provide positive interactions between researchers and participants, which encourages people to be willing to participate in the future. The logical bookend to our own transparency and ethical conduct is a willingness to report misconduct we observe by other researchers. If we come to find that a colleague is not operating with informed consent, is causing harm or unnecessary risk to participants, or is otherwise behaving badly in the field, we are responsible to report this for review by our professional associations or universities. While difficult and uncomfortable, peer-review accountability structures—from research design to fieldwork to dissemination of results—challenge our colleagues and ourselves to do research as ethically as we all can and to produce the best findings possible.

What about our responsibility to the public? Do we have responsibilities to society as a whole? We do. Arguably, the single most important responsibility we have to the public at large is to understand the potential harm that may come from the products we disseminate and to make our results available but in ways that minimize harm. On the one hand, we need to accurately portray the people whom we study. On the other hand, we have many choices to make about how to tell their stories and how to present our interpretations. We need to critically reflect on how our writings, films, or other products we disseminate—including our interpretations—may affect how the public views this group of people who are our focus. A classic example of the potential harm that can

come to people as a result of choices in what and how to disseminate is the way in which the public's perception of the Yanomamo was slanted toward focusing on violence and brutality—even primitiveness—as a result of Napoleon Chagnon's portrayal of them in his ethnography. Even if we are not advocates or activists, we should always keep the risk to those whom we study in mind and remember that the public, to a greater or lesser degree, may be influenced by our work.

We also have a responsibility to conduct our research with integrity—not just in terms of virtue but in terms of maintaining the research design's necessary conditions and requirements to answer the research question. We shouldn't agree to conditions that funding agencies or other entities set that would substantially change the research (in ways that make it impossible to answer the research questions) or that compromise our ethics. In short, we need to be willing to improve our research design in various ways—to address peer reviewer concerns from funding-review or IRB panels, to collaborate with participants and incorporate their feedback, and to respond to emergent limitations and challenges in the field—but we also have to be vigilant about not compromising our ability as researchers to answer our research questions and to act in accord with ethical standards.

Discussion

Consider all the different groups to whom you have responsibility as a researcher—participants, the community or population that you study, fellow researchers and your discipline, and the public at large. In what ways do you think these different responsibilities support each other—what works together? In what ways do you think these different responsibilities may conflict? Can you generate one or two examples of potential conflicts in responsibilities and how you might respond to them?

Ethical Dilemmas

Ethical dilemmas are almost inevitable if someone conducts research for any substantial length of time. This isn't because the researcher has a poor moral compass or is unprofessional. Rather, there are gaps between professional standards and personal ethics (the overarching and very general standards set by professional associations and the specific ways in which you feel you should act within certain contexts). Ethics in codes and on paper, before you are in the field, usually seems easy. But the world is messy, and you're bound to be faced with uncomfortable, awkward, or even dangerous situations where you must make a choice about specific actions you will or won't take. Some of these dilemmas happen so frequently across fieldwork in many different contexts that we can discuss them ahead of time and begin to pose questions to ourselves about whether or not we anticipate encountering them for our own research topic. These dilemmas are

built into the nature of social science research itself and have to do with conflicting (or multiple) “goods”—that is, positive goals that conflict with each other by their very nature in certain contexts.

Cause versus Culture

Activist anthropologists, particularly, may find themselves torn between a cause (such as ending human slavery or having equal rights for women) and the culture of the people they are studying. All sorts of practices that are widely decried in Western cultures, such as child labor, child marriage, slavery, and limiting the rights of women—including to their own bodies—exist in many cultures all over the world. Researcher responses to this have ranged from moral relativism on one end of the spectrum to activism on the other. **Moral relativism** posits that no one can judge another culture’s practices, because morals are relative to their historical and cultural context. That is, we can be against child labor in our own culture and nation, but we can’t tell a group from somewhere else that they can’t (or shouldn’t) have children work. **Activism**, on the other hand, positions the researcher in service to a cause—for example, the cause of ensuring global human rights for children, including the right to education and to not be put into working environments at the expense of education. Somewhere in the middle is **cultural relativism**, where the researcher seeks first to understand a practice or belief within its own historical and cultural context (and without judgment) and may later take a stand, but with this outsider position acknowledged and kept in mind.

Human Rights versus Cultural Continuity

In a similar but broader vein, researchers often must face questions about whether they attempt to align with the concept of universal human rights or whether they uphold the right of cultures to continue as they are (if they wish to do so). As the world has become more globalized, international political structures and nongovernmental organizations have increasingly pushed for certain inalienable universal human rights. These rights include access to meeting basic needs (e.g., food, water) and having basic securities and freedoms (e.g., not being physically harmed for one’s religious beliefs). On the positive side, a movement toward universal human rights often protects groups within any society that are most marginalized and vulnerable—those who have the least amount of power to advocate for themselves. Outside bodies, such as the United Nations or human rights watch organizations, provide external checks on societies to attempt to avoid horrible abuses of power that can result in genocide, widespread sexual assault and violence against women, and other acts that widely—in many cultures—are thought to be tragedies. Yet at the same time, human rights declarations and reviews by outsiders also carry on a legacy from colonialism that posited Western values, beliefs, and practices as superior to non-Western peoples’ cultures. Just as the Christian ideas of manifest destiny (the idea that Western Christian people had not only the right but the god-given destiny to convert and change “primitive” people) led to a great deal of suffering and cultural erasure for indigenous peoples all over the world, arguably human rights rhetoric carries the same implications—that Western or outsider values should trump the rights of a culture to continue its practices and beliefs.

Moral relativism The idea that no one can judge another culture’s practices, because morals are relative to their historical and cultural context.

Activism The idea that the researcher is in service to a cause.

Cultural relativism The idea that the researcher first seeks to understand a practice or belief within its own historical and cultural context, without judgment, but may later take a stand.

Conflict within Cultures

One of the most difficult dilemmas arises from the variance within cultural groups themselves. Let's return to the first two dilemmas. It's one thing to consider how you'd respond if an entire cultural group wanted to maintain a practice that you disagreed with. But how would you respond if only *some* of the people in the group wanted to maintain the practice, and others wanted to get rid of it? What about if you noticed differences in power between these disagreeing groups—that one group was more powerful and perhaps benefited more from the practice, while the other was more vulnerable and paid the price of the practice? Disagreements within communities or cultural groups we study are common and are usually uncomfortable for the researcher to respond to. If we conduct participant observation and live in a location for months or years, it often becomes even harder to navigate these complex differences among our participants and maintain openness and trust while also potentially trying to work with disagreeing people. We may also develop our own opinions or experiences that cause us to feel as if we'd rather take on an activist or advocate role for one group, which comes at the expense of the other. There are no easy answers to this dilemma, but it's important to consider whether we may face it in our research. Some topics are specifically oriented to studying conflict and may make us more prone to encountering this dilemma than others; if we anticipate such “warring factions” within our participant group (or, more broadly, the community or population we study), it behooves us to think about how we'll handle this ahead of time.

Place versus People

Finally, there is a problem that is a bit like a subset of the cause-versus-culture dilemma combined with the conflict-within-cultures dilemma—and this is particularly challenging for environmental researchers, such as environmental anthropologists or political ecologists. This is the dilemma of place versus people. Environmentally oriented researchers frequently address research questions that attempt to understand why people manage resources in a certain way, what the environmental outcomes of that management system are, and whether they are negative—how to persuade people to change so that we become more sustainable on local-to-global scales. In this way, environmental researchers face a particularly interesting and unique cause-versus-culture dilemma—particularly because in some cultures (whether the researcher's or those they study), places, plants, animals, and other natural nonhuman beings are considered persons—complete with their own rights. Geographically bound places or specific resources frequently have competing stakeholder groups who are at odds as to how the places or resources should be used, distributed, and managed—and power differences, just as they play out for other cultural practices, usually matter for whose knowledge counts, whose voices are considered, and which groups are given rights to manage and use resources. Environmental researchers may feel torn at times, not only between these different conflicting stakeholder groups but also between their work toward sustainability overall for a place or resource and their commitments to not harming participants. The question of harm to participants is particularly problematic with regard to environmental research because such topics may have short-term versus long-term consequences that are at odds with each other. For example, research that exposes poor

management practices in a fishery may cause immediate economic harm to fishermen in the study area when new regulations are put in place, but those regulations might ultimately preserve the fishery for future generations in the community. The complexity of environmental issues, often with many unknowns about how certain actions will eventually affect people in the study area, make it particularly difficult to assess risk over time.

Discussion

Think about your research topic or one that you've read about for any class. Identify one or more ethical dilemmas that were present in the topic or fieldwork scenario and how you would respond to them. Now, consider the four problems of multiple goods as a whole. Where do you stand on these issues? How would you define yourself as a researcher—more activist or advocate? More neutral observer? Try to imagine one or two scenarios that would test your sense of identity and baseline stance on these matters—how would you respond?

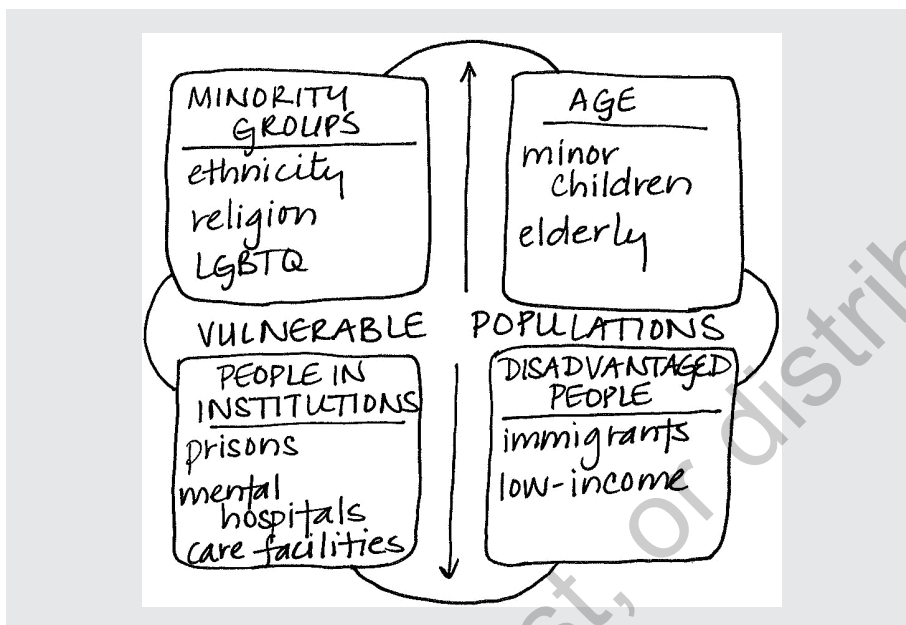
Vulnerable Populations

Aside from multiple goods, a rather specific issue that arises when conducting social science research, especially in the United States, is the issue of vulnerable populations. **Vulnerable populations** are already at greater risk in their lives than the rest of the population of a cultural or social group. Generally, vulnerable populations include certain age groups (minor children and the elderly), institutionalized populations (in prison or inpatient mental hospitals), minority groups (based on ethnicity, religion, gender and sexual orientation, etc.), and disadvantaged people (such as immigrants, those who do not speak the national language, and low-income people; see Figure 2.2).

Vulnerable populations are less likely to be able to advocate for themselves and are often more easily taken advantage of, and they are at particularly high risk for negative effects (including being negatively perceived by the public). As a consequence, researchers have to be especially careful when assessing risks and benefits for vulnerable populations involved in their studies. They need to weigh the immediate risks to participants in a vulnerable population against the greater good that may come to the population as a whole. For example, if we study sexual assault on college campuses, there is considerable emotional risk to victims who participate in interviews about their experiences and decisions about reporting. At the same time, if we design our research well and commit ourselves to disseminating findings in ways that speak to policy, such research could illuminate the barriers to reporting and prosecuting sexual assault cases on university campuses and lead to substantially better experiences for victims in the future (as well as eventually reduce incidences of sexual assault).

Vulnerable populations Groups within a society who face greater risk in their ordinary lives than the rest of the population.

Figure 2.2 Vulnerable Populations



In studies of broader research questions that could or could not include vulnerable populations as participants, we need to carefully consider whether the inclusion of vulnerable participants is necessary and whether excluding such participants would further marginalize them. There is no one right answer; it always depends on the research question and context. For example, a student might do a project on how people perceive the benefits of yoga and why they selected yoga as a form of exercise. The student decides to focus on drawing participants from three different yoga studios in their town. While they imagine that yoga might have some particularly unique benefits for people who experience mental illness, is it the best choice for them to specifically ask participants about their mental health and try to recruit participants who have experienced mental illness? Or will that do more harm than good in establishing trust and answering the overarching research questions? On the other hand, another student might do research on how people respond to extreme-heat warning days—when meteorologists warn that the temperature is high enough to cause people physical distress. In that case, the student should consider that if they exclude a vulnerable population such as the homeless, they are further marginalizing a population that is most likely to be the most negatively affected by the topic they are studying. Special efforts to reach out to these vulnerable populations, under those contexts, should be made—including finding ways to give back (or monetarily compensate when appropriate).

Discussion

Consider the research topic you selected in Chapter 1 of the workbook. What vulnerable populations may be involved as participants? Do you think it is necessary to include them, to make efforts to exclude them, or does it not matter? Why? If you are planning to exclude vulnerable populations, what negative effects could occur as a result? If you are planning to specifically recruit certain vulnerable populations, how will you minimize their additional risk?

Positionality and Privilege

Aside from considering our population and whether some members may be vulnerable, we have to consider our positionality relative to the people we are studying. **Positionality** is how facets of our identity are positioned vis-à-vis our participants, usually based on class, ethnicity, and other attributes that describe how we are alike or different. Are we wealthier or poorer? Of the same ethnic background or different? More or less educated? Positionality matters for two primary reasons. First, in ethnographic research, you interact with your participants. This means that they will respond to their own assumptions and biases about your assumed sociocultural characteristics. It is best if you acknowledge the ways in which you are positioned relative to your participants, as well as whether or not this is likely to cause challenges in developing **rapport** and how it might affect the types of responses you receive and topics you can address. When one of the authors (Kimberly Kirner) studied cattle ranchers and cowboys, her experience was different from what she would've experienced if she'd been a man. In fact, cowboys would tell her how they would take care of her, giving her the best horses and making sure she was out of harm's way, because she was a woman. This afforded her lower physical risk than if she'd been a male researcher, whom some cowboys said they would have hazed with problem horses and harder and more dangerous physical tasks. At the same time, she almost certainly didn't receive access to all the same conversations that a male researcher would have, given the male-dominated nature of the occupation. Whether or not this matters depends on the research questions. Because the focus was on land management, it was unlikely that the participants would have responded substantially differently to a male interviewer. But had the study been on occupational culture, gender, and sexuality, that could have been very different and more problematic.

The second way positionality can affect your research is through your own bias, often due to assumptions based in privilege or because you have insufficiently recognized the ways your worldview differs from your participants. **Privilege** is a way of describing the additional, special benefits and advantages that some groups receive in a diverse society. Most people have some ways in which they have privilege relative to other groups and some ways they do not. For example, the authors have privilege

Positionality How facets of our identity are positioned vis-à-vis our participants, usually based on class, ethnicity, and other attributes that describe how we are alike or different.

Rapport Trust between a researcher and their participants, such that participants feel that they can be open and honest.

Privilege A way of describing the additional, special benefits and advantages that some groups receive in a diverse society.

as white women, compared with people of color. They don't face the same systemic racism as people of color. However, the authors have less privilege than men. Privilege can affect your research in multiple ways. You have to be careful not to assume that your own experience would be like that of your participants, and you also should not assume that your experience as a researcher would be the same as another researcher. You also have to handle the challenges that arise when you have more privilege (and sometimes more power) than your participants. It's important to be aware of the ways you might receive special advantages in the broader society and the ways in which your representations of your participants can help or hinder them, especially if their groups are routinely marginalized by the broader society. It is important to always remember the first rule in ethics in anthropology: *Your responsibility is first to the well-being of your participants.*

Ultimately, as researchers' careers progress and the support they receive is from diverse entities, they may face increasingly complex ethical dilemmas that arise from attempting to meet the directives of many different entities: their own research interests and personal ethics, their family's needs (especially if they take their family with them to the field), the people they study (in all their diverse, potentially conflicting subgroups), funding agencies providing financial resources to do the work, agencies from which permits or permission was necessary to do the work (national governments, local community leaders, etc.), the researcher's university or research institution, the researcher's colleagues and research team members, and the myriad laws and procedures that are required for both the researcher's nation and the host nation. Practicing anthropologists, who operate in applied settings outside of universities to solve social and environmental problems, may face even more challenges. In many social science fields, the majority of practitioners operate in nonacademic contexts (whether clinical or applied research). In anthropology, for example, more than 50 percent of all anthropologists work outside of academia, including 22 percent of PhDs. Employers, often nonprofit organizations or government agencies, bring their own agendas, biases, and standards to applied research—and practicing anthropologists frequently must orient their research agenda and practices to their employer's goals and procedures. While this sounds complicated and challenging—and sometimes is—practice-based or applied research has the capacity to do what academic research rarely can: to effect meaningful change for people in the short term. For many practitioners in the social sciences who desire to make a difference in the world through their work, this is worth the additional effort it takes to navigate the complexity of applied research.

Discussion

Consider your sociocultural attributes: your gender, sexual orientation, class, ethnicity, and so on. When you reflect on the research population you selected in Chapter 1 of the workbook, how are you positioned relative to your participants? What challenges might arise as a result of your positionality? How will you handle these challenges?

The Institutional Review Board Process

We've been mentioning the institutional review board (IRB) throughout this chapter, which is one of many layers of peer review (or review of one's research by colleagues) involved in academic research. **Institutional review boards** (or **IRBs**, which refer to both the board and the process) review and approve all research involving human and animal subjects. They are usually made up of administrators and faculty and are internal entities to all universities (there are also independent IRBs paid to provide oversight to non-university entities). All universities have specific IRB procedures and documents that researchers must file, and sometimes there are additional documents that the researcher must file with funding agencies, such as the National Institutes of Health. Every research project has to be approved by the IRB first, before the researcher can get started with data collection. IRBs provide review of our research to ensure that all participants are protected from physical, emotional, and financial harm and that they are warned of project activities and potential risk and impact in advance of a decision to participate. The IRB will designate research *exempt* from further review (usually, because the project carries no risk and collects no **identifying information**—no names, addresses, or other ways to track participants) or *non-exempt*, which means that further review is necessary before approval. Non-exempt research usually has one or more of the following features: It collects identifying information, it carries risk of some kind, and/or it requires informed consent. The more risk and lack of anonymity a research project demands, the more scrutiny the IRB will generally give the project. This means that participant observation and survey projects, which are often low- or no-risk and anonymous, are often considered exempt, while intensive interview projects—especially on emotionally difficult subjects, such as war or immigration—would be non-exempt.

Institutional review board (IRB) A board or process that reviews and approves all research involving human and animal subjects.

Identifying information Information that identifies participants and allows them to be tracked in the real world.

Protocol A detailed plan that presents the significance of the research and plans for dissemination, the sampling and methods, an assessment of risk to participants, and how the researcher will minimize risk.

You might recall from earlier in this chapter that informed consent is a form and process that ensures respect for participants' autonomy by giving them all the information up front about the project, answering their questions and concerns, and asking them to sign off that they understand their rights. Informed consent is a process, often entailing revisiting questions and concerns as they later arise, and the informed consent form is not a legal contract so much as the start to a conversation. This conversation details what participants can expect to experience in the project, how much time and which tasks will be asked of them, what (if any) risks they will face, and what the proposed products for dissemination and impact will be of the project. The form is a guide for that conversation, ensuring they understand their rights to anonymity and confidentiality, to withdraw their participation (and when it is too late to do so), and where and how their information will be stored and used. The informed consent form should, as much as possible, be in language understandable to the public (free from jargon and at a basic reading level) and should be discussed with potential participants, encouraging them to ask questions about what they don't understand or what concerns them.

Generally speaking, IRB documentation includes a **protocol** (a detailed plan that presents the significance of the research and plans for dissemination, the sampling and

methods, an assessment of risk to participants, and how the researcher will minimize risk) and auxiliary forms, such as informed consent forms, method instruments (such as surveys or lists of interview questions), and evidence that the researcher is qualified to conduct the research (a curriculum vitae or résumé). Collectively, the documentation demonstrates that the researcher has carefully considered the potential positive and negative effects of their research and adequately planned to minimize risk and harm. The documents also ensure there is a clear plan that outlines the proposed methods, tools and instruments, and dissemination outcomes. Because of this, IRB protocols can serve as useful frameworks not only to plan for participant risk but also more generally to plan for the implementation of the proposed research project. A researcher's protocol details the what, why, where, when, who, and how of the research project, providing clarity for both the researcher and others. While such details often change once the researcher is in the field (and these changes are communicated back to the IRB and approved as needed), having a plan to begin with provides the maximum chance for the researcher's success and a baseline from which to modify as conditions demand.

Pairing the Textbook and Workbook

As you think carefully about your own ethics and how you'd integrate them with field research, and as you work toward your culminating activity for this chapter in the workbook (Activity 2.7), it is important to remember that ethics is grounded in a combination of your interpretation of your discipline's professional standards, the unique risks and circumstances your field situation involves, and the ways in which you are positioned relative to your participants. Keep asking yourself these questions:

- How can I best protect my participants? How can I best demonstrate reciprocity with them?
- What is my position relative to my participants, and what challenges may happen as a result? How can I plan to meet these challenges?

- How do I interpret the standards written by my professional association(s)? What do these mean to me?
- What potential kinds of risk are involved in my research, and how do I plan to minimize these risks?

Reflective Prompts

1. How do I take notes or call out important terms or concepts while reading?
2. Can I explain how ethical dilemmas occur despite ethical codes?
3. Do I understand potential problems concerning recruitment, population and positionality, and risk assessment and management?

Case Study

Magliocco, Sabina. 2005. *The Two Madonnas: The Politics of Festival in a Sardinian Community*. 2nd ed. Long Grove, IL: Waveland Press.

Available for free through www.academia.edu.

The Project

I did this project for my dissertation and post-doctoral field research, funded by two Fulbrights. I worked in northwest Sardinia, an island off the coast of Italy, and I looked at religious festivals and the effects of globalization. At that time, I talked about globalization as social and economic transformation. There were changes that had introduced a market and tourist economy. In the 1960s to 1970s, government-subsidized sheep pastoralism occurred, and prior to WWII, this had happened with wheat production. I looked at how these impacted one particular town and its surroundings.

One theme that emerged was the change in gender roles. There were huge changes for women in the period of the 1930s through the beginning of the twentieth century: They gained economic autonomy, they became more highly educated than the men, they participated in wage labor, and they participated way more in the planning of festivals. Some of the other themes were the close relationship between local festivals and local politics. Festivals served as a way for people on the upper end of the social scale to offer hospitality to others in the community and gain social recognition. But because of how the festivals were financed by the end of the twentieth century, it also allowed them to demonstrate their ability to navigate bureaucracy. So people who were more experienced in organizing festivals were more

likely to run for political office and win, since they demonstrated that skill.

There were merged inside and outside versions of identity; the harvest festivals in summer became tourist attractions. But there were other festivals revived for generating *communitas* among community members. Tourist festivals became expensive and included non-participatory events to demonstrate regional identity. Smaller, ancillary festivals were about local identity; people put on these events for themselves. They included local musicians, local food provided by individual donations leading to communal meals, and participatory dance. These were temporary returns to communal identity at a time when global economic and social forces were pushing people to a more individualized identity and pushing the town's identity more toward one oriented toward tourists—outward-looking rather than inward-looking.

What ethical issues arose during your research?

Let's start with my relationship to the community. My relationship to the community came from a personal connection to a woman who had worked as a domestic helper for my grandmother for many years and retired back to her village. So she was both a mother figure for me, and there was also this class difference. Domestic labor can be exploitative. She was not a social equal to my grandmother. Italian society was quite hierarchical. Many of my ethical difficulties in the community stemmed from that. As a daughter-like figure in her home, I was expected to adhere to all the social norms and rules as if I were in that relationship in

the family. This included not forming political relationships with opposing families and not borrowing things from others outside the family.

But my responsibilities as an ethnographer were very different. I needed to not limit my contacts to only one particular subgroup of society. So that created unease. I truly tried to talk to people all over the village: every social class, every political persuasion, every gender. Sometimes that created tension inside my living situation with the woman who hosted me and her family. I might talk to a family they didn't have good relationships with, for example. I became close to some people, one of whom was vice-mayor, and she belonged to a political party that my host and her family didn't belong to. So the situation was complex. It got more complex, because during my fieldwork, one of the festivals was taken over by the Christian Democrats. They took control of the festival from my friend on the left, who was in name running it, but who let them take control because she wasn't that invested in the festival. As a result, the Christian Democrats were elected to city council immediately following my fieldwork. This was interesting for me in terms of studying festivals, but it created a lot of tension between my host, my friends, and me.

I wanted to work with a local ethnographer who offered me the opportunity to publish my book in Italian in a series he was doing on Sardinian ethnography. I was thrilled by this, because I had the idea of giving back to the community that had hosted me. So I worked on the translation, and I asked for feedback from the community on the book so it would be their book as well. Then I got it from both sides. Both sides felt I got it wrong and felt I listened too much to people from "the wrong side." This was the result of interfamily politics in families

that for generations had been on different political sides. I ended up with hard feelings on both sides of the political spectrum, and it was really a tough time for me. When that went down, the publisher decided he didn't want to publish the book anymore because it was too politically controversial, and he himself lived in a town dominated by Christian Democrats and he didn't want to be on their bad side. So I had to publish with a different publisher. When the book was eventually published, with help from friends on the left, the right-wing city council took this out on my host by taking away a piece of her property. I felt awful. For a long time, I felt I couldn't go back to the town. I felt that by trying to give back to town, I hurt the person I was closest to and to whom I owed the greatest debt.

What are your reflections on these issues now?

Obviously, hindsight is 20/20. I wish I'd understood going in that in Sardinia, politics are family-based and there is no expectation or understanding that anyone could be neutral. My mistake was going in as an outsider and thinking that I could be neutral. This idea did not exist to the people I was studying. If I'd understood that from the beginning, it might have been easier to cope with. But the situation was complicated, and it'd be difficult for anyone to be caught up in these local politics.

What advice do you have on ethics, based on your research career, for beginning researchers?

You have to be honest with people about what you're doing. You have to be honest with yourself, about your own biases and limitations going into the field and how they might color the way that you see things. And I think you have to get over any romantic notions you have about trying to do good or help people in the community. There's

(Continued)

(Continued)

a limited amount you can do to help people in the community. I'm taking a group of students to the town in Sardinia where I did fieldwork this summer, but this was initiated by the community, and we're using all local vendors. It is a different kind of process. This will give back to the community economically in a very concrete way, and was their idea. But does our ethnographic work help communities? It's really difficult for that to happen. It's very challenging, because there are many competing forces at work. The best way I have given back to that community is through friendship. It's the relationships we build in our field communities that give back the most. We're giving back emotionally, but on a very small-scale, individual basis.

Case Study Reflections

1. Reflecting on Magliocco's experience in the field and what she wishes she'd known before she started it, what kinds of information should you try to find out before beginning your fieldwork?
2. Micro-level politics (conflicts in power and wealth between families, local groups, or local villages or towns) are relatively common around the world. How can you prepare yourself for handling conflicts between your participants in the field?
3. Why do you think it is difficult for ethnographers to meaningfully give back to the communities where they study? Why is academic research and publication often insufficient for meaningfully giving back?
4. What do you think Magliocco means when she says that our relationships in the field (our friendships) give back the most? If you approach your participants in this way (as friends), how does this change the way you would conduct your research and approach relationships in the field?

STUDY GUIDE

Note: Students should study each concept with attentiveness to defining, explaining with examples, and describing or demonstrating process. This is not a list of terms to define; it's a list of concepts and processes to master.

Ethics

Ethical codes

Responsibilities to people we study

Human subjects

Participatory research

Key informants

Intellectual property

Fieldworker

Informed consent

Responsibilities to scholarship

Responsibilities to the public

Moral relativism

Activism
Cultural relativism
Common types of ethical dilemmas
Vulnerable populations
Positionality
Rapport

Privilege
Institutional review board (IRB)
Peer review
Identifying information
Exempt and non-exempt research
Protocol

FOR FURTHER STUDY

American Anthropological Association Committee on Ethics. n.d.-a. *AAA Ethics Forum*. Accessed July 22, 2018. <http://ethics.americananthro.org>.

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American Association of Physical Anthropologists. 2003. *Code of Ethics*. Accessed June 26, 2019. <http://ethics.iit.edu/codes/AAPA%202003>.

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