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Informed Consent, Deception, and Research Freedom in Qualitative Research

A Cross-Cultural Comparison

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Does there exist only one, universally valid, research ethic? Are informed consent and ethical committees the best means to ensure the moral correctness of research? Again, what consequences ensue from the introduction of these instruments for the freedom of research and the quality of its results? This article addresses these issues by first recounting an ethnography conducted by its author in the oncology department of a large Italian hospital. To carry out his research the author initially had to conceal his identity and the purpose of his presence from the patients. Only later was this mode of conducting his fieldwork abandoned. The rest of the article compares this experience with very different ones reported by a number of American ethnographers. The article concludes by examining problems, such as the influence of the cultural context on the ethnographer's moral choices, or the value of informed consent and ethical committees, in the light of the empirical materials previously presented.

Keywords: *cancer; ethnography; informed consent; IRB; research ethics*

Social research on the terminally ill raises a number of important ethical questions. The theme has received considerable attention in the Anglo-Saxon literature, among other things because of significant changes in recent years. I refer to the formation in those countries of a complex system of ethical committees and codes set up to ensure the ethical correctness of the research methods used by scholars. The intention is to have social research respond to the same values that inform biomedical research (which are also the values most widespread in those societies).¹ In this way, where extreme measures may even be calling a halt to the research work or

forbidding publication of its results, the belief is that patients' welfare and dignity are protected and that the potential for emotional or physical harm by the researchers is reduced.

The phenomenon mainly concerns qualitative research, of course, and ethnographic research in particular. It does so not only because it is difficult to imagine the use of other research methods in this area of inquiry but also because by definition qualitative approaches involve close contact and interaction between the sociologist and/or anthropologist and the participant, which heightens the risk that damage will be inflicted, harm caused, or the right to privacy of patients and their kin violated.

In this article I describe what happens when qualitative research on the terminally ill is undertaken in a context very different from the Anglo-Saxon one in which not only are ethical issues less debated but also the same moral principles are interpreted in very different ways.

Informed Consent and Social Research in Italy

In Italy, doctors tend to keep their patients ignorant of the prognosis of their condition, and they often do not disclose the diagnosis either (Gordon, 1990; Gordon & Paci, 1997; Marzano, 2004). The patient's autonomy, his or her ability to freely decide whether or not to submit to surgery, or to chemotherapy or radiotherapy, is treated as a marginal good, a value not to be taken in great consideration. The reason for this is that the terminally ill are regarded as psychologically unable to make the best decisions for themselves. The argument put forward (often implicitly) by Italian doctors is that their dying patients are too distressed to make rational decisions that would protect their interests. Telling them the prognosis (and in certain cases also the diagnosis) would therefore be an act of cruelty not only pointless but also harmful because it would cause patients to make choices detrimental to their interests, while irreversibly damaging that well-being, the residual psychophysical health, and the will to live, which only the hope of recovery can sustain. Therefore, the duty of acting in patients' best interests is transferred to their families, and especially to health care personnel, who must make the therapeutic decisions and "protect" the patients from the many dangers that surround them—above all the danger of learning the truth about the future that awaits them. In this context, the practice of informed consent, which was introduced some years ago in Italy as well, is only formally applied insofar as it affords protection against possible charges of malpractice.

How can ethnographic research be conducted in such a setting? The considerations that follow are prompted by ethnographic research on “dying of cancer” that I conducted in 2000 and 2001 in the oncology and palliative therapy units of a large hospital in northern Italy (Marzano, 2004).

I began my research by contacting, through a doctor friend, the chief consultant in the oncology unit. During a brief conversation in his office, he told me that I could begin research in his department immediately. The only condition was that I had to draft a letter to the hospital management in which I agreed to halt my research immediately if he decided that my presence in his unit (a) was interfering with the staff’s work or (b) was harmful to the patients. This amounted to writing a “blank check” with which I accepted that the consultant could banish me from his department at any moment, and that no appeal could be made against his decision. No further mention was made of the letter in the months that followed.

Some days later, the consultant invited me to attend a morning briefing session for the medical team in his unit. He rapidly introduced me to his doctors on the margins of the meeting and briefly outlined my project—nothing more.

My presence in the unit thus began with no precise research project description apart from my intent to observe the social interactions among the place’s inhabitants, and with no legitimacy apart from that deriving from the brief mention of my presence by the consultant at the end of the first meeting. Not knowing how to behave, feeling lost and awkward in a new environment, and being interested, at least initially, in studying the interaction between staff and patients, I decided to accept the advice of a “senior” doctor and wear—with the consent of the consultant and amid general indifference—the stage costume of the dominant group: namely the doctor’s white coat. The decision was treated as entirely obvious and natural.

Every morning, as soon as I arrived in the department, I entered the doctors’ room and put on one of the white coats of my size hanging on the pegs, only making sure that the name of a female doctor or of the chief consultant was not printed on the breast pocket because this would have made me ridiculous and immediately identifiable. Thus disguised, I spent my day in hospital following the doctors on their morning rounds, talking to them and the nurses in the wards or the infirmary, sitting in on medical examinations in the surgeries, and watching interviews with patients’ family members.

The most difficult part was handling patients who spoke to me about events of the past few hours, describing their symptoms and asking (often implicitly) for reassurance, confirmation, or simply moral support. My response was to play the unusual role of the “silent” doctor, of a 35-year-old intern a

little behind in his studies, not even asked to measure blood pressure or to take temperatures, generally ignored by the doctors during examinations or when clinical records were compiled, and always silent. In any event, no patient ever asked me, even indirectly, about my odd behavior. I believe this was because, given the advanced stage of the tumors afflicting the patients in the ward, they were mainly concerned with fighting their diseases and coping with their symptoms. Many other aspects of their daily lives were consequently of no interest to them. Moreover, they were used to frequent changes in the medical staff and were naturally deferential to the doctors, the absolute masters of their domain and the dispensers of residual hopes of survival.

The patients must have thought to themselves,

If that goon the white coat one size too small, without pens in his breast pocket, with the embarrassed air and never a word to say, comes into my room with Doctor Rossi, who I know very well and whose treatment I desperately need, well, my doctor knows what he's doing; if he goes around with the guy he's got a good reason for doing so.

From this point of view, the disguise was not particularly useful: I could probably have obtained the same information by presenting myself as who I really was. I realized later that it was my assiduous presence in the department, and not the mask represented by the white coat, which afforded me insights into its social life. Nevertheless, the suggestion that I should wear the white coat was difficult to refuse, at least at the beginning, because it was made by the most influential group in the hospital, on whose benevolence the continuation of my research depended.

Needless to say, I found myself in embarrassing situations. One day, for instance, I was visiting one of the female rooms in the ward in the company of the chief consultant. One of the patients stripped the lower part of her body completely naked to show the team a swelling that had appeared in her groin. I immediately raised my gaze to avoid the sight, meeting the eyes of the consultant, who was as embarrassed and distressed as I was.

Only the more educated and better informed patients—the small group who every morning openly discussed the progress of their disease and therapy with the doctors—would have seen through my disguise, and they were immediately told who I really was.

As the months passed, I found this manner of conducting my fieldwork increasingly intolerable. My desire to abandon my voyeuristic position grew day by day, and with it my desire to stop the obsessive watching, scrutinizing,

spying in the hope of surprising people in unexpected poses. I wanted to get to know the patients at last, to talk to them, to hear the meanings they gave to their experience in their own words.

Three months after the beginning of the research I wrote in my diary as follows:

I'm sick of these visits because I can't stand masquerading as a doctor any longer, watching the vivisection of these poor devils, forgoing any fully human relationship with the patients. Especially the ones I already know. Yesterday I was terribly upset. I took off my white coat and ran away. I couldn't stand the weight of the deception any longer.

My most difficult day was the one when a young Chinese woman died. In the dramatic final minutes of her agony, doctors and nurses alternated with the husband, children, and other relatives at her bedside amid the frenzied emotions reserved for the death of the young and that contrast so sharply with the serenity and calm that attend the death of the elderly. I watched the scene from the corridor, feeling impotent, embarrassed, unable to participate in the suffering within the room. I was prevented from expressing my grief by my disguise, by the mask I was wearing. I felt that all those present were silently accusing me of being a ghoul, of harboring a macabre and inhuman curiosity in the pain of others.

Another event in that period made maintaining my anonymity with the patients even more difficult. Some time earlier I had talked about my research project with the president of a voluntary organization working with cancer patients. She had told me that if I really wanted to know the experience of cancer patients, I should become a voluntary worker and spend some time in the day hospitals where her organization operated. After some weeks of reflection, I decided to try, persuading myself (and also deceiving myself) that I would be an observer and a genuine voluntary worker. I would be able to talk to numerous patients, not only gathering information useful for my research but also giving them some sort of moral comfort. I would consequently not have to wear a disguise or deceive the patients. This is also what I told the other voluntary workers whom I met at the time.

Of course, I would have to change hospitals, given that I could certainly not present myself in the guise of a voluntary worker at the hospital where I had conducted my research thus far.

It took just one day for me to realize that the idea was not going to work. When I arrived at the day hospital, two voluntary workers gave me a coat

to wear and briefly described the patients who would be present that day. I wandered around the rooms for a half hour. Then I wrote in my diary:

I can't do this thing (the voluntary work) because it's my job to write books, not to keep up this fake cheeriness with the patients, poor wretches. No, I can't think of forming such a false relationship that I worm information out of them on the pretense of being a voluntary worker² (and then there's my cowardice, my enormous fear of discovery, of being caught out in my disguise). Covert research is possible in only two cases: 1. when one wants to study a phenomenon which cannot be investigated otherwise (as in the case of Humphreys, 1975, or of those who, for example, want to study gossip, where it is obvious that they can only collect it licitly or otherwise; 2. when there are good political reasons for not seeking access to the leaders of a certain organization which one intends to study (like Dalton, 1959, or Martin, 1992, who wanted to be free to write as they wished and consequently did covert research). In my case, the thing won't work because exploiting these poor people and their problems is unthinkable . . .

I therefore radically changed strategy for the next phase of my research. By now I knew the hospital well, and to extend the setting, I asked to be granted access to the palliative care unit of the same hospital. Its newly appointed chief consultant told me that he could not make the decision on his own, and we therefore decided that my access would be conditional on the assent by all the department's doctors, nurses, and psychologists. The meeting at which with the members of the unit discussed the matter was rather animated. The group of psychologists (four of them, all young, and none of them a permanent member of the hospital staff) were rather hostile to the idea of my constant presence in the department. One of them maintained that I should get every patient to sign an informed consent form; another said that I should explain the nature of sociology to those patients who did not know what it was and spell out the details of my research; yet another said that I should submit a forecast of my results so that the usefulness of my research could be assessed and compared with the costs of my presence to the patients and the staff. The oldest of them (who left the unit some weeks later) manifested his disapproval by constantly getting up and leaving the room, switching on the photocopier, and talking loudly on the telephone. By contrast, the majority of the doctors were in favor of my presence. However, many of them insisted that my identity should be disclosed to the patients and their wishes regarding involvement in my research respected. Only a neurologist explicitly declared his opposition to my presence, doing so on the grounds that it would alter his relationship

with his patients, preventing them from spontaneously and sincerely describing their symptoms and discomforts, and thus prejudicing the efficacy of their treatment.

In the end it was decided that I could carry out my research. I would not have to wear a white coat, and the patients would always be informed about my work by the health worker present at the time. A probable reason for the difference of attitude between the personnel of the palliative care unit and the oncology department was that the former did not administer therapies and did not have in-patients, only surgeries for medical examinations and a small infirmary used mainly as a waiting room. These features probably made the presence of a sociologist less troublesome than in the oncology department, where there was a greater risk of my upsetting the hospital's precarious social order.

Finally, although I was asked to declare my professional identity to the patients, I was never required to explain to them the subject of my research, which was dying from cancer, and not more generically "the everyday lives of cancer patients, their experiences of the disease." The reason given to me was that this was a solution that left the patients free either to continue to deny the existence of their disease during their meetings with me or to talk explicitly about their imminent death.

Ethical Committees and Informed Consent: The Anglo-Saxon Experience

In the past decade, ethical committees have become widespread in Italian hospitals as well. However, as my account shows, the process has not concerned social research. What would have happened if I had carried out my research in a different cultural context, for example that of an Anglo-Saxon country?³ Imagining that there was particular concern for the ethics of social research, would the quality of my research have benefitted if a hospital ethics committee had supervised my work, monitoring its every stage? Could I have thus avoided some of the "moral harm" caused during my fieldwork?

Despite the discontent widespread in the scientific community (Adler & Adler, 1994; Becker, 1982; Bulmer, 1982; Lincoln & Guba, 1989), it is unfortunately not easy to find useful descriptions of the effects of the action of ethics committees on research, particularly on the work of ethnographers. For this reason, one may presume that in many cases the supervisory work of these bodies does not create serious obstacles against social

research. However, some researchers (Kipnis, 1979; M. D. Murphy & Johannsen, 1990) reported some of the severe dangers that arise from the excessive power of these institutions. Pearce (2003) efficaciously described the many obstacles raised by local research ethics committees (LRECs) against those wishing to conduct qualitative research in British hospitals. Patricia and Peter Adler (2002, p. 34) described with alarm the increasingly difficult climate encountered by qualitative research in the United States. The directives and judgments of these boards have evolved, becoming considerably more restrictive, and they now represent a major bane and obstacle to the active researcher. Although they present themselves as something other than petty, narrow minded, restrictive bureaucratic “rangers,” it is often hard not to suspect otherwise. The Adlers have recounted the vicissitudes of numerous research projects by their students, obstructed or blocked by an increasingly invasive and obtuse system of bureaucratic control on research activity. The situation is made even more difficult by the inconsistency of the criteria used, so that some universities are stricter than others in screening the research projects of students and academic staff.

The problem is naturally more acute for qualitative sociologists, given that, among other things, it is difficult for them to establish a well-defined boundary between situations in which they are clearly conducting research and others in which they are simply conversing with their informants. Even a casual chat in a hospital corridor may end up in a sociology text, and it is indeed difficult on such occasions to ask the interlocutor to sign a consent form!

The Adlers suspected that the real objective of ethics committees is to protect not so much the persons observed by ethnographers as universities and publishing houses, both of which are mainly concerned to avoid any unpleasant consequences of research.

If you fundamentally—the Adlers ruefully concluded (2003, p. 42)—shut down research there is no risk to the participant because the researcher will not know anything. However, should be the researcher be willing to pay the price of losing knowledge about huge chunks of society because people with the most to lose are the most likely to see the consent form as barriers?

There is no doubt that the most striking account is the one provided some years ago by Stefan Timmermans (1995), the author of the important ethnography “Sudden Death and the Myth of CPR” (1999) on resuscitation practices in the United States.

Timmermans (1995) reconstructs in detail the many difficulties that arose in his relationships with the ethics committee of the Green Hospital

where he carried out some of his ethnographic research. At the meeting preceding his access to the field, one of the hospital doctors warned him about the sensitivity of the research subject that he had chosen⁴ and recommended he should not let his prejudices prevent him from seeing the factual reality. Despite these initial remarks, Timmermans' project was approved, with the committee imposing the condition that a doctor should flank him during his observations. Some months later Timmermans was horrified to discover that at the beginning of his research he had unthinkingly signed a document in which he undertook not only to treat the data obtained from patients and staff as confidential but also to explicitly state the name of the hospital in the presentation of his results. Above all, however, he had undertaken to accept as coauthor of every publication using his research data the doctor who had flanked him from the beginning and was uncooperative with his research. Apart from the obvious contradiction of having to state the name of the hospital while respecting the confidentiality of information about patients and personnel, the document imposed a condition that could not be accepted without entirely violating the principle of the freedom of research. Timmermans immediately took corrective action by asking to be flanked by another doctor, who, at least informally, was much more willing to waive the coauthorship condition and his right of veto on Timmermans' future work. The doctor accepted, and the change was soon ratified by the committee. However, Timmermans' problems were not over. Some weeks later, the committee notified Timmermans that it intended to withdraw authorization for his research. The most serious accusations brought against his work were that it was not generating "valid" and sufficiently generalizable data and that it painted a partial and impressionistic picture of reality at the hospital. In short, it did not respect the canons of rigorous scientific analysis. Of course, the charges arose from the fact the members of the committee had no confidence in qualitative analysis or in the constructivist and phenomenological approaches. After careful consideration, and essentially not to prejudice continuation of his research, Timmermans decided to defend himself against the committee's accusations, emphasizing the merely "descriptive" nature of his work, its cumulability with analogous research, the weakness of its sampling procedures, and pointing out that it served for hypothesis forming or as exploratory research for subsequent, more useful survey work.

Nevertheless, during the committee hearing, Timmermans was effectively put on trial, being accused not only of using unscientific methods but also of damaging the reputation of the hospital, and of not understanding certain essential properties of human physiology and medical work.

“The numbers should come through in the paper. This is not systematic. What about statistics! And don’t you sociologists write an introduction, method section, findings, discussion and conclusion?” I answer “I think I wrote an introduction, a theoretical section, a methodological section, findings, . . .” Dr. Bourdeax interrupts fiercely: “You did NOT do theory, only hypotheses. (He yells and waves his hands violently). If you write something, we should know HOW MANY PEOPLE said WHAT, there should be NUMBERS in here. There is NO DATA in this paper.”

The story had a happy ending. After consulting a lawyer, Timmermans convinced the chairperson of the committee to desist from interfering in publication of the research work and from conditioning its content and methods. However, a high price had been paid: the 3 months of forced suspension of the research inevitably weakened the trust relations between researcher and staff (founded on the ethnographer’s assiduous presence in the field and the continuity of his personal relations in the setting). Timmermans was thus obliged to change his research strategies and henceforth to rely mainly on interviews.

Analytic Considerations

In this section I examine certain consequences ensuing from comparison between the two cultural contexts.

1. Although the first consideration is rather banal, it is often neglected by analyses of ethical problems: *the wider cultural context decisively influences the researcher’s methodological and ethical options*. The ethical values that research is required to respect are often the same values that prevail in the place where the research is conducted.⁵ For example, if the principle of informed consent is taken seriously by health care workers, as it is in the Anglo-Saxon countries, it should also be respected by social researchers, who will be required to adopt the same attitude toward the ill as taken by doctors. The reason for this is that the values of medical ethics and research ethics reflect those obtaining in the wider social community.

It is the cultural setting that marks out the boundaries within which research is possible. This is a principle that cannot be ignored without seriously prejudicing the possibility of completing one’s research. Thus, for example, it is impossible for British researchers to flout the ethical rules

laid down by committees, given that even if they found a way of doing so, it would be difficult for them to find a journal editor willing to publish the results of their research. In my case, it would have been equally impossible to continue my research if I had decided to ask one of my informants what Julia Lawton (2001) was able to ask one of hers: What does it mean to be “terminally ill.” If I had used that expression with one of the patients in the Italian hospital, I would have been immediately expelled from the setting, and never allowed to return.

In many respects, as Atkinson (1997) suggested when discussing his research, my identity was only *one* of the items of information that the doctors did not disclose to the patients. On entering the field, the researcher inevitably accepts that she or he is in the same boat as the participants under observation; that she or he is constrained by certain normative practices and institutional and cultural arrangements; and that she or he is involved in power relations among the persons and groups that populate an organization (Atkinson, 1997, p. 53).

2. The second and less obvious point concerns the harm that social research may cause for its participants. If it is decided to adopt an absolutist or deontological approach (Beauchamp, Faden, Wallace, & Walters, 1982; Kvale, 1996; Macklin, 1982; Pinkard, 1982) grounded on the standard principles of medical ethics and apply them rigidly to social research, no compromise is permissible; one must judge not only the results but also the intentions. From this point of view, social researchers should abstain from research in organizational settings where people’s rights are not fully respected. If the ethnographer behaved otherwise, she or he would in some way act as an “accomplice” to immoral actions and responsible for actions that besmirch the reputation of the scientific community to which she or he belongs.

This is a highly debatable point of view. The prior certification of ethical correctness, like that of informed consent, is in many respects a myth. It is a socially legitimated myth that enables researchers to resolve by means of a bureaucratic procedure the ethical problems inevitably caused by their presence in the setting and to protect themselves against attempts to attack the moral legitimacy of their work or contest its results.

In broad settings such as hospitals or hospices, it is in fact impossible for all participants to be equally knowledgeable about the research project (Hammersley & Atkinson, 1995; Lawton, 2001). It is highly likely that there instead exists a “hierarchy of consent” (de Laine, 2000) where the gatekeepers are aware, before and better than others, of the researcher’s

intentions. Moreover, the participants are very often informed of the researcher's presence only at the beginning of the research. Thereafter, as a consequence of the researcher's regular presence in the setting, especially if she or he performs some sort of active function in the health institution,⁶ they tend to forget the peculiar nature of his or her work and treat him or her like any other member of the organization. Some authors suggest that this drawback can be dealt with by periodically reminding the participants involved of the modes and purposes of the research, from time to time renegotiating the conditions that regulate it. This, however, only makes matters worse because, in many cases, it may encourage ad hoc behavior and severely prejudice the "naturalness" of the everyday lives of the persons observed (Hammersley & Atkinson, 1995).

In the case of the terminally ill, added to all this is the fact that when they have reached a certain stage of their illness, they are often unable to say whether or not they want their involvement in the research to continue (Lawton, 2001). Moreover, even when they have consented to furnish data for the sociologist, it is difficult for the latter to guarantee that the data will be used in a way that respects their opinions and attitudes (Lawton, 2001).

Finally, by subordinating the conduct of research to formal assent by the participants studied or to prior approval by committees, the proponents of deontological positions attribute to participants an ability to make rational comparison of the costs and benefits of their involvement in the research that is very difficult to perform at the beginning of the research and that obscures the presence in the relation between researcher and participants of forms of action not based on interest or mere calculation (Corrigan, 2003). This is a merely procedural conception of research ethics in which it is presumed that when consent has been obtained and the limits on the researcher's action established, the ethical problems have been finally resolved and power differences eliminated or at least greatly reduced (Denzin, 1997).

On utilitarian or consequentialist grounds (Elms, 1982), and endeavoring principally to evaluate the effects of research and not the means that have produced them, it is instead reasonable to argue that harmful effects on the ill of sociological research like mine are not nearly as significant as the positive effects deriving from better understanding of their daily lives. Is this not enough to provide moral justification for research like mine? In Italy, the main objective of the reformers—those who challenge medical paternalism and the conspiracy of silence surrounding terminal disease—is a change in the quality of communication with patients, the introduction of an open awareness policy, and the spread of palliative care. The problems

raised by the ethics of social research, and the harm that the latter may cause for the ill, are in this context of secondary importance. If the researcher reaches some sort of compromise with his or her values, light will be shed on the workings of the system and change will be set in motion. What harm could be caused to the ill by breach of the rules on informed consent by a social researcher if those same rules are applied by doctors and other health practitioners only on paper? Is it not the harm caused by the sociologist's untruths, relatively unimportant and amply compensated for in terms of better knowledge about the phenomenon, perhaps the lesser evil, compared to the lies about prognoses told everyday by doctors?

3. Moreover, the rigid application of rules of such stringency as those that apply in the Anglo-Saxon countries does not favor the production of original research results. In particular, the influence of ethical committees is highly debatable, for such bodies comprise people (doctors, administrators, bioethicists) often insensitive to the knowledge interests of social research and principally concerned to protect the reputation of the institutions to which they belong or the prestige of certain professional groups (Timmermans, 1995, p. 156). The risk is that, in this situation, researchers will seek to evade the barriers raised by the watchdogs by opting for less problematic research projects (Lee & Kristjanson, 2003) and that they will espouse an epistemology of scientific inquiry (Timmermans, 1995, p. 157) in which predominate criteria (those best suited to appraising quantitative research) that are not necessarily shared by a large number of researchers.

The main advantage of conducting research in Italy is that it is possible to work with an open and flexible research design, which is defined as the research proceeds and can be constantly adjusted. This is a situation particularly appropriate to ethnographic research. The aim of participant observation, and its specific contribution to interpretation of social life, is to understand the meanings that persons assign to what they do, and of the main activities (ritual or more generally cultural) that serve this purpose. A study of this kind requires a long period of fieldwork precisely because it is only with time that a researcher is able to discover the most interesting and original aspects of the culture being studied—or, indeed, the most important questions to ask the participants observed. The autobiographical accounts of their research experiences frequently published by ethnographers are full of narratives about false starts, scrapped projects, and illuminating discoveries made in the field, often by chance and which move the research in an entirely unexpected direction.

In his preface to *Asylums*, Erving Goffman (1961) writes that he began his participant observation in the St. Elizabeth's psychiatric hospital of Washington, where he worked as an assistant on the gymnastics course. When he was asked what he did he answered that he was "a scholar of community life." Only the management knew the real purpose of his presence in the hospital. On granting Goffman permission to carry out his research, the hospital management asked if it could read and comment on the first version of his work and requested him not to furnish information that would enable identification of staff members or inmates. That was all. Perhaps today we would not be able to read Goffman's ethnography (and many other sociological works: Punch, 1994; Thorne, 1980) if his research project had been scrutinized by an ethics committee or if he had had to respect all the small print of an informed consent form.

4. It is better to admit that the events that accompany a qualitative research study are largely unpredictable beforehand and that its ethicality rests mainly on the researcher's shoulders, on his or her moral maturity, ability to make decisions in the field that do not differ too greatly from his or her values, capacity to adjust his or her behavior when it obstructs the growth of excessively insincere relations (Lieberman, 1999; Wax, 1980). In sum, as Bok (1978) argued, the principal victims of research conducted by deceit may be the researchers themselves. They risk treating lies and manipulation on a par with standard practices, teaching them to their pupils, becoming cynical and morally indifferent to sincerity in human relationships, while fuelling the public's distrust in social research that it equates with deception.

Whyte (1955) ran this risk when his realization that he had agreed to act as a repeater in an electoral fraud organized by the staff of Senator Ravello (while also risking discovery and arrest) induced him to sacrifice his moral principles for his research interests and to forget, at least for a moment, that the researcher in the field is still a person with a stock of moral values and norms to be safeguarded. Whyte's comment on this episode in the appendix to *Street Corner Society* is still valid almost 50 years since it was written:

I also had to learn that the field worker cannot afford to think only of learning to live with others in the field. He has to continue living with himself. If the participant observer finds himself engaging in behavior that he has learned to think of as immoral, then he is likely to begin to wonder what sort of person he is after all. Unless the field worker can carry with him a reasonably consistent picture of himself, he is likely to run into difficulties. (p. 317)

Events like those recounted by Whyte should not be treated merely as “accidents,” false moral steps, or, worse, as circumstances that obstruct or delay the research plan (Lieberman, 1999). They should instead be considered an integral part of fieldwork, stages in the “moral career” of a researcher who is thus forced to come to terms with his or her own identity, to reflect on the nature of the social relations that she or he constructs in the field, on the legitimacy of his or her observation, on the distribution of power (Schwandt, 1995). After all, fieldwork is this as well: an opportunity to discover (or construct) one’s moral identity, to measure the consistency and resilience of one’s values under the pressure of events and the urgency of decisions.

This happened to Carolyn Ellis (1995) when she discovered to her distress the harmful effects of her research when she returned some years later to the small fishing village where she had conducted her first ethnography. And it also happened to John Van Maanen (1983): when he was asked to testify about the beating of a colored man who he had witnessed, he decided to refuse to hand over his notebooks and not to testify against the two police officers arraigned for the beating, who for many weeks had accepted his presence as an observer in their car. On that occasion, when faced with the ethical dilemma of choosing between two equally important goods, Van Maanen discovered that his loyalty to the police officers who had accepted him into their car was greater than his duty to protect the community against police violence.

In my case, too, what happened in the field was a “moral career” opportunity, an occasion to “examine the connections between self, other, and world and reflection on what it is right to do and good to be as a social inquirer” (Schwandt, 1995, p. 134).

In the final analysis it must be admitted that ethnographers are not endowed with boundless rationality, and that even the best research projects (ones that are as detailed and analytical as possible) do not shield the researcher (and society) against the unforeseen and ethically problematic decisions which inevitably arise during fieldwork, and with regard to which the sociologist has no other recourse than reference to his or her *own morality*.⁷ In other words, the ethicality of a research project does not wholly reside in a declaration of intent but is inevitably completed within the face-to-face relations in which the Other, suffering and dying in my case, becomes real, acquires body and substance, and is transformed into a moral constraint and a source of obligations.

5. The main price that researchers must pay in Italy is the paucity of “friendly” settings in which to conduct research. In the Anglo-Saxon

countries, social research on the terminally ill seemingly receives greater support from the public institutions and individual health facilities. It is this factor, not the preventive action of committees, that constitutes the major premise for the creation of an “organizational climate” favorable to research and represents the best guarantee that the researcher will not breach common ethical principles. It is through face-to-face interaction with practitioners willing to recognize the benefits of social research for the terminally ill that the reciprocal trust, the basic agreement, is constructed so that the researcher can act in harmony with the ethical principles prevalent among those practitioners. By contrast, the reception awaiting me in the hospital where I carried out my research was cold, my presence in the field was precarious, and the legitimacy of my work in the absence of a clear initial negotiation was often questionable. I remember my fear when patients would cry during interviews as they told me the “story” of their illness or remembered some event from their past. I was afraid that a member of staff would discover what had happened and accuse me of causing psychological or moral harm to a patient, and consequently demand my ejection from the department.

A friendly climate can certainly help reduce the “moral solitude” that afflicts the ethnographer, and at the same time it signals the community’s concern to supervise the researcher’s work and to assist him or her in taking choices respectful of common values. Lawton (2000) recounts that she was warmly welcomed by the management and staff of the hospice that she selected for her research, and indeed they actively involved her in a project to assess the quality of the service. My consultant, too, had very probably “enlisted” me in service of his personal project for change in the department. However, it took place “in the dark,” so to speak, without my being aware. In the Italian context and ones similar to it, the function of social control and gatekeeping for research is performed exclusively by doctors. It is they who decide whether or not the researcher may enter the setting, and on what conditions. It is to them that society has delegated responsibility for patients’ well-being and the power to make all decisions in their regard, including their participation in social research.

Summary

Does there exist only one, universally valid, research ethic? Are informed consent and ethical committees the best means to ensure the moral correctness of research? Again, what consequences ensue from the introduction of

these instruments for the freedom of research and the quality of its results? The article addresses these issues by first recounting an ethnography conducted by its author in the oncology department of a large Italian hospital. To carry out his research the author initially had to conceal his identity and the purpose of his presence from the patients. Only later was this mode of conducting his fieldwork abandoned. The rest of the article compares this experience with very different ones reported by a number of U.S. ethnographers. The article concludes by examining problems, such as the influence of the cultural context on the ethnographer's moral choices, or the value of informed consent and ethical committees, in the light of the empirical materials previously presented.

Notes

1. Many of the exhortations and recommendations contained in the Anglo-Saxon literature on the topic are inspired by the principle of beneficence and nonmalevolence, others by the principle of autonomy: (a) respecting the principle of beneficence means subordinating the scientific results of research to the production of tangible benefits for the participants investigated; respecting that of nonmaleficence means not inflicting harm on the participants in the research (E. Murphy & Dingwall, 2001, p. 339). According to this principle, "researchers should only proceed where they can show that the anticipated benefit of a study outweigh its potential risk" (E. Murphy & Dingwall, 2001, p. 340); (b) the principle of autonomy or self-determination states that researchers must respect the desires and values of the participants of their research. Those who invite respect for this principle argue that the ill must give their full and informed consent before research can begin or continue. Kristjanson, Hanson, and Balneaves (1994) stresses that all the benefits and costs that may derive from the research should be explained to potential participants. Seymour and Ingleton (1999) also emphasize that the participation of the participants should be repeatedly renegotiated as the research proceeds: The advance of disease, in fact, may radically change the psychophysical conditions of patients and their willingness to take part in the research. Consequently, the consent given at the beginning of the research should never be considered definitive.

2. Also Lawton (2000) felt the same ambiguity, fearing the consequences of having the patients tell her stories out of friendship that she would then use for research.

3. The Italian situation is very similar to the British one of some time ago, before the introduction of ethical committees and informed consent. Paul Atkinson (1997) tells a story very similar to mine when describing his experiences in a Scottish hospital during the second half of the 1970s. He recalls that, according to the initial agreements made with the doctors, the patients were to be informed that he was a sociologist. This did not happen, however, and Atkinson was never explicitly introduced as a researcher to the patients, for whom he could have been a student or a "particularly silent" doctor. Atkinson thus found himself conducting what amounted to covert research, at least with regard to the patients. "From my own point of view," he writes on page 52, "this was less a deliberate research strategy, but more an exigency forced on me by the situation I was in." Control of the situation, including disclosure of the ethnographer's identity, pertained to the stronger group, that of the doctors obviously. Atkinson reached the same conclusions that I drew 20 years later: "For me to attempt to enter

into separate negotiations, and to achieve an open identity for myself when the clinicians remained silent, would have been to question the position of the doctors. It could have endangered the entire enterprise”.

4. “Everyone likes sausages, but no one wants to know how sausage is made” was the elegant metaphor used by the doctor.

5. This is an aspect undervalued by analysts such as Bok (1978), who when criticizing covert research does not consider the influence that the cultural and organizational environment may exert on the choice among different research strategies.

6. This often happens in the Anglo-Saxon countries, also owing to the fact that professional practitioners undertake the research.

7. Under these circumstances, writes Wax (1980), *consent* becomes a negotiated and lengthy process—of mutual learning and reciprocal exchanges—rather than a once-and-for-all event. Ethnographers can never take their roles wholly for granted, but must always be concerned to sustain their presence as welcome guests and responsible persons. If they are wise, ethnographers will communicate as much as possible—given the distortions of language, culture and worldview—concerning their hopes and intentions, but they must also adapt their information to the interests and sophistication of their hosts. Needless to say, the conventional “consent form” is so irrelevant as to be a nuisance to all parties (p. 275).

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