

Exporting ethics: a narrative about narrative research in South India

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ABSTRACT The article notes some problems with the prepositional discourse of research ethics that is dominant in the West, and joins the call for an ethics-in-context approach in the human sciences. Using detailed examples from my fieldwork in South India to develop a narrative about ethical conflicts, I explore the problematics of informed consent, confidentiality and other concepts central to research ethics in the USA. The article underscores the inherent and practical risks associated with ethical universalism – applying ‘universal’ moral principles that have been constructed (that is, derived) in one cultural context and exporting them, without modifications, to another. The personal narrative includes my emotions in the field; they do moral work. The article draws theoretically from Bakhtin, Rabinow and feminist scholars of the Indian diaspora.

KEYWORDS *ethics; infertility; informed consent; narrative*

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ACKNOWLEDGEMENTS I thank Mark Freeman, Elliot Mishler, Susan E. Bell and the anonymous reviewers for helpful comments, and Indian informants for their teachings.

How can an investigator determine what is good and just in complex field relationships? Where do the ethnographer’s emotions about ethical conflicts belong in scholarly writing? These questions drive me to story-telling: about dilemmas I faced during fieldwork in South India in 1993–4. Looking back on field notes, interview transcripts and memories, I join a growing movement calling for ethics-in-context, realized in the give and take of research relationships on the ground, rather than in abstract principles. The investigator’s emotions are highly relevant to conversations about ethics because emotions do moral work: they embody judgments about value (Nussbaum, 2001).

During the last decades, we have witnessed major transformations in

human subjects' protections, as others in the Special Issue review. Less often have ethnographers written in the first person about ethical conflicts in fieldwork and writing. First-person accounts occupy a contentious place in social science writing, dismissed as 'confessional tales' or 'navel gazing' by some, or 'empathic fables of rapport'. Others argue that autobiography can be a form of social analysis (Visweswaran, 1994). My essay aligns with the latter position, and takes up Rabinow's (1985) challenge to experimental ethnography – to call ourselves into question in our written representations. Commenting on Clifford, he writes: 'All anthropologists work with informants. Anthropological understanding arises out of the give and take between them. How to bring this dialogic dimension into the anthropological texts is an important problem' (Rabinow, 1985: 5). The dialogic dimensions I open up here concern divergent expectations and assumptions about ethics that distinguished informants and investigator, evident to me now as I review interview transcripts and field notes I constructed 10 years ago. My narrative adds to a growing movement concerned with confronting ethical issues in research relationships and seeking to resolve them in a dialogic manner. As others have before me, I return the gaze in a personal narrative from Other to self and back again, contextualizing moral decision making in the real world of emotionally charged fieldwork relationships: first, when I imported US consent procedures into a village in South India and, second, when as a participant observer in an infertility clinic, I witnessed gross violations of western standards of medical ethics, yet continued to try to observe research ethics. But first, some orientation to the 'complicating action' of my story.¹

Orientation

Links between narrative and ethics are strong and enduring, articulated by others in this Special Issue. Mishler notes the 'narrative turn' in the social sciences and practicing professions – there is virtually no field of inquiry that remains untouched. The 'narrative turn' in ethics is similarly wide: in bioethics, for example, abstract theorizing has given way to examination of stories of patients and practitioners – what the greater good may be in particular situations (Widdershoven and Smits, 1996; Nelson, 1997; Charon and Montello, 2002).

Narrative researchers face a particular set of dilemmas that challenge the thinking of institutional review boards, accustomed to assessing risks and benefits in drug trials and other treatment regimens. Social researchers working in narrative traditions interpret stories. Oral storytelling – extended accounts of experience that develop in particular contexts in interaction with particular audiences – is a relational practice that occurs in an evolving (and often intimate) conversation between teller and listener; the performative context can make demands on participants to 'say more'. Listeners, in turn, can be deeply affected by the narratives they hear, experiencing emotions that are sometimes difficult to bear.

Storytelling pivots on relationships – between teller and listener, researcher and researched, reader and writer. Form and meaning emerge between people in social and historical particularity, in a dialogic environment (Bakhtin, 1981).

Many narrative researchers tape and carefully transcribe interview conversations (and sometimes have to argue with human subject committees about preserving tapes, rather than destroying them). Transcriptions of narrative accounts provide specificity and detail often missing from other kinds of research materials; it can be difficult to disguise identities, and some participants do not want to be disguised (see Mattingly, this issue). Video diaries and other visual data further challenge conventions of confidentiality. Even when we return to informants with sections of text we want to use for presentation or publication – a second level of consent typically beyond requirements of review boards – power relations may constrain possibilities for refusal, especially for vulnerable subjects. Using research materials ethically and responsibly involves ongoing negotiations – a perspective, again, that reaches beyond the narrow, one-shot agreement spelled out in the typical informed consent document.

Social researchers can face these issues at unexpected moments. Sue Estroff (1995) received a telephone call at 3 a.m. from an irate woman, who had just read what Estroff had written about her many years before. The informant felt ‘wounded by the images of herself in the past . . . exploited . . . misunderstood . . . unmasked’. The ethnographer’s gift of the book – the final product of intensive fieldwork among a group of chronic mental patients (Estroff, 1981) – had opened up unspeakable pain for one informant: she recognized herself and was deeply troubled by the representation. Estroff uses the incident to raise a series of compelling questions about ethnographic authority, voice and responsibility in field research. She asks: ‘Was it possible for this person to consent to a process whose product [an ethnography] she could not imagine?’ (Estroff, 1995: 98).

From the beginning, Brinton Lykes (1989, 1991) acknowledged her power in a collaborative research project with Guatemalan women who had witnessed atrocities of war:

I had come to this project with a clear analysis of my power as Other, with my role as a university professor with a Ph.D. and as a white North American. Yet I was also a concerned researcher who was acutely aware of the way in which researchers have taken advantage of subjects, misinterpreted their reality, and given them inadequate access to their own labor. I recognized the many ways in which the participant both makes her/himself vulnerable in sharing his/her story and has no real control over how the researcher reconstructs that story. (Lykes, 1989: 177)

Despite acute awareness of inequalities of power in her narrative project, Lykes did not anticipate women’s resistance to the informed consent form she had so carefully construct to ‘protect them’: it became

a barrier and forced me to confront the chasm between the needs and demands of research conducted within the bounds of the university and the systems of trust and mistrust and of sharing and withholding that were already a part of this collaboration. (Lykes, 1989: 178)

Although Estroff and Lykes write from different political standpoints, both suggest that ethical dilemmas can have powerful emotional resonance. Troubling emotions in the life world stimulated ethical self-scrutiny for each investigator, eventually joining with cognitive understandings in writing. Others, of course, have written about authority, power and representations of 'the other' (Clifford and Marcus, 1986; Behar and Gordon, 1995; Clifford, 1997), although few with the emotional power that Estroff and Lykes evoke. Social science is no stranger to the intellectual debate, even if representation of the researcher's embodied emotions as a force in the field remains relatively rare.² Emotions are taboo, not recorded often, for they may be suspect, impediments to knowledge, rather than another source of knowledge (Kleinman and Copp, 1993). Approaching research relationships dialogically requires ethnographers to constitute and interrogate 'ourselves as the kind of subjects who are in dialogue with other equal subjects' (Rabinow, 1985: 5). All parties in the dialogue have subjectivities and emotional lives that they bring to research relationships.

Review boards and professional associations have attended primarily to one side of the dialogue in developing guidelines for human subjects' protection. Protecting investigators from harm is rarely part of the conversation (but see Whittaker, this issue). Beyond physical danger, fieldwork can unsettle, even traumatize an investigator when she witnesses gross inequalities, or when informants communicate details of atrocities. Oral historians can have strong reactions to narrators' testimonies (Yow, 1997). Some medical educators are facilitating emotional development of students through narrative study (Charon, 2000); other health professionals describe severe physical and emotional responses, paralleling those of research participants, when interviewing about difficult topics, such as battering (Dunn, 1991; Hyden, 1994). Brinton Lykes hired a 'supervisor' to assist her during fieldwork in post-war Guatemala, as the stories she heard from women were impossible to bear alone (Lykes, personal communication). Funding agencies, of course, are concerned with protecting informants. In Diane Scully's study of convicted rapists, she writes that the funding agency was concerned about a possible court order, which might force disclosure of information revealed in interviews with prisoners. The agency did not help her anticipate the threatening letters she was to receive from inmates, which 'were frightening' (Scully, 1990: 23). These brief examples of intruding emotions and conflicts draw attention to muted voices that belong in writing about ethics.

I now turn to the 'complicating action' of my narrative of fieldwork, constructed as all narratives are from a point of view, in a context and to

an audience. Composed of several episodes, each has setting, characters (real and imagined) and plot. The first turns on the meanings of informed consent where my identity and the purpose of the study were not understood by a family. The second extends issues of confidentiality and privacy from the first episode to a clinic setting, where my taken-for-granted western assumptions about medical ethics made it difficult to practice research ethics.

Episode 1: informed consent and ruptured understandings

I begin in a small village in Kerala,³ South India, where I was conducting fieldwork in 1993–4 on the meaning and management of infertility – an invisible problem in the Indian context. My research proposal, written in a distant voice for an audience of reviewers of Fulbright applications, included procedures for obtaining informed consent from childless women. Modeled on the procedures of my university, I included a consent form to be signed and witnessed, consistent with procedures in sociological research in the USA at the time. I did not question the practices then. But, as Lykes (1989) states, the very language of western research practice – ‘obtaining’ informed consent – indicates who will be in control.

The first hint of trouble happened shortly after I joined my host institution, the research unit of a small college in Kerala. I had selected a research assistant, Liza⁴ – a 26-year-old Malayali graduate-level social worker, educated in Kerala. She was personally interested in the study – unmarried at that point, anticipating an arranged marriage in several years and expecting to have children. She pitied married women who were childless, and was sympathetic with my theoretical focus on stigmatized identities. She was surprised, however, by my consent form: ‘we don’t do that here’, she told me gently. She was trying (I now see) to communicate local knowledge gained from working on many surveys for the Indian government. I persisted, and asked her to translate into Malayalam the form I had prepared according to my university’s guidelines. Displaying deference to authority I was to experience over and over again, Liza dutifully complied, translating the form. She expressed curiosity about research ethics in the USA – she wanted to learn.

I began to learn when we started interviewing women in towns and villages, and others who were patients in an infertility clinic. Liza explained to potential informants that we were talking to childless women to learn about their lives; whatever they told us would remain confidential; with their permission we would use a tape recorder so that we could listen attentively; tapes would be identified only by number; names and other identifying information would remain anonymous in publications; they could stop the interview at any time – the usual assurances that US institutional review boards require. Because women in Kerala are educated and literate, many informants read along as we communicated the contents of the consent

form. Most women signed it.⁵ A significant number, however, were reluctant to affix their names. They were suspicious, not about interviewing or taping, but about the form. Perhaps they thought it a government document. Liza communicated the women's concerns to me (translating⁶), and gently suggested we proceed. Over the many months we worked together, I sense Liza minimized the importance of informed consent, even deleting specific provisions. She decided what was relevant in the particular interview context, disrupting western practices.

Reflecting now on the refusal of some women, I hear their worry. The consent form *was* a government document – an import from the West, designed to meet my university's institutional review board requirements that are, in turn, dictated by the National Institutes of Health, a US government agency. Signing documents in the Indian context carries a history of well-deserved suspicion: government intrusion into property rights, inheritance, marriage customs and reproductive health. Strangers seeking information and bearing forms are not easily trusted, especially in rural villages. A European colleague studying HIV in South Africa had a similar experience to mine: many of her informants disrupted the informed consent process by using 'glamorous' names ('Pamela') or joking that they would write 'Nelson Mandela' on the form (Squire, personal communication). The act of signing a form carries meanings in post-colonial settings that are different than the protective intent embedded in western discourse. Informed consent functions, in the real world, to release the sponsoring university and funding agency from liability, and to establish firm control over the information gathered – ownership passes from participant to researcher (Lykes, 1989). Signing occasions can provide opportunities for participants to disrupt power and introduce perspectives relevant to their situations, challenging the pre-defined purpose of an investigation.

I faced another ethical problem during fieldwork that threw into question a related western assumption – privacy, a necessary condition for confidentiality. My idea of privacy, at least in village contexts, was clearly a foreign import, not simply because of limited space in dwellings. A case in point was our relationship with Celine⁷ – a 26-year-old Christian woman, married 6 years to a Hindu fisherman, who suffered greatly because she did not have a child. At the time we visited her, she and her husband were residing with her natal kin. After enjoying the cool drinks her family provided, Liza and I discovered we could not talk to Celine without interruption. Family members – her parents, sisters, husband (Rajiv) – expanded upon Celine's brief answers. Nieces and neighbors clustered about the door, watching and listening. Other western ethnographers have faced similar problems (Good and Good, 1994; Inhorn and van Balen, 2002). Our expectation of a confidential interview was simply not understood.

I should have grasped the message: infertility is inauspicious, consequently an issue for family and community. Multiple perspectives on the study issue should have been built into the research design. Instead, Liza

asked if there was a private room where we could be alone with Celine. Her mother gladly led us into a small bedroom hung with laundry; the three of us sat on a hard platform – the marital bed. Privacy turned out to be important: Celine’s account of discrimination and beatings in the context of the joint family, when she did not conceive after six months of marriage, could be told in the quiet space, overriding a cultural prohibition against talk with strangers about family problems (Riessman, 2000a). As our interview was ending, Celine said she felt ‘relieved’ to have talked about the violence she had endured.

Beneficial as privacy was, it also perpetuated a misunderstanding. Despite repeated statements that I was a sociologist interviewing many childless women, the family continued to see me, I now believe, as a gynecologist.⁸ During a tea break, a family member asked whether I had diagnosed Celine’s problem yet. As the interview was ending, Celine asked: ‘Will you be taking this to the hospital?’ – referring to the information she had provided. Completely misunderstanding, I assured her ‘the hospital won’t know about this [what she said in the interview, it would remain confidential] . . . We are interviewing many women to find out how it is for women when they do not have children.’

Our conversation was saturated with conflicting expectations and assumptions. I had constructed participants as sources of social knowledge; Celine and her family had constructed me as someone who would provide medical knowledge. They had entered into the relationship thinking I had something to offer, while I entered the relationship seeking knowledge from women about an ‘invisible’ problem in reproductive health in India, obsessed with fertility control. Looking back now, I think they could not fathom what I was doing and why I was doing it. My goal was a social critique, inspired by C.W. Mills (1959): how a ‘personal’ trouble (such as infertility) could expose public issues, such as compulsory motherhood in India and social exclusion when the dominant cultural narrative fails. Because I viewed infertility as a social problem, I tried to ‘demedicalize’ childlessness in interviewing. Celine and her family assumed the problem was medical: they had located the ‘fault’ in the body of the woman, and expected it could be corrected. For them, assurances of confidentiality were irrelevant; for me they were central to protecting her stigmatized identity in any written report. This was a clear case of ruptured understandings and conflicting expectations. Importantly, however, in their ‘misunderstanding’, the family was actively shaping how they wanted the issues represented.

Informed consent assumes that research participants understand the general purpose of a research project before they agree to be part of it. In the case of Celine and her family, such an understanding was never reached. Yet Celine had signed the consent form. (What did it mean to her, I now wonder?) Technical requirements of the institutional review board had been satisfied. I suspect that similar ironies are widespread in various

settings, illustrating how signed informed consent forms are not always what they seem. They certainly are not sufficient. Critically interrogating their conditions of production offers one way for investigators to contextualize in writing the process of negotiating consent.

As the incident also reveals, investigators can be given identities in research relationships that differ from the identities they hold. Estroff's (1995) presence in the life of a mental patient had a different meaning than she experienced or intended. Issues of informed consent, responsibility and authority are compounded when the ethnographer works in the developing world. In these contexts, how does an investigator responsibly represent herself and how is she, in turn, represented by research participants? Marsha Henry (2003), drawing on her experience as a diasporic – a woman of South Asian descent, who grew up in Canada, moved to London and later returned to India to do fieldwork – writes about her experience in each setting, where she was represented differently. Drawing on Caplan (1993), she urges investigators to ask, 'Who are we for them? Who are they for us?' Asking such questions forces us to interrogate ourselves in research relationships in ways that go beyond abstract guidelines.

Looking now through the prism of ethical reflection, I am troubled by the failures in communication, even as I now hear voices insisting on representation. Like Lykes (1989) and Estroff (1995), I came upon ethical problems unexpectedly, through engagement in field relations where intentions were misunderstood and imported procedures for 'protection' were insufficient. Unsettling emotions drove the process of discovery – discomfort when trust did not negate status and power inequality – which eventually coalesced into cognitive understandings. Skultans argues that ethics means 'recognizing and responding to the otherness of the other' (2003: 159). Though useful, how does the formulation take into account power differences between investigator and participant?

What does it mean for an investigator to present narratives of the marginalized collected under conditions of inequality and ethical uncertainty? Does the potential good that might come out of a project, in spite of ruptured understandings, compensate for the absence of 'truly' informed consent? I did not remove Celine from the sample (as some might think appropriate), which would have denied readers access to a compelling narrative of resistance to family violence (Riessman, 2000a), and discussion of ethical issues here. In pursuing one good, I was in conflict with another.

Episode 2: the infertility clinic

Dr Gulati,⁹ the Director of OB-GYN of a government teaching hospital, was enthusiastic about the research when we met in her office. For uneducated and poor Hindus, she said, 'a family without a child is not considered a family . . . family means children'. They constitute the glue that keeps arranged marriages together. The importance of children has intensified,

she believed, with the trend toward nuclear families. Barren women are highly stigmatized, not accorded full personhood:

Our doctors have no time to listen to the suffering of women who come to the infertility clinic. We don't have a social worker to provide counseling about adoption, family conflicts, other things . . . It will be great to have you here.

Thus I was introduced to the medical staff, together with Liza: we were seen as women who, unlike busy doctors, would spend time talking with patients. The challenge, I quickly realized, would be to maintain an observing eye, at the same time as we listened to women's desperate stories about the fertility expected of them immediately after marriage. Thinking now about our entry into the clinic context, there are commonalities to the village setting described earlier: we were expected to provide a service in exchange for information. Unlike the village, however, reciprocity was possible in the clinic.

Dr Gulati found us a private room for interviewing (it was one of the rooms used for 'paying patients', she said), directly upstairs from the infertility clinic. She instructed the medical staff to send us a diverse group of patients, representative of the range of situations seen in the clinic. The room, I soon realized, was on the obstetric service – a bed and bassinet had been pushed to the side. From down the hall came cries of hungry newborns. And so my moral conflicts began – deep gratitude for the generous welcome and private room, and deep worry about possible meanings of the space for women suffering with infertility. Fearing the space might cause distress, I thought of my obligation to do no harm to research participants. Emotions overwhelmed me; all I could do was write: 'I feel badly for the women about the [interview] context – a place for birthing, not for childlessness.' Looking back, I wish I had asked to have the bassinet removed.

The infertility clinic served a diverse population; this government hospital was the tertiary care facility for a region of Kerala. Very affluent families could travel to Delhi, Bombay or the USA for lengthy private treatment (the new reproductive technologies – IVF, embryo transfer, GIFT – had just entered the Indian marketplace when I began fieldwork in 1993).¹⁰ The reproductive industry had not yet penetrated Kerala; 'It will come in the near future,' Dr. Gulati said with resignation.

The clinic accepted patients on Tuesdays and Thursdays. The waiting room was always mobbed. It was not uncommon to see the small room filled with 40 women, about half as many men (husbands are required to come for the first visit to be screened for the 'male factor'). Many women were accompanied by family members, often mothers-in-law. Returning patients held containers (specimens from post-coital tests, I learned) and pink spiral notebooks the clinic provided, in which doctors wrote test results and other information – the medical record. I was struck by the young age of the women, most in their early 20s.¹¹

Adjoining the small waiting room was a large room – the medical area.

Along one wall a line of women stood waiting to be examined behind a wooden screen (four cots, no curtains between cots). Along the opposite wall stood a line of men, paper cups in hand, waiting to use the single toilet to produce specimens. A long table, covered in a white tablecloth, divided the two spaces. Dr Gulati told me she brought the tablecloth from home to make the place 'less dreary'. Along one side of the white table, male physicians sat in a row, asking questions and recording answers in the pink spiral notebooks. Along the other sat a row of women patients answering questions, and looking pleadingly at the doctors as they placed their specimens on the tablecloth. A small makeshift lab occupied a corner of the room, and included a microscope, hot air oven, a vat for sterilizing instruments, incubator, a hot plate and pressure cooker and a sperm-washing machine.

Thinking that evening about the gendered spatial organization – bodies everywhere, segregated by function, the currency of body fluids – I wrote angrily, 'There is no privacy.' As in the village context described earlier, I had imported western assumptions about the 'private' nature of information about reproduction. But I had learned elsewhere that reproduction is a public affair in India, subject to questioning by strangers and surveillance by families (Riessman, 2000b). But there was an additional issue here: I had imported assumptions about the privileged nature of conversations between women and their doctors – a standard of care for medical practice in the USA. Here, each woman could hear about the sexual activity of the woman sitting next to her at the table who was conversing with another doctor. Perhaps women did not listen to each other, or even care about privacy, given their desperation. But I cared, and felt acutely uncomfortable being an observer in the space.

I was not the only observer. Groups of men and women stood behind the table with prying eyes and ears, listened intently to the conversations between doctors and women patients. Who were these intruders? Writing that evening, I struggled with what I learned:

I asked the attending physician [he had completed a fellowship in gynecology in the USA] if the people standing around and watching the interviews were medical students. He laughed at me, and then said no – 'family and anyone else who wants to come'. They can't keep people out of the interviewing area, despite gates, signs and other efforts . . . So a couple's infertility is 'public' in more than one sense: not only does everyone in the village know, and ask about it . . . but details of a couple's sex life that may be revealed to the examining physician are public too. People just stand around and listen, and there's nothing doctors can do to maintain control. They laugh about it.

It was emotionally wrenching to witness what were for me gross violations of ethics of clinical care. I felt as if I should leave the setting – doing research felt like complicity. How could I do ethical research in an unethical setting? Was there any moral ground to stand on? Were my western values and

feminist health politics simply irrelevant here? I told myself that I was naïve about medical practice in the developing world. Women patients did not comment on the lack of privacy (but, in all honesty, I did not ask).

The medical literature speaks to my conflicts although it does not resolve them. National commissions and the World Health Organization have evolved standards for ethical clinical research in the developing world that include respect for patients as a guiding principle (Varmas and Satcher, 1997). In my view, 'respect' includes privacy for women in gynecology settings, but is that a universal understanding? Is the right to privacy a western matter or a human matter? The reality in medicine is ethical relativism (some might call it ethical opportunism). As Marcia Angell reluctantly notes in a debate about clinical trials, 'the fact remains that many studies are done in the Third World that simply could not be done in the countries sponsoring the work' (1997: 848). Extending her point, it is highly unlikely that I, as a social researcher, could have conducted interviews and observed patients with the freedom I had in South India in an infertility clinic in the USA. I benefited from the absence of formal procedures for access to human subjects in the infertility clinic (Dr Gulati alone allowed me entry), even as I railed against physicians who failed to respect patient privacy. The ethical ground under my feet cracked as I struggled with ambiguity.

Knowledge of institutional forces helped me interpret clinic practices. I had witnessed doctors in village polyclinics providing humane care to women with reproductive tract infections. The lack of such standards in the infertility clinic was a direct outcome of government policy. The clinic was under-resourced, overwhelmed with patients, staffed by doctors who wanted to honor ethical principles, but could not. When allocating health resources in Kerala, the Government does not give priority to infertility treatment (or any tertiary service, for that matter); money goes for primary care at the local level. I saw the benefits of that policy when a rural village with a polyclinic was 'the field'. Now, positioned in the infertility clinic, I saw the issues differently.

As happens to ethnographers over time, I became accustomed to the cultural world of the clinic; the strange became familiar. With changes in my emotional positioning, I could see small instances of caring, practiced under impossible conditions. I continued to set limits on what I would ethically tolerate: I always refused, for example, when doctors invited me to observe pelvic exams – done behind the wooden screen – women laying in cots along side each other, each exam visible to others. Women were never asked permission for me to observe. At one point I was pulled back into almost unbearable conflict. This time, the ethical problem was unequivocal. I did not need to ruminate about cultural relativity, alternative meanings or my own naïveté.

Liza and I were interviewing a teacher in our private room upstairs – such a luxury in the clinic – when there was a loud knock at the door. One

of the gynecologists, an urgent look on his face, introduced a 'post-vasectomy case'. A woman was sobbing loudly, her husband, dressed in a simple lungi, comforting her. The doctor seemed relieved to turn over the couple to us. As they waited outside, we quickly completed the interrupted interview (resuming talk about adoption), the woman's sobbing audible to all.

They were scheduled caste Hindus who had come to the clinic for the first time that day after 10 years of marriage. He had been screened for the 'male factor', she had been examined, and results were communicated – no sperm. A physical examination of the husband revealed vasectomy scars. She wept as she related the history that had been pieced together minutes before: years before their marriage, her husband and other men in his village had been called to a meeting, asked to sign a form and underwent a minor operation, for which they received transistor radios. Her husband may not have understood at age 14 what a vasectomy was. Ten years later, the couple married – it was a love marriage. Together they had purchased land, built a house and waited for children. Only when they came to the clinic that day had they discovered why their efforts had failed.

The case was fraught with history: the Emergency period, which ultimately brought down Indira Gandhi's administration in 1977, included coercive sterilization targeted at the lower castes. Medical personnel were expected to meet sterilization quotas. It was a shameful period, rarely included in the history of medical ethics. Salman Rushdie (1994: 26) developed a poignant short story about the time, 'The Free Radio'. He ridicules the gift: 'It is how the government says thank you.' Hearing history through fiction lent me compassion for the grieving wife, and her husband who – at the age of 14 – had been coerced into robbing himself. But knowledge did not help with emotions directed at the thieves: the Indian government and the medical personnel who carried out its policies. I could barely control my rage during the interview. That evening, in emotional outpouring that field notes could not contain, I wrote about reaching for 'her rage . . . it wasn't there . . . too soon . . . [I feel] undone by this day.'

I asked Dr Gulati a few days later about the 'post-vasectomy case', which she had heard about from her staff. She shook her head in sadness. The gesture may also have carried shame – her profession had implemented Indira Gandhi's policy of mass sterilization. The couple would be offered surgery to try to reconnect the vessels, she said, but the prognosis was doubtful, given how many years had passed. They would be offered donor artificial insemination if surgery failed. Together we reflected on crimes against bodies, enacted in the 'national interest'.

When time came to end fieldwork in the clinic, I felt bad about leaving. (I wonder what Liza's emotions were.) Doctors had come to rely on us. We had provided a needed service, listening to childless women's narratives of social exclusion. We had talked with women about adoption, while also doing research. Our multiple positions – both social workers, young woman

and older woman, Malayali and American, not-yet mother and mother of three – forged paths for dialogic understanding, across difference. Though set apart in some ways, we were aligned in others: I, for one, had come to a kind of imaginative identification with various actors in the setting. Informants had become people. Listening to stories, I had come to care. Who would listen to women's stories of suffering and discrimination now? I wanted to leave something – make a gift. The money would be used for medical supplies, Dr Gulati said, and to repair the sperm-washing machine that had been out of service for months.

Questions remain to this day: privacy and confidentiality – do such abstract principles of medical ethics have a place in a clinic burdened with too many patients and too few resources, situated in a sub-continent plagued by overpopulation? Is it appropriate to speak about research ethics in such resource-deprived contexts? Thinking about the range of problematic clinical situations I observed or heard about, I have no ambivalence about coercive sterilization. Robbing individuals of the human capacity to bear children, if they want to, cannot be justified on the basis of the 'national interest', because there are other means to achieve population control. Amartya Sen (1999) convincingly shows how non-coercive policies, such as educating girls, can bring down birth rates (and have, over time, in Kerala). But what about other veiled forms of coercion, and general surveillance of women's reproduction, witnessed in both clinic and village contexts? Rituals of gynecology care in the USA (draping, curtained cubicles for internal exams and other medical rituals) typically shield women's bodies from the gaze of strangers – practiced more routinely with middle-class compared with poor women, to be sure. I was horrified to see the rituals I was used to violated. I suspect many affluent 'westernized' Indian women would be similarly horrified, but the issue cannot be reduced only to class privilege. As a feminist, I know there is cultural variation across the world in the unequal treatment of women; forms of surveillance of their bodies – however subtle, sometimes – can be found in all countries, including western ones. Why was the absence of privacy and confidentiality in a gynecological service so deeply troubling? I think I assumed in a medical context that bodily privacy is an ethical given – the 'right' of any patient. Consequently, it felt wrong to participate in a setting where it was not treated that way. My decision to remain in the infertility clinic, and to write about what I saw, should not obscure the profoundly ambivalent nature of ethical decision making in this instance.

Returning home to the USA brought additional perspectives to my observations. As infertility patients in specialty clinics in Kerala endure inhumane care, and have little access to new technologies, in Massachusetts infertility treatment is guaranteed; expensive reproductive technologies are covered by public funds and private health insurance. Yet many in Massachusetts do not receive primary care. How can one reconcile such inequalities of access (paradoxically reversed in this case)? Surely this is an example

of the 'unjust world problem' (Mishler, 2004), a topic that rarely enters into conversations about research ethics.

Coda

In two linked episodes about fieldwork in South India, I have added to a growing corpus of 'stories that researchers provide of their own situated ethical problems and decision makings' (Plummer, 2001: 229). Linking experience and reflection, I begin to question taken-for-granted, socially constructed categories – informed consent, patient autonomy and respect, privacy and confidentiality – the techno-speak of institutional review boards. Rather than writing in the propositional voice of mainstream scholarship, I chose narrative – another way of knowing (Bruner, 1986) – that allows for many voices and subjectivities. A narrative representation required that I place myself in dialogic situations and include my emotions, typically stripped from the social scientist's account. Making the backstage visible challenges the rules of much scholarly writing, including the 'monologism' that characterizes some narrative accounts. Erasing the presence of the investigator, they yield a false objectivity. Allowed my emotions into 'the field', one voice among others in a polyphonic textual experiment, no one had the final word (Bakhtin, 1981). Navel gazing and self-indulgent? I hope not.

How did emotions aid ethical reflection? Though 'messy' and 'disorderly' they played an important role in my thought about 'the good and the just' (Nussbaum, 2001: 2). Troubling emotions intruded when I sensed my failure to negotiate meaningful informed consent (Episode 1) – village informants did not understand what I was there for – and when I witnessed women receiving gynecological care in a clinic where medical ethics were not observed, and heard about past atrocities (Episode 2). Emotions came into play when there was trouble in relationships (e.g. ruptured understandings) or when I saw the weight of an unjust world (e.g. the post-vasectomy case). Emotions served as warnings, red flags about what deeply mattered: the possibility for women to live with others in social conditions that are just, albeit with varying cultural practices.¹² As Hawkins articulates,

the moral life cannot be conceived apart from one's relationships with others – a claim that contrasts to modern notions of the self as an isolated unit and that challenges the notion of the moral life as guided by abstract ideas, rules, and principles. (2002: 73)

Abstract rules did not help me when I got into ethical trouble. Interrogating my situated emotions during fieldwork and afterwards did get me through, albeit without a clear map.

Some readers may be disappointed that I do not offer specific ideas – a program of policy change for institutional review boards. My purpose has been to make problematic western normative discourse about research

ethics with vulnerable populations in clinical and community settings, not to offer a program of change. I have underscored, by using a narrative voice and several detailed examples, the inherent and practical risks associated with ethical universalism – the problematics of applying ‘universal’ moral principles that have been constructed (that is, derived) in one cultural context and exporting them, without modifications, to another.¹³ Committees have been guiding investigators with universal propositional ethics; many of us in the field need alternatives – an ethics-in-context, grounded in the exigencies of settings. This is not the same as ethical opportunism, but a situated ethics needs to provide room for particularities that unfold during fieldwork. I leave it to others, including the contributors and readers of this special issue of *health*, to formulate specific proposals for change that can be taken to the institutional review boards and human subjects committees.

Like all interpretations, my narrative about fieldwork is situated in time and place, crafted from field notes, letters, interview transcripts, memories and recent reflections. As narrators do, I have re-imagined the past from a position in the present. At one level, the essay can be read as an effort to make sense of a difficult time (we are all meaning-making creatures), when taken-for-granted categories of value to me began to unravel. At another level, the essay speaks to moral issues faced by all ethnographers and narrative researchers who value a dialogic approach and self-reflexivity. Rabinow lays out the issues:

What kind of subjects do we want to be? What kind of relations do we want to have with other subjects? How much can they be forged? How? How does writing connect with these projects? What are the relations of ethics and politics at different conjunctures? (1985: 12)

More questions, no easy answers, in the inevitable dialogic construction of knowledge.

Notes

1. Readers familiar with narrative should hear the voice of Labov (1982), although I do not use his model of analysis here.
2. For classic exceptions in anthropology, see Briggs (1970), Rabinow (1977), Myerhoff (1978), Myerhoff et al. (1992).
3. I have elected to identify the state as the site of my research because its unique characteristics are highly relevant to understanding participants and context. Located along the southwestern coast of India, Kerala is an exceptional state on a variety of indicators: a 75 percent literacy rate (vs 39 for India generally) for women, a life expectancy at birth of 73 (vs 57) for women and a sex ratio of 1036 females (vs 929) per 1000 males. The effective female literacy rate in Kerala approaches 86 percent (Gulati et al., 1996). On the political economy, ecology and unique history of Kerala, see Nag (1988), Jeffrey (1993), Sen (1999).
4. Liza agreed to be identified by her first name in publications.

5. The signing of informed consent forms is by no means universal in social research, especially in Europe. It is the gold standard in the USA in sociology and many other fields.
6. Malayalam is a member of the Dravidian family of languages spoken in South India. My representation of the translated interviews has benefited from conversations with Liza while in India, and with India specialists since my return to the USA. For more on issues of translation and meaning see Temple (1997), Temple and Young (2004), Riessman (2000a).
7. A pseudonym.
8. The misunderstanding may, in part, have been due to the name I was given: Liza introduced me as 'Dr Catherine'.
9. A pseudonym.
10. For an account of the politics of introduction of new reproductive technologies in India, see Bharadwaj (2002).
11. The involuntarily childless women over 40 whom I interviewed (few in number) had organized their lives around principles other than motherhood, defying the cultural mandate. See Riessman (2002).
12. Feminists have written about these and other complexities of research ethics for some time. See Thorne (1980) and Gluck and Patai (1991).
13. I thank an anonymous reviewer for this language.

References

- Angell, M. (1997). The ethics of clinical research in the Third World. *New England Journal of Medicine*, 337, 847–9.
- Bakhtin, M.M. (1981). *The dialogic imagination: Four essays*. Austin, TX: University of Texas Press.
- Behar, R. and Gordon, D.A. (1995). *Women writing culture*. Berkeley, CA: University of California Press.
- Bharadwaj, A. (2002). Conception politics: Medical egos, media spotlights and the contest over test-tube firsts in India. In M. Inhorn and F. van Balen (Eds.), *Infertility around the globe: New thinking on childlessness, gender and reproductive technologies*, pp. 315–34. Berkeley, CA: University of California Press.
- Briggs, J. (1970). *Never in anger*. Cambridge: Harvard University Press.
- Bruner, J.S. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Caplan, P. (1993). Learning from gender: Fieldwork in a Tanzanian coastal village, 1965–1985. In D. Bell, P. Caplan and W.J. Karim (Eds.), *Gendered fields: Women, men and ethnography*, pp. 168–81. London: Routledge.
- Charon, R. (2000). Medicine, the novel, and the passage of time [personal time]. *Annals of Internal Medicine*, 132, 63–8.
- Charon, R. and Montello, M., Eds. (2002). *Stories matter: The role of narrative in medical ethics*. New York: Routledge.
- Clifford, J. (1997). *Routes: Travel and translation in the late twentieth century*. Cambridge: Harvard University Press.
- Clifford, J. and Marcus, G.E. (1986). *Writing culture*. Berkeley, CA: University of California Press.
- Dunn, L. (1991). Research alert! Qualitative research may be hazardous to your health! *Qualitative Health Research*, 1, 388–92.

- Estroff, S.E. (1981). *Making it crazy: An ethnography of psychiatric clients in an American community*. Berkeley, CA: University of California Press.
- Estroff, S.E. (1995). Whose story is it anyway? In K.S. Toombs, D. Bernard and R.A. Carson (Eds.), *Chronic illness: From experience to policy*, pp. 77–102. Bloomington, IN: Indiana University Press.
- Gluck, W.B. and Patai, D., Eds. (1991). *Women's words: The feminist practice of oral history*. New York: Routledge.
- Good, B.J. and DelVecchio Good, M.J. (1994). In the subjunctive mode: Epilepsy narratives in Turkey. *Social Science and Medicine*, 38, 835–42.
- Gulati, L., Ramalingam and Gulati, I.S. (1996). *Gender profile: Kerala*.
- Hawkins, A.H. (2002). The idea of character. In R. Charon and M. Montello (Eds.), *Stories matter: The role of narrative in medical ethics*, pp. 69–76. New York: Routledge.
- Henry, M.S. (2003). 'Where are you really from?': Representation, identity and power in the fieldwork experiences of a South Asian diasporic. *Qualitative Research*, 3, 229–42.
- Hydén, M. (1994). *Women battering as marital act: The construction of a violent marriage*. Oslo: Scandinavian University Press.
- Inhorn, M.C. and van Balen, F. (2002). *Infertility around the globe: New thinking on childlessness, gender, and reproductive technologies*. Berkeley, CA: University of California Press.
- Jeffrey, R. (1993). *Politics, women and well being: How Kerala became 'a model'*. New Delhi, India: Oxford University Press.
- Kleinman, S. and Copp, M.A. (1993). *Emotions and fieldwork*. Thousand Oaks, CA: Sage Publications.
- Labov, W. (1982). Speech actions and reactions in personal narrative. In D. Tannen (Ed.), *Analyzing discourse: Text and talk*, pp. 219–47. Washington, DC: Georgetown University Press.
- Lykes, M.B. (1989). Dialogue with Guatemalan Indian women: Critical perspectives on constructing collaborative research. In R. Unger (Ed.), *Representations: Social constructions of gender*, pp. 167–85. Amityville, NY: Baywood.
- Lykes, M.B. (1991). Creative arts and photography in participatory action research in Guatemala. In P. Reason and H. Bradbury (Eds.), *Handbook of action research*, pp. 363–71. Thousand Oaks, CA: Sage Publications.
- Mills, C.W. (1959). *The sociological imagination*. New York: Oxford University Press.
- Mishler, E.G. (2004). The unjust world problem: Towards an ethics of advocacy for health care providers and researchers. *Communication, Medicine, and Ethics*, 1, 97–104.
- Myerhoff, B. (1978). *Number our days*. New York: Simon & Schuster.
- Myerhoff, B., Metzger, D., Ruby, J. and Tufte, V., Eds. (1992). *Remembered lives*. Ann Arbor, MI: University of Michigan Press.
- Nag, M. (1988). The Kerala formula. *World Health Forum*, 9/2(2), 258–62.
- Nelson, H.L. (1997). *Stories and their limits: Narrative approaches to bioethics*. New York: Routledge.
- Nussbaum, M.C. (2001). *Upheavals of thought: The intelligence of emotions*. Cambridge, UK: Cambridge University Press.
- Plummer, K. (2001). *Documents of life 2: An invitation to critical humanism*. London: Sage Publications.

- Rabinow, P. (1977). *Reflections on fieldwork in Morocco*. Berkeley, CA & London: University of California Press.
- Rabinow, P. (1985). Discourse and power: On the limits of ethnographic texts. *Dialectical Anthropology*, 10, 1–13.
- Riessman, C.K. (2000a). 'Even if we don't have children [we] can live': Stigma and infertility in South India. In C.C. Mattingly and L.C. Garro (Eds.), *Narrative and cultural construction of illness and healing*, pp. 128–52. Berkeley, CA: University of California Press.
- Riessman, C.K. (2000b). Stigma and everyday resistance practices: Childless women in South India. *Gender and Society*, 14, 111–35.
- Riessman, C.K. (2002). Positioning gender identity in narratives of infertility. In M. Inhorn and F. van Balen (Eds.), *Infertility around the globe: New thinking on childlessness, gender, and reproductive technologies*, pp. 152–70. Berkeley CA: University of California Press.
- Rushdie, S. (1994). The free radio. In *East, West*, pp. 17–32. London: Jonathan Cape.
- Scully, D. (1990). *Understanding sexual violence: A study of convicted rapists*. Boston, MA: Unwin Hyman.
- Sen, A.K. (1999). *Development as freedom*, 1st edn. New York: Knopf.
- Skultans, V. (2003). Editorial: Culture and dialogue in medical psychiatric narratives. *Anthropology and Medicine*, 10, 155–65.
- Temple, B. (1997). Watch your tongue: Issues in translation and cross-cultural research. *Sociology*, 31, 607–18.
- Temple, B. and Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, 4, 161–78.
- Thorne, B. (1980). 'You still takin' notes?': Fieldwork and problems of informed consent. *Social Problems*, 27, 284–97.
- Varmas, H. and Satcher, D. (1997). Ethical complexities of conducting research in developing countries. *New England Journal of Medicine*, 337, 1003–5.
- Visweswaran, K. (1994). *Fictions of feminist ethnography*. Minneapolis, MN: University of Minnesota Press.
- Widdershoven, G.A.M. and Smits, M.-J. (1996). Ethics and narrative. In R. Josselson (Ed.), *Ethics and process in the narrative study of lives*, pp. 275–87. Thousand Oaks, CA: Sage Publications.
- Yow, V. (1997). 'Do I like them too much?': Effects of the oral history interview on the interviewer and vice versa. *Oral History Review*, 24, 55–79.

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