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Toward a vulnerable ethics of research practice

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ABSTRACT This article considers ethical dilemmas concerning the protection of confidentiality that often arise in carrying out ethnographic research. A number of problematic assumptions are highlighted that generally (implicitly or explicitly) guide the practice of contemporary research ethics review committees: (1) ethical rules are context free; (2) there is always an ethical 'right answer'; (3) there is an objective position from which to judge what one ought ethically to do. Notably, this is a position of emotional detachment from the situation; (4) this objectively identified ethical position can be articulated in explicit and unambiguous public language. The troublesome character of these assumptions is raised in the context of fifteen years of ethnographic research among African American families in clinical settings within the urban United States, with special attention to an ongoing relationship with one research participant the author has known for eight years. Finally the article suggests an alternative ethical framework drawn from recent philosophical work in an Aristotelian-inspired 'virtue ethics'.

KEYWORDS *ethnography; informed consent; medical anthropology; narrative; virtue ethics*

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Introduction

I have been carrying out research in American hospitals for 15 years. In 1986, when I embarked on my first study – a two-year ethnography that took place in a large teaching hospital in Boston – the informed consent forms I designed were a page and a half, and easy to read. I used the same

form for patients and for clinicians who agreed to participate in the research. Permission for videotaping was also part of the research. In my current study, my research colleagues and I have eight different informed consent forms we use, depending upon whether the participant is a patient, a family member who is a parenting kin, a non-parenting family member, a clinician, a child within various age categories and other factors. The densely written forms, replete with required legalese, are five single-spaced pages long – although shorter for younger children.

The length and complexity of these forms are merely one material manifestation of the increasingly complex procedures now commonplace for research in clinical settings. University and hospital institutional review boards (IRBs) scrutinize proposals and, especially, consent forms, with a level of critical attention unheard of when I began in the mid-1980s. Even research proposals that have been awarded large federal grants (and therefore have been approved by a panel of seasoned researchers) are often challenged by hospital and university review boards over basic research design issues. Qualitative research has been particularly questioned.¹ The research my colleagues and I have been carrying out in a number of studies over the last dozen years worries institutional review boards. Study designs always involve videotaping clinical and home interactions, thus raising confidentiality issues. The studies focus upon children with chronic illnesses and disabilities, and therefore prompt consternation about the rights of minors. Because these studies explore health disparities, they target minority groups such as African Americans and Mexican Americans, another source of concern. As is typical with ethnographic research, the studies have involved comparatively intense involvement with small samples. This means that participants must agree to multiple extended interviews and observations. And, the research is longitudinal. Some of the participants enrolled in the current research we are conducting, for example, have been followed for seven years and will continue to be followed (with their permission) for at least another year.

A key concern of review boards is the issue of privacy. Review boards often find ethnographic methods ‘intrusive’, and worry about how to protect participants from having their lives invaded by researchers. In one instance, the review board asked for a meeting with the principal investigator to discuss worrisome aspects of our design. Though the study had been awarded a large federal grant, the review board members were horrified to discover that we intended to actually go to the homes of families whose children were in the study. Why did we have to observe and interview people in the privacy of their own homes, they asked with shocked dismay? Couldn’t we simply conduct our interviews in the hospital when families brought their children in for appointments?

There are good reasons to try to inform and protect participants about what might happen to them if they agree to become part of a research project. It is not surprising that confidentiality, in particular, has been of

focal concern to research ethics committees when reviewing ethnographic designs that yield in-depth information about a few people. However, the notion that tricky ethical matters can be handled by a single set of universal standards (embodied in a legal-sounding document) is itself problematic. Such an approach is likely to raise ethical issues of even weightier proportions than it solves. I always approach the consent-signing process with trepidation. Even when I have had several conversations with a potential participant and they are enthusiastic about being involved, I reach for the form with a heavy heart. 'Oh well,' I say apologetically as they read or we read it together, 'I know how this sounds but, uh, well, it's necessary for you to sign up before I can actually interview you or anything.' I stumble through the process, trying to translate written words that sound as cold as any lawyer's into some kind of human conversation. I try to convey the impression that I am not the person behind this unfeeling language. Sometimes, as the African American participants read paragraph after paragraph of defensive prose, they mutter jokingly about the Tuskegee experiments. (It never sounds like a joke to me.) I often wish I could just start the research, so that people could get an actual feel for what it is like, recognize that I am serious about not coming to their home or the hospital when they do not want me to, turning off the tape recorder when they do not want something recorded – enough so they realize I am not repeating to others in the study one word of what they say, not telling the doctor the grandmother's complaints about his incompetence or the parents what the nurse really thinks of their childrearing. Then, after having me on a trial basis, they could make a truly informed decision. While such issues are discussed in the consent document, they are stated in such an unfriendly way, so objectively, they seem sly. Not one word sounds trustworthy. And yet this document is the centerpiece of a negotiation about trust that comes exactly at the point in the research process when the researcher and a potential participant are strangers.

When 'confidentiality' turns into disrespect

Once relationships have been established, new difficulties arise. The confidentiality concerns, so important early in the research relationship, very often shift. Instead, participants often want their stories to reach an outside audience, and to reach others in a way that makes participants – and not just the researchers – visible. This has especially been the case with the African American parents caring for children with serious disabilities and illnesses. Some begin to see these studies as a place to be heard, to tell their stories, to voice their perspective on what it is like to care for a very ill child or negotiate with the health care system. Their participation in the research emerges as an avenue for redressing the anonymity, the sheer invisibility, they regularly experience in the world of health care. They do not want their names, or the names of their children, to remain anonymous. Why do

we have to use pseudonyms, they will ask? Why can't their children be honored with their real names? Others are grateful that we will never disclose their true identity.

Sometimes, too, they want to participate in the research in a different way, not as subjects or informants but as fellow researchers of their own lives and those of their children. They adopt the methods and tools of the anthropologist, taking notes, copying medical records, making videotapes and audiotapes, taking photographs. They offer to share these rich treasures with us. Refusing such gifts is terribly disrespectful, virtually unthinkable. But accepting them raises any number of problems that one would never want to admit to one's local research ethics committee.

The case of Shanelle and her dying daughter Neika

The following example, which concerns a family I have known for nearly eight years, illustrates how problematic the issue of privacy and confidentiality can be in the context of a developing relationship with those studied. When some level of trust has developed between a researcher and an informant, as it did between Shanelle and me, attempts to ensure privacy can sometimes seem more like rendering someone anonymous than protecting them. To Shanelle, it seemed as though I were treating her like just any other 'research subject'. She often confronted me by offering me data that supported her sense of having a special relationship with me.

I came to know Neika in the fall of 1997 when she was four and a half, just a few weeks after she was diagnosed with brain cancer. I became particularly close to her mother, Shanelle. As often happens in this kind of research, once Shanelle got to know me, she asked me to videotape important family events, including not only birthday parties and Halloween, but also the funerals of Shanelle's sister, her father, her eldest daughter's father. Shanelle (I use pseudonyms here, of course) is the sort of person who cherishes her memories and, as her daughter grew sicker, she created a veritable museum of Neika artifacts. I regularly gave her tapes of the 'home' videos we made.

Shanelle began to assist in the research in ways that were sometimes fraught with ethical difficulties. Once, for example, when we went together to an appointment with Neika's school psychologist and speech therapist, Shanelle introduced me to the professional team as her sister. I said nothing to contradict her and though we got some curious looks (it is unusual to see interracial families in south central LA), no one said anything. Since I had not received permission from these professionals to audiotape, and in any case had unexpectedly been turned into a family member, I simply sat quietly while Shanelle and the professionals talked together. When the meeting was over, Shanelle motioned me to her car and there, with a big grin, she pulled a tiny tape recorder out of the purse she had taken into the meeting. She showed me her tiny recorder, still recording, removed the tape

and gave it to me. I grinned back conspiratorially. Maybe they had the power to deny her child permission into their special education program, but she had her own secret weapons. Laughing, I thanked her profusely. To this day that tape sits in my closet at home, untranscribed.

I had been videotaping Neika for months but, when she grew more ill and frail, Shanelle bought a video camera. She became an unflinching recorder of her daughter's life, taping not only trips to Disneyland, birthday parties and visits from cousins but also Neika's seizures, her trips to the emergency room, even her last days at home in a coma. This act of recording, not as a solitary venture but in a kind of collaboration with me and the rest of the research team, offered one way for Shanelle to live with the tragedy that was unfolding in front of her eyes. Her daughter might die, Shanelle seemed to say as she shot roll after roll of film, but she would not be forgotten. This defiance, this insistence, was part of a transformation that I had witnessed in Shanelle. When I first met her just weeks after her daughter's diagnosis, she told me that if her daughter 'didn't make it' she was 'not going to make it either'. Two and a half years later, Shanelle had changed. She videotaped her daughter's final seizures while waiting for the ambulance. As she told me later, every single part of Neika's life was precious to her. She refused to forget one single instant, even the moments of intense pain. Far from being suicidal as she once was, Shanelle has been a resource for other parents she met in the hospital whose children were also dying. On the first Mother's Day after her daughter died she took food baskets to parents who were staying in the hospital with their ill children. She has been trying to raise money for a foundation to help other parents cope with caring for ill and dying children. It should come as no surprise that this foundation is named after her daughter.

I have included this story about Shanelle to illuminate how complex an ethic like 'confidentiality' becomes in the context of real-life circumstances and research relationships. I now face an ongoing dilemma when I give presentations or write articles about Shanelle and her daughter. It is very difficult for Shanelle that I cannot use her name and especially her daughter's real name in a public way. She wants her brave daughter to be known, and she wants her story to inspire other families facing this situation, as well health professionals who treat such children.

When I am going to give a presentation, I sometimes tell Shanelle beforehand. On one such occasion, at a conference organized primarily by the British Medical Association and held at Cambridge University, I finally conceded to use her daughter's first name but omit her surname. I decided to tell a story about the role of her daughter's oncologist – a story I recount below in abbreviated form.

Neika's oncologist and the case nurse had come to know Neika and her mother very well over the year and a half that she was treated. Shanelle had to put her trust in this oncologist for together they made a number of key and difficult decisions – such as not to try a bone marrow transplant that might have saved

her life because Neika was so weak the physician was afraid the operation would kill her. The personal care and affection the physician displayed toward Neika made Shanelle feel secure that she had located a doctor who was looking after Neika's interests, who was genuinely concerned about her daughter. She invited the oncologist and the case nurse to Neika's funeral. Neither of them came. Nor did they send a card or return any of Shanelle's calls. A few weeks later, Shanelle sent the oncologist a card thanking him for all his care of Neika and leaving her address and phone number. He never contacted her.

This was not a bad or uncaring doctor; his actions speak to typical boundary-setting practices in American hospitals. This physician, whom I have known for several years, is kind, extremely well respected by colleagues and works hard for his patients. In failing to contact Shanelle after Neika's death, he was acting in a perfectly ordinary, professional way. Perhaps he was even protecting himself from the inevitable deaths that so often follow a child's cancer.

In the absence of any contact from the oncologist or nurse, parents may wonder, as Shanelle began to do, about the quality of her daughter's health care. Had her doctors and nurses really tried to do everything to save her? Shanelle worried for if she had not located the best professional care for her daughter, then she had failed in her responsibility. Though a parent cannot cure cancer, she can do everything possible to ensure that her ill child gets the best care available. For African American parents, this concern is likely to be interlaced with fear that because of race, they will not be able to find health professionals who are both expert and compassionate – ones who will try just as hard to save a black child as a white one. Especially a poor black child. This is not an abstract fear. In Shanelle's case, for instance, for a full year before the diagnosis of a malignant brain tumor, she brought Neika to emergency rooms on a dozen or more occasions because of her severe vomiting and headaches. Shanelle tried the emergency rooms in every major hospital in the city. Neika was misdiagnosed repeatedly and sent home while her brain tumor grew unchecked. She was finally correctly diagnosed only after Shanelle stormed into one hospital's administrative offices (off limits to patients), daughter in her arms, and refused to leave until someone looked at her child.

I felt this was an important story to tell doctors because it is clear that health professionals rarely realize the tremendous importance of small kindnesses. I am extremely glad I violated the confidentiality requirement by dropping pseudonyms on the occasion of my speech in Cambridge, because at the end of the conference where I told this story, a doctor approached me. He had written a personal note to Shanelle, telling her how much he was touched to hear about her daughter. Since he knew her name and her daughter's, he could address the letter to her. When I returned from the conference, I handed the doctor's letter to Shanelle. She cried when she read it.

Ethnography and its challenges to a universal research ethics

My ongoing relationship with Shanelle, and the complicated ethical situations it has engendered, illuminates the poverty of a research ethics that is

supposed to be standardized, applied regardless of context. In suggesting that a standardized research ethics, as imported into current institutional review processes, does not fit the actual ethical issues that arise in research practice, I am echoing a position voiced by many ethnographic researchers over the years. (I speak especially from anthropology here, my home discipline.) This is not surprising since the dilemmas I have raised are by no means uncommon in ethnographic research. They speak to ethical issues discussed in several decades of literature within ethnographic and qualitative research traditions, ones that revolve around the complexities of the research relationship with informants who also, in some way, become research partners – issues of ownership, authorship, representation and authority in ethnographic work (Wax, 1977; Pels, 1999). ‘Whose story is it anyway?’ asks Estroff (1995) in a provocative essay on the matter. Concerns over authorship, ownership and representation are connected to issues of trust and the complex process of negotiating relationships with those one studies. How much should one share one’s interpretations with informants? How does one handle the complex and often conflicting requests for confidentiality, on the one hand, and authorship and ownership, on the other? What constitutes consent? What becomes coercive? Such troublesome questions have been raised by ethnographers with some regularity for many years (Jorgensen, 1971; Trend, 1978; Adams, 1981; Fleuhr-Lobban, 1993, 1998, 2003; Givens, 1993; Skomal, 1993; Scheper-Hughes, 1995; Gerlach, 2002; Caplan, 2003).

What is comparatively new is the way ethical matters – especially the issue of informed consent – have increasingly become institutionalized and regulated because of the growing reach and visibility of university institutional review boards and their oversight of anthropological research (Murphy and Johannsen, 1990; Marshall, 2003). The history of efforts to impose ethical standards on research – especially gaining informed consent by participants – originated from abuses under the name of research that were made public in the Nuremberg Medical Trial. Since the end of the Second World War, it has been abuses of medically related research, including the assignment of patients to clinical interventions without their knowledge or consent, that has shaped the research ethics process (Kaufman, 1997). Weindling notes: ‘Informed consent has been an axiom of post-World War II clinical research and practice’ (2001: 37).

Medical anthropologists are likely to be much more familiar with IRBs than most other anthropologists because so many do studies in clinical settings or are supported through federal funding (like the NIH) where IRB approval is required, but this is rapidly changing. IRBs are beginning to routinely scrutinize all university-based research, and they are less likely than they once were to exempt ethnographic studies. Reviews themselves have also become much more extensive. This has introduced new issues, including the fact that reviewers are unlikely to be familiar with ethnographic methods. This unfamiliarity and the problems it raises can be

exacerbated for medical anthropologists when reviewed by IRBs largely staffed by clinical researchers whose focus has been predominately upon potential risks of participating in clinical trials (Gordon, 2003; Marshall, 2003).

By and large, anthropologists have not found it easy to justify their designs to multi-disciplinary, non-anthropology review boards and they have often objected to the ethical criteria they are expected to conform to. In one way or another, all these objections point to the problem of presuming that any universal set of ethical standards can govern the concrete exigencies of actual research practice. One commonly raised challenge is that anthropologists work in a wide variety of cultural and political settings, settings that raise a host of issues about how to conduct an informed consent process cross-culturally (Wax, 1977, 1995; Christakis, 1992; Plattner, 2002, 2003; Gordon, 2003; Marshall, 2003). This is not necessarily a subtle issue; it raises, for instance, the question of what it means to ask for written consent from non-literate peoples (Gordon, 2000, 2003). As Christakis puts it: 'An incomplete fit between the ethical expectations of researchers and subjects raises an important question: Is it possible to formulate ethical rules governing the conduct of investigators from one cultural background performing research on subjects from another?' (1992: 1080).

The cultural and societal diversity characterizing anthropological research is not the only factor that makes it so difficult to impose a universal set of ethical standards. There is also the nature of anthropological research practices, in which the researcher does not ordain ahead of time (at least not in any rigid way) what will constitute relevant data, but attempts to remain open to new formulations and possibilities as these unfold in the field. This openness is a fundamental part of an anthropological commitment to trying to discover what is 'at stake' for the people one studies and a recognition that this discovery emerges in the course of carrying out research itself. Furthermore, ethnographic researchers do not have the same power and control over their research subjects that clinical researchers do. When one shifts from biomedical research to fieldwork, Cassell notes,

the perceived power of investigators, their control of the setting and context of research, and the unidirectionality of interaction all diminish . . . investigators will have increasing difficulty predicting just what will occur during interaction, or defining in advance just what they will consider 'legitimate' or studiable behavior as opposed to 'noise'. (1980: 32)

Cassell goes on to make the strong case that for these reasons 'it becomes self-contradictory for investigators to secure "informed" consent before the research is initiated' (1980: 32).

There is a political edge to the objections anthropologists raise. They have also argued that the procedures dictated by IRBs for implementing standardized practices – especially the informed consent process – do not even necessarily reflect an ethical concern to protect informants. The legalistic

tone, especially of informed consent protocols, suggests another concern – institutional self-protection. Gordon notes that ‘respondents commonly view consent forms as a mechanism that primarily serves to legally protect the physician and/or institution as opposed to protecting themselves’, a perception that is exacerbated when ‘investigators are required to include the scripted boilerplate at the beginning and end of research forms’ (2003: 305).

In response to these issues, anthropologists have called for a research ethics that does not impose a rigid set of standards instantiated in an even more rigid and ‘boilerplated’ set of protocols but, rather, speaks to the spirit of ethical research and recognizes that ‘informed consent is a process, not an event’ (Gordon, 2003: 305; see also Plattner, 2003). This attitude is made clear in the Code of Ethics of the American Anthropological Association (approved in 1998). It offers a set of ethical guidelines that suggests the difficulty of creating ethical standards that can be applied universally or without posing ethical dilemmas. As the Preamble states: ‘It is inevitable that misunderstandings, conflicts, and the need to make choices among apparently incompatible values will arise’ (American Anthropological Association, 1998: 1). The introductory section further notes: ‘No code or set of guidelines can anticipate unique circumstances or direct action in specific situations’ (American Anthropological Association, 1998: 2). While the anthropological Code of Ethics clearly recognizes the need for flexibility, perhaps more can be offered to support the kind of ethics needed in anthropological research. It is this line of argument I take up in the final sections of this article.

The need for a vulnerable ethics: a view from the ‘Aristotelian revivalists’

‘Ethical theorists’, Newton argues, ‘have traditionally defined freely-determined action according to a law or rationality from which they can derive criteria for moral behavior at once universalizable and intrinsically intelligible’ (1995: 12). This formulation ‘subsumes particular and contingent facts under a general and totalizing order’ (Newton, 1995: 12). The vision of ethics that has informed the development of university and hospital research ethics committees is based on the presumption that ethical behavior can, to a large extent, be standardized. The basic idea is this: it is possible to create a kind of contract between researcher and research participant guided by universal, context-free ethical norms that – if properly followed – will ensure the researcher’s ethical behavior. In problematizing this picture of ethics, I have turned to one particular ethical norm that poses special problems for qualitative researchers, one that has been an enduring focus of ethics committees – the preservation of confidentiality. Thus far in this article, I have drawn upon examples from my research to consider the problem of standardization in general and

standardization concerning matters of participant confidentiality in particular. I now want to examine the picture of ethical practice and ethical reasoning that undergirds the current practice of research ethics committees. For it is the flawed character of this vision that puts qualitative researchers in impossible situations when they try to enact these principles in the real world of research practice.

There are four problematic premises that I want to highlight: (1) ethical rules are context free, and therefore the actor (i.e. researcher) need only apply the correct rules in each situation where he/she must act. A corollary of this premise is that practical action requires no interpretive judgment; it simply involves the application of universal rules, norms or theories. (2) There is always an ethical 'right answer'. That is, there are no ethical conflicts in which all choices are, in light of some highly valued norm, wrong. (3) There is an objective position from which to judge what one ought ethically to do. Notably, this is a position of emotional detachment from the situation. Personal relationships and the emotions they engender will be likely to lead to ethically questionable behavior. (4) This objectively identified ethical position can be articulated in explicit and unambiguous public language, with complete clarity and lack of ambiguity.

While members of a research ethics committee might not be ready to agree to all of these propositions, stated in the bald way I have just done, it is not difficult to see that the practices we have developed to try to govern our ethical behavior (including the ethics of doing research) have emerged from western ideals of practical and ethical reasoning that contain these deep assumptions. In what follows, I challenge those four presumptions and outline an alternative ethical framework. In doing so, I rely heavily, though not exclusively, upon Martha Nussbaum's (1986, 1990, 2001) brilliant account of Platonic versus Aristotelian versions of practical rationality and how Plato's views, in particular, have shaped the western tradition of thought about ethical matters. The ancient Greek picture of ethics and especially the challenges that Aristotle raised against a Platonic ethics have been revived and developed by a number of contemporary philosophers (Arendt, 1958; Murdoch, 1967; MacIntyre, 1981; Williams, 1981; Nussbaum, 1986, 1990, 2001). Sometimes this school of thought has been referred to as 'virtue ethics'.

Ethical matters are not context free

Aristotle challenged Plato's presumption that ethical action can depend upon the application of universal norms and rules. He argued, against Plato, that practical action is necessarily uncertain in its results. It is vulnerable to external forces, to fate – what the Greeks called 'luck' – that must be reckoned with but can never be completely controlled. While general theories can give us rules of thumb, Aristotle (1985) asserted in *Nicomachean ethics*, they do not give us certain guides to action. Nor can they allow us to predict exactly what the consequences of our actions will be in

any particular circumstance where we act. Practical reasoning, that is, reasoning about how to act, is vulnerable to the exigencies of circumstance. This is because the consequences and even the meaning of any act depend upon the particular contexts in which the action is carried out. The context of action is always, in some respects, unique, particular. Aristotle states that to act well, the agent 'must come to know particulars, since [the practical actor] is concerned with action and action is about particulars' (1985: 1141a30). We can gain wisdom, especially through the accumulation of experience, that can help us to act well in unforeseen circumstances but such wisdom can never completely protect us from the vagaries of chance. Aristotle also contended that 'matters of conduct have nothing fixed or invariable about them . . . agents have to consider what is . . . [suited to the occasion]' (as cited in Toulmin, 2001: 109).

Notably, in traditional Greek thought, 'matters of conduct' do not refer to some special type of action or to a specialized and isolated vantage point on practical action. In the traditional Greek conception of practice (with which Plato disagreed), and certainly for Aristotle, ethics could not be separated from other practical considerations. Action, at least action directed to and involving other humans, is *always* an ethical matter. Ethics were considered to be inextricable from all other matters that the practical actor must consider, including such matters as the availability and efficacy of technical means to achieve the desired ends. But the central question (what made any practical action necessarily an ethical matter) concerned the 'ends' of an act. To deliberate about what to do was necessarily to ask about what constitutes 'the good' in a given situation. The practical agent must deliberate not only about what technical means are best suited to achieve some set of ends, but also deliberate about what kind of 'good' constitutes the 'best good' for this particular situation. Even the ends must be reconsidered, depending upon circumstance.

Goods are particular and can be in conflict

Ends themselves are *particular* and cannot be reduced to a single measure of the good or interchangeable goods. This incommensurability of goods also means that, in Aristotle's scheme, goods can be in conflict. In choosing to pursue one good, we may find ourselves in conflict with another good. We can find ourselves in tragic situations in which every choice to act, honoring one good, violates another one.

Nussbaum (1986) points out that Plato hoped to save humans from vulnerabilities that made practical action so uncertain, so dependent upon circumstances. He argued against the reigning ideas of his time, working to construct a conception of rationality and of the good life that would protect humans from uncertainty. For Plato, the aim of reason is control. Though he argued against many of his contemporaries, it is Plato's conceptions of rationality and ethics – including the possibility of their separation – that have taken hold in the history of western thought.

There is no objective or universal position from which to judge ethical matters

Plato argues that good actions can be guided by truths – laws – that are immutable and stable, not the contingent and shifting reality that Aristotle embraces. These immutable laws are not subject to particular circumstances or to the mind or desires of some particular individual. Instead, truth has an objectivity – it presents itself in clear, unwavering terms – the intellect is ‘pure sunlight’, Plato maintained (Nussbaum, 1986: 20). The important good or ends of action are similarly independent of an individual’s or community’s particular history, commitments or other unique features – they are universal. These context-free ends can be applied in every concrete situation. For Aristotle, by contrast, practical reasoning involves deliberation about which ends to pursue in a particular context.

Not surprisingly, Aristotle is, at least as compared to Plato, a ‘communitarian’ who believes that ends are themselves social. The social world, the world of other actors, plays a completely different role for Plato than for Aristotle. Plato advocates a rationality that is ‘self-sufficient’, not dependent upon the actions of others. The good life is not within a community and with friends but solitary. While Plato seeks ‘rational self-sufficiency’, Aristotle argues that ends are social, even communitarian. Friendship, for Aristotle, is an essential component of ‘the good life’. Aristotle would not commend an ethical vantage point that did not consider the context of friendship, of the social relationship, in determining what course of action one should take.

It is also not surprising that Aristotle and Plato differ on the matter of emotions and the place of the body generally. Plato repudiates desire and other emotions as being unstable, leading the actor away from a reasoned life. Aristotle not only allows for emotions; he also believes morally cultivated emotions are necessary in order to discern proper ends.

The place of narrative in ethical considerations

A centerpiece of this article is a story, or more accurately a series of stories, told about one mother with a seriously ill daughter, and my changing research relationship with her. I chose to tell stories to elucidate the kind of dilemmas that occur in real situations of research practice. Through the stories of Shanelle and me, I have tried to reveal the poverty of general ethical rules. It is not surprising that I couched my challenge in rather detailed narratives.

MacIntyre’s (1981) well-known work, *After virtue*, offers one of the clearest discussions of a narrative ethics. Drawing upon Aristotle in particular, MacIntyre makes the case that ethical questions are, at heart, narrative. Aristotle argued that the essential ethical problem is determining ‘What is the good?’ in particular situations. MacIntyre adds that this determination is fundamentally narrative. For addressing the question of ‘the good’ requires answering the question of ‘what story or stories do I find myself a

part?’ Following from this, ‘the good’ is not judged by subsuming a particular situation under an abstract ethical rule. Rather, it is judged by locating oneself in a history, or set of histories, that not only point toward a past but toward a future – histories that are still unfolding. While this problem of locating oneself in particular stories one is living out can sound like a purely individual affair, such is not the case.

Notably, Aristotle viewed stories (of a particular sort) as an essential source of wisdom about the good life and practical action. He particularly looked to Greek tragedies in which protagonists were presented with agonizing moral dilemmas, in situations where they had remarkably little control over outcomes, where a great deal was at stake, and where choices resulted in tragic consequences – there was no ethical ‘happy ending’. Nussbaum notes that unlike in contemporary thought, in which philosophy and literature are taken to be different enterprises,

For [the Greeks] there were human lives and problems, and various genres in both prose and poetry in which one could reflect about those problems. Indeed, epic and tragic poets were widely assumed to be the central ethical thinkers and teachers of Greece; nobody thought of their work as less serious, less aimed at truth, than the speculative prose treatises of historians and philosophers. (1986: 12; see also 1990, 2001)

Aristotle turned to the Greek tragedies as exemplars of the vulnerable human life. Unlike Plato, he believed that these stories were essential to the cultivation of the wise actor, the one who would be able to judge how best to act and what ends ought to be pursued in the difficult life circumstances humans find themselves. Stories like the Greek tragedies present complex situations in which the protagonists face conflicts over ends, the loss of those they love, the murkiness and confusion of concrete situations where one must act and where the stakes are high. Aristotle argued that such stories provided Greek citizens with a necessary moral education, a vehicle for cultivating moral emotions.

How is it that stories offer such a vehicle? Stories not only concern actions; they also offer us a window into the mental and emotional life of story characters, taking place on a ‘dual landscape’ of outward action and inner mental states (Bruner, 1986, 1990, 1996). They teach us about connections between our emotional life, our actions and the consequences that follow. Nussbaum (2001) argues that emotions are essential to practical reasoning. Emotions figure into practical reasoning in the sense that emotions concern something that is ‘at stake’ for us. They inform us about what deeply matters to us. Like Aristotle and also like most anthropologists, she takes emotions to be culturally shaped, connected to beliefs, and teachable.² Powerful stories present their characters in emotionally charged situations; they do so in a mode that draws the audience in so that they, too, imagine what it might be like if they were facing such situations.

Stories concern human (or human-like) action. They connect beliefs,

motives and intentions to the actions that protagonists carry out, reveal something about the concrete circumstances in which the actions take place and then describe the consequences of the actions. Complex narratives depict enough of the circumstances surrounding actions and their consequences such that we get a picture of the values and ‘ways of life’ that move the protagonists, why they care about the things they do, what risks they take, how they respond to difficulties. The motive–action–consequence chain so essential to narrative structure gives us

the history of a complex pattern of deliberation, showing its roots in a way of life and looking forward to its consequences in that life. As it does all of this, it lays open to view the complexity, the indeterminacy, the sheer difficulty of actual human deliberation. (Nussbaum, 1986: 14)

And in stories, dilemmas are presented not ‘pre-articulated’, for the drama’s characters are shown to be actively ‘searching for the morally salient’ (Nussbaum, 1986: 14).

Stories may help provide a moral education by helping us judge and value the particular. Nussbaum argues that rather than distanced objectivity, an understanding and valuing of the particular is precisely what ethical action requires:

For stories cultivate our ability to see and care for particulars, not as representation of a law, but as what they themselves are: to respond vigorously with senses and emotions before the new; to care deeply about chance happenings in the world, rather than to fortify ourselves against them; to wait for the outcome and be bewildered – to wait and float and be actively passive. (Nussbaum, 1990: 184)

Vulnerable ethics and confidentiality: the case of Shanelle

How does a ‘vulnerable ethics’ speak to the complexities of research confidentiality in the case of Shanelle? I briefly review each of the above points with this case in mind.

Ethics are contextual

The situated nature of an ethical rule (in this case ‘research confidentiality’) is obvious here. Protecting confidentiality, as a general rule of thumb, reasonably presumes that people do not want to have their personal lives exposed in ways that will identify them. In health research, there is also an implicit presumption that the information gathered by researchers could be potentially shameful or in other ways harmful if participants were personally identified. And it was probably the case that this protection was important at the beginning of my relationship with Shanelle. How did she know who I would talk to? What if I told health professionals treating her daughter what she had told me?

But, as she got to know me – and thus, as the context changed through our changing relationship – she became confident that I would not expose

her in harmful ways. And then she wanted another kind of protection – protection against being seen and treated by me as simply another anonymous research subject. She had a story to tell. Even from the beginning, she had opened her life to me in part because she thought her experiences might help others. Thus, the ethical issue shifted from one of protecting her from exposure, to protecting her from the experience of being – yet again, as so often happens in the clinical world – just another invisible ‘subject’.

Neither of us could have known, at the beginning, that our relationship would develop in such a way that she would begin to see me as a potential ally and advocate – someone who could help her to bring her personal experiences into a public forum, reaching audiences she could not speak to directly herself. The unexpected outcome of our shifting relationship and the trust that built between us opened new possibilities. For Shanelle, she saw that participation in the research could give deeper meaning to the suffering of her daughter. If there had to be such pain, at least her life and struggles could become an ‘object lesson’ that others, including clinicians, could learn from.

Goods are particular

The ‘good’ that emerged from our relationship – the possibility that I could help Shanelle use her experiences as a lesson for others – could not be measured in any simple way against the ‘good’ of confidentiality. These are particular goods. They are goods that, as in the case of Shanelle, may conflict, posing tricky ethical dilemmas. There is no general solution for this conflict. Rather, in each situation where I give a presentation and draw upon my research with Shanelle, I must weigh how to navigate between them. This is not merely a matter of weighing my obligation to fulfill IRB requirements as against Shanelle’s commitments to ‘the good’ of having her story told. To make it more complex, since Shanelle’s story involves not only herself and her daughter but also health care professionals and institutions that would prefer anonymity, even without IRB regulations, I would face the ethical dilemma of conflicting goods. It also becomes clear, in this case, that confidentiality is a particular kind of good, a good that cannot be measured in simple quantitative fashion against other goods.

No Archimedean perspective

How can such conflicts be adjudicated? It does not seem very helpful to appeal to a single universal or objective position with which to judge what to do. Rather, judgment more reasonably involves a ‘case by case’ consideration of how much to reveal or how far to protect confidentiality. When, for example, I give talks in the local area where institutions or individual clinical practitioners might be identified, I am much more careful about how much I reveal when I draw upon the case of Shanelle and her daughter.

Narrative and ethics

Discerning 'the good' in my ongoing relationship with Shanelle clearly seems to be something that cannot be determined by subsuming this situation under a general rule. It is a changing matter, one best understood by a kind of historical understanding, by placing myself in a history, or set of histories. These include both my particular history with Shanelle and Shanelle's own history as a mother of a critically ill child who (unlike some other parents in this research study) develops a remarkably strong personal commitment to using her experience to educate other parents and clinicians. It is telling that Shanelle, like Aristotle, believes that her story can help others in their own ethical dilemmas and in finding their way morally. For her, learning to parent a dying child is a matter of hard-won wisdom. From her perspective, it requires a difficult willingness to face the vulnerability of life in a way that still makes hope possible. This may not be the hope that her child will be cured, but it is at least the hope that her daughter's death can give something to others. Shanelle further believes that acquiring such wisdom, however much she has longed for a different fate, gives her something – notably, a story – she is obliged to offer to others.

Conclusion

Ethnographic researchers increasingly face not only struggles to carry out research they find ethical, but also struggles to justify their research design and practices to IRBs. I have focused on the paucity of traditional ethics to provide an adequate framework. In particular, anthropologists often find themselves arguing that standardization is not possible because of the peculiarities of the anthropological research process. While this is true enough, I have tried to go farther by arguing not only that the ethical principles underlying current IRB practices are themselves flawed, but also that an alternative kind of ethical vision – a narrative ethics – that is being developed within philosophy holds promise as a more adequate framework for anthropological research.

I have sketched, though in a very cursory way, a narrative ethics that recognizes the dilemmas and especially the 'radical particularity', as Newton (1995) puts it, that characterizes practical decisions about the good. The particularity of ethical decisions and actions is a narrative particularity, to follow not only MacIntyre (1981) but a number of others in this philosophical vein (Arendt, 1958; Murdoch, 1967; Taylor, 1979; Ricoeur, 1984, 1992; Carr, 1986). What can a narrative ethics offer to a consideration of the informed consent process or to dilemmas about confidentiality? Admittedly, I have not offered a practical picture of an IRB process restructured to correspond to this narrative ethical vision. I am suggesting, however, that the challenges that anthropologists have been raising to IRBs are indicative of more than a struggle for certain exemptions or even a call for a more

flexible review stance. These struggles also indicate the difficulties of any standardized ethics to regulate practice.

My unfolding relationship with Shanelle, one of dozens I have formed in the years I have conducted research, illustrates the necessity of a different sort of ethics. The narrative ethics I have sketched is one that makes a place for the particularities of context. It is also an ethics that recognizes the ability to foresee or control many of the circumstances that will develop. Rather than an application of universal standards or protocols, the ethical question becomes discerning how to act in any given circumstance and this depends upon a narrative reading of those circumstances. What (research) story am I in?

Notes

1. It should be noted that the ethical issues I raise here are consistently more problematic for researchers working within qualitative paradigms than quantitative ones, and may not pose difficulties for some types of research. Research genres that depend upon developing personal relationships with those studied, as most qualitative approaches do, raise questions about the way research ethics have been framed. They particularly raise questions about how far ethical norms and rules can be usefully standardized across research practices and particular contexts of research.
2. However, Nussbaum's cultural acknowledgement does not go far enough for some anthropologists. Shweder, for example, has taken Nussbaum to task because he believes she has an insufficient regard for the relativity of ethics, emerging as they do from particular 'local moral worlds'.

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