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# Study of Ethics in Society

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#### **HELPING TO HARM?**

THE ETHICAL
DILEMMAS OF MANAGING
POLITICALLY SENSITIVE DATA

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#### Helping to Harm?

The Ethical Dilemmas of 
Managing Politically Sensitive Data

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Presented to the WMU Center for the Study of Ethics in Society

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of the same caliber: Dr. Lewis Walker, chair of the Sociology Department at Western Michigan University, is always gracious and supportive. His scheduling my teaching to facilitate ongoing out of town research activities and commitments to respondents over extended weekends is only one of the many acts of kindness he has extended me. Dean Douglas Ferraro's support is one of the many reasons I value being at Western Michigan University. Each of these mentors' expectations are challenges I value!

The invitation to present these materials on March 19, 1993 provided me with a warm, receptive and intellectually challenging audience, to whom I am grateful.

#### HELPING TO HARM?1

#### Background<sup>2</sup>

Andrew: Can I tell you some'ing real private? Ain't never told no one before ... people who knew for sure ..., they'se dead ... all dead but me ...

Sylvie: Anything you tell me is strictly between us. When I write about people who talk to me about AIDS, I make sure their own mother wouldn't know them.

I feel safe, yet know I shouldn't: this is a 'squatter' basement apartment in an abandoned building in a part of an inner city few people choose to visit in daylight. I have run from one interview to another for 20 hours, eating fast food at the wheel. No one knows where I am - in part because they would fuss. I recall the police officer's comment: "your body might never be found." It is roughly 3:00 a.m.. Andrew mainlined cocaine twice in five hours: his is a decade-long habit, and he is at least as lucid as I am.

Andrew: This could really blow big time . . . When Ted said he could really talk to you, I figured it was all shit . . . I don't trust white

folk . . . but it's like you ain't shocked by nothing, and this thing really bothers me. . . . [Andrew cries softly].

I know that I hold his unbelievably dirty hand because he is vulnerable, which, to my mind, entitles him to sympathetic understanding. Fleetingly, I realize that I identify with his sorrow. The first five hours, sitting on this filthy floor, with this very rough looking gentle man and a few thousand cockroaches, were a test: now comes what may be Andrew's deathbed confession.

Andrew: I did do it on purpose, like . . .

As I settle in for the long haul, I know I am hearing words never meant to be spoken . . . and I know I will not reveal them before Andrew's death. I never owned his words. They are not mine to give. I add my confidante role as I shift my weight on a moldy couch cushion over bare cement. As the pillow spills its guts, so does Andrew.

I thank my intensity of listening: however exhausted I may be, I can somehow replay hours of interviews in my head, adding tone and wardrobe and decor and body language. I conceptualize this ability as *empathic focus*: nothing matters but the emotions behind the eyes, the tones and sensations behind the words! Most of all, my commitment is to the role of *privileged listener* (Siegel, 1987): it hinges on what is most precious: Andrew's and my shared humanity.

I could not leave this very sick, lonely man. I recall how, for many colleagues, this represents the worst possible option. Choosing to hear but not to tell is, to their minds, 'bad science.'

It is the only ethical science I know to do.

Research, by definition, challenges our definition of the known. Truly rewarding research may even allow *epiphanies* - glimpses so far into the unknown, so powerfully absorbing, that we have little sense of their interpretive parameters (Denzin, 1988). As social scientists adopt research areas traditionally reserved for and guarded by medical or legal practitioners, sociological praxis increasingly presents very real dilemmas. Fear of personal and professional consequences fuels defensive postures historically associated with those

professions. This includes discussions about "What to do before and after a subpoena on data arrives" (Knerr, 1982), and many of us, myself included, carry hefty professional liability coverage.

Unfortunately, fears and defensiveness can - and do - create a backlash against reciprocal relationships with vulnerable respondents. Similarly, social scientists are burying themselves in data dissociated from real persons. This resembles the way in which physicians prescribing every known test 'just in case' often lose contact with the humanity of the patient. In both cases, detachment stems partly from the very defensiveness mandated by procedurally dehumanizing treatment.

My particular concern is the failure of sociologists to recognize or acknowledge the unavoidable link between the power dimension intrinsic to the research enterprise and consequent obligations toward respondents (Bartlett, 1991). Effective integration of ethics requires forethought: this allows anticipating management both of the research process and of subsequent data. Sometimes, data can range

from behavior the researcher labels 'odd, ' 'disgusting' or 'perverse, ' to respondents admitting willfully inflicting harm to themselves or others. Researcher and respondent safety, researcher integrity qua person and qua scientist and, ultimately, the future of the profession, depend on careful, ongoing development and ready deployment of an 'ethical voice.' I define this attribute as 'the mature implementation of choice and actions despite the constraints of Ethical voice includes the oppression. affirmation of moral agency, the valuing of choice among alternatives, and the conception of self as committed to making a difference through affirmative choices.' As Hoagland suggests, "[m]oral agents are autokoenonous beings" (1988, p. 231).

I fear that dissociative segmentation foments a belief in a professional "protoself" (Gagnon, 1992: p. 224) which allows for conduct deemed inappropriate in other contexts but justified by the presence of a unique, private, professionally endorsed source of meaning. This protoself, imbued with individualist autonomy, allows sociologists to allow themselves exemptions. They ignore social embeddedness as a necessary

component of justice. Rawls argues that any just system of necessity includes equality of liberty, and a restructuring of social and economic inequalities. This actively compensates most those who are neediest. Thus, justice in the Ralwsian sense is intrinsically social. To my mind, an orphaned, disabled, unemployed, drug-addicted, homeless minority HIV-positive man experiencing the early manifestations of full-blown AIDS is far needier than an assistant professor of sociology, albeit untenured! Unfortunately, not every scale is so obviously tipped, not every researcher cares to see if it is, and not everyone who sees that it is feels a responsibility to do anything about it!

This paper focuses on the ethical complexities of professional decision-making when research findings concern vulnerable populations. Specifically, I want to address situations when publication or presentation may clearly inflict harm to project participants or the population to which they belong (Oakley, 1981). Like every researcher, I bring a particular perspective to the question. I have sat at deathbeds holding people's hands when they thought they would die; lain on hospital beds holding adults dying

of AIDS and begging for hugs denied them since the diagnosis, and sat overnight with people talking their fears away. I cannot dismiss those who honor me with their stories. My perspective is therefore that of someone neither seeking nor pretending 'objectivity.' It is the standpoint of someone who cares deeply about the pain HIV/AIDS brings all those it touches<sup>3</sup>.

As a result, my fieldwork starts from two absolutes. First is a conviction that, depending as we do on the goodwill of respondents, we owe them preeminent concern. Secondly, I recognize that our presentation of self encourages the most vulnerable to 'let us in.' Therefore, I know that the notion of 'informed consent' is at best glorified, and, at worst, wilfully negligent. To my mind, 'consent' is a much-abused concept . . . which we use as the operational definition of respondent autonomy. I argue that unless respondents are deliberately and fully informed as to the political risks of participation, they have not consented to such risk.

I contend that neither profession nor institution

has sufficient moral authority to mandate the release of data given by respondents, when those respondents lack the access or the training to understand the analytic context eventually framing those data. Using evidence from my own research among Persons with HIV/AIDS, I suggest, and offer reasons why, researchers aware of significant possible risks to the respondents or their populations carry full moral responsibility for protecting them from the consequences of the very process of research.

### Sociology as Apostle of the Status Quo: An ethical embarrassment?

Researchers whose respondents are not selfevidently needy could become alert to ethical
concerns because of the weight of the 'moral
errors' which mar our disciplinary landscape.
The history of the social sciences is strewn with
research projects that have inspired heated
debates: the Wichita Study, the Milgram
experiment, and Project Camelot are mere
background to more recent debacles. Readymade excuses - "this could never happen again"
"think of all we would yet have to learn without
Milgram" - must make way to realism: the
urgency of situating our work within a

thoughtfully articulated ethical perspective (Noddings, 1984). Unfortunately, careful contemplation is increasingly giving way to the pressures of doing the work. When universities promote the mass production of the lowest publishable units ('LPU's')<sup>4</sup>, individual faculty members are torn between irreconcilable loyalties.

Specifically, I fear the ease with which ethical considerations are set aside (Tourigny, 1992). The current academic climate promotes a gradual but steady erosion of awareness of the immense debt we owe those whose time we appropriate 'for the benefit of science' (Savage, 1992). We are too busy hoping that HSIRB reviewers will ask few questions, that response rates will remain acceptable, and that journal editors will accept manuscripts quickly, to think very much about the people whose lives we write about.

Yet, the definition of 'sociology' implies far broader responsibilities than the simple gathering of data for publication (Zeitlin, 1984). As we branch out into ever-more-complex areas, we need growing sensitivity to the breadth and depth of concerns required by our social mandate. Doing so effectively mean starting long before circumstances require it.

When I first witnessed physician-assisted suicides over a decade ago, in a jurisdiction explicitly banning them, I was grateful for my training. I had been required to reflect on the implications of events such as these for my own professional decision-making.

Training into forethought helped ensure my ethical and moral sense of well-being. When the occasion arose, I stopped a potentially fatal 'medical accident.' I knew I would . . . and I knew I could live with the results. I had spent time - and filled notebooks - analyzing the distinctions between morality and legality, and between individuality and 'universal precepts.' I still fill those notebooks: my greatest debt accrues to the respondents whose stories - each more troubling than the last - keep me alert.

No doubt, professional expectations that we publish hurriedly, certainly without ever 'suppressing findings' (Who has the luxury?) stem in part from a profound and eminently defensible commitment to academic freedom.

Paradoxically, however, this very commitment to the freedom of researchers may spawn rules facilitating disdain for respondents' autonomy as persons. In given sociohistorical and sociopolitical contexts, the release of controversial findings may fuel policies researchers know carry a high probability of causing significant harm to the population studied, if not to the individual respondents themselves.

There are obvious ideological frames to these arguments. However, I want to present tangible cases before clarifying my own theoretical commitments. Only careful articulation of situational perspective can help identify ethical commonalities. These, in

turn, may enable us to transcend methodologies and political climate!

#### SOME SAMPLE DILEMMAS

The nature of my inquiries into the management of HIV/AIDS unavoidably leads to discussions about coping with daily life - and with the dying process. This, in turn, frequently opens detailed formulations of past behavior or existing plans to which respondents are irreversibly committed.

The most dramatic challenges of research with Persons diagnosed with HIV/AIDS involve dealing with the social consequences of the stigma that remains attached to respondents. Health care providers with a profound commitment to their patients face difficult decisions, because HIV/AIDS-related care presents a variety of challenges. They do, however, operate within a context recognizing that HIV/AIDS poses a full spectrum of new challenges.

Social scientists - and sociologists in particular - have used traditional arguments in favor of 'objectivity,' adopted and integrated within the professional culture when positivism was defined as an aproblematic achievement. Therefore, stringent rules about 'non suppression of data' were devised . . . when 'data' meant 'survey responses,' and deleting identifiers ensured anonymity.

As an ethnographer employed by a public university and working among socioeconomically marginalized inner-city minority persons with HIV/AIDS and their loved ones, I leave paper trails. Anyone interested in

the specifics of my research needs only to obtain copies of my Human Subjects Institutional Review Board clearance to know precisely the names of the clinics and of the physicians with whom I work. From there, identifying persons who have consented to meet with me becomes a simple matter of verifying with staff at each institution (also public).

As a result, I confront painful decisions about whether to present findings, and if so when, how and to whom. My profession informs me that I have no right to make these distinctions: since I cannot know with absolute certainty that respondents would be prosecuted or that law enforcement would subpoena my records identifying individual respondents (documents I keep outside the U.S. for that very reason), my 'job' is presumably to report all findings promptly, without regard to the political climate or the consequences for respondents.

The legal as well as the emotional and ethical dimensions of the findings heighten the complexity of the situation. The following examples have occurred in settings with which I have no current association, at the invitation of

participants who included me because they understood my commitment to understanding the specifics of coping with HIV/AIDS.

## "Doctors Death": Suicide, Murder, or Death with Dignity?

The current debate about Dr. Kevorkian's decision to ease patients' attainment of a death they define as timely seems to suggest that his behavior is unique. In fact, the only extraordinary feature of his behavior is his willingness to be open and public about his 'death machine,' thus challenging the legislature of the state of Michigan to acknowledge that technology enabling physicians to keep patients alive indefinitely may be conflicting with the well-being of those patients<sup>5</sup>.

Facilitating death - even at the request of a competent adult suffering a life-threatening illness - is nonetheless currently illegal in most U.S. jurisdictions. While many health care providers disagree with the law, few are ready to throw their careers into the self-sacrificial pyre of public opinion. This is not to say that they do not act on their convictions. Instead, the process of easing patient death is cloaked in

mystery and fear.

Because patient populations - and gay men in particular - have developed a strong sense of community, practitioners willing to help patients become known:

My family is visiting for [a national holiday] . . . That is all I have left to do . . . My lover is dead, I am blind and am starting to lose my memory . . . [My lover] lost his mind before he died . . . I hurt all the time . .. [Dr. X] will help ... I've been there several times when [(s)he] helped other people, and they did not hurt . . . not like the others, who scream and cry and plead until their bodies finally give out . . . I am so grateful to [Dr. X] for caring enough not to let some Board of healthy doctors condemn me to living out to the last breath . . . who knows how much longer. Please be careful with this information . . . nothing must stop [Dr. X]'s work. If you don't believe me, ask some others who are not so sick yet. .

Several other people's stories confirm [John's]

own preparations for death:

I met with [Dr. X] today for the first time . . . ; I had decided to kill myself yesterday, after I saw someone I used to know ... he has a bunch of degrees and he used to be so sharp, and now all he knows is pain . . . Ain't no way I'se going through this. My sister-in-law spent the night holding me, so I wouldn't do anything . . . and my friends called [Dr. X]. As long as I know that someone is ready to help me die when the time comes that my self-dignity is gone, then I can go on and maybe do some good. If anybody stops [Dr. X], I'll do myself in, though, in a minute . . . Too many people wait too long and all they'se got is pain and they can't do it no more because their mind's gone, or their bodies won't let 'em. Not me, not ever, no ma'am . . .

Under these circumstances, at what risk do I place others who are choosing to stay alive, to educate and enlighten others about HIV/AIDS, if because of my work, ancillary health care workers or law enforcement personnel tighten their inquiry into 'timely deaths?' Given that these clinicians have examined their own ethical

stance and decided to act, at what social cost do I let them be identified?

#### "Who'se gonna feed my kids?"

[Rose] is a stunning twenty-two year old woman; she looks healthy, well-groomed . . . not at all the popular vision of a Person with AIDS. She used to have a 'respectable job,' until her husband left her. A few months later, she had a visit at work:

His woman came by, screaming at me . . . I couldn't even make out what she was saying at first, accusing me of trying to kill her. I thought it was almost funny she takes my husband when he has three kids under the age of eighteen months, and she says I try to kill her. . . . Then my blood froze. She was yelling over and over "You done give him AIDS and he's given it to me." Well, that was the end of my job and it was my diagnosis . . . I had nowhere to go, my parents have no money -- they'll help sit the kids, but they can't feed us or nothing. I hit the skids . . . ; I guess I was drunk the first time this guy rented a hotel room. It was fancy, like we used to go to back

when I wasn't alone with the twins and the baby. I remember thinking while he was doing it to me "how's the rent gonna get paid?" Then, he left me three hundred dollars..

I ain't gonna say I'm proud of what I do, but shit, at least it's honest work. If folks care so much, maybe they can change the laws so I qualify for benefits. I'se got AIDS now, but not the right kind to qualify for the full benefits. My mother just paralyzed, so when I die . . . I'm trying to leave something for the kids. . .

Condoms? Sure, I carry them. Most guys ain't interested, though. They gotta know the percent of us who've got the virus, and they pay extra not to use a condom. Who'se crazy here? . . My biggest fear is getting arrested, because I'll be quarantined. I don't "spread it on purpose," but I've got enough to do to care for me and my kids. So that's my shtick . . . you ain't gonna turn me in, are you?

If I did, who would care for her children, two of whom are HIV-positive?

#### Analytic Comments: Seeking guidance

While federal regulations require mechanisms for institutional management of ethical concerns (Office for Scientific Integrity, National Institutes of Health; etc.,) each profession remains free to exercise its own judgment over research procedures, "allowing for exceptions to [its own] ethical standards if . . seem[ingly] justified by the uniqueness of the situation" (Lowman & Soule in Kimmel, 1981, p. 63). While sociology can set realistic standards, sociologists interpret them without much regard for respondent welfare. The motivations seem to lie in allowing themselves the built-in flexibility to streamline exceptions. profession has always challenged its members to gain access to governments and power brokers, and sought to equilibrate the relationship by making allowances for work done under conditions of disempowerment. Armed for combat with the powerful, sociologists may be harming the vulnerable.

Evidence of the cultural grounding of professional mores is irrefutable. The British Sociological Association harks back to traditions of *noblesse oblige*, with its call to

accountability:

Sociologists should be aware that they have some responsibility with regard to any use to which the results of their research may be put . . . They have the responsibility to consider the effects of their research upon further research. Sociologists have a particular responsibility for considering the possible application of research findings since this is in itself a sociological problem, concerned with the prevention of the misuse of research results (1982; my emphasis).

The American Sociological Association also admits that research may involve significant risks and that respondents need protection:

**B.7.** Confidential information provided by research participants must be treated as such by sociologists, even when this information enjoys no legal protection or privilege *and legal force is applied* . . . (1989; my emphasis).

However, a preliminary clause stipulates clearly that:

A.4. In presenting their work,

sociologists are obligated to report their findings fully . . . When work is presented, they are obligated to report their findings fully and without omission of significant data. . .(1989; my emphasis).

Resolution to this potentially radical contradiction is a bit facile. A colleague involved in disciplinary ethics suggests most forcibly:

This is intended to give you support once you have been asked by the law to turn over your respondent code lists. It absolutely does not mean you can suppress any data either in publication or presentation. You must analyze and present all you find. You cannot anticipate law enforcement reactions, so you should not try . . . You must always remember those are not your decisions(!) (Emphasis in the tone of voice of the informant!)

Further evidence of disciplinary self-absorption appears in the emphasis and tone of suggestions written for, marketed to, and well-received by American " . . . Students and Internal Review Boards" as "helpful advice:"<sup>6</sup>

The advantages of . . . openness and cordiality are enormous . . . Sensitivity and willingness to accommodate [subjects' and gatekeepers'] . . . interests, however inconvenient for the researcher, pay off in the long run. Insensitivity . . . has often resulted in a researcher being asked to leave the field before the project is completed (Sieber, 1992, p. 39, my emphasis).

Nowhere is there mention of the inhumanity of insensitive conduct in research . . . of the inappropriate nature of any behavior one would find objectionable if *subjected* to it, particularly in the context of research! These recommendations do not warn against harm to respondent, but rather rail against the potential inconveniences of respondent self-empowerment as a response to undue pressure by sociologists!<sup>7</sup>

Sieber suggests further that "Scientific knowledge is a most appropriate benefit . . . in return for research participation. Unfortunately, researchers often promise to give subjects the

results of their study" (Sieber, 1992, p. 101; my emphasis). This disingenuous lack of distinction between the purported 'scientific knowledge' derived by respondents and the benefits accruing to the career of a social scientist is an affront to the powerless.

Social scientists are invited to find comfort in the knowledge that 'subjects' are content with knowing that we do our jobs, get merit raises, tenure and promotion, and the sense that they have done their best by allowing strangers insights into their lives. It appears, from that perspective, that they should not expect to ever discover what we say about them, unless they learn the inner workings of academic journals and the libraries housing them!

No doubt, professional expectations that we publish hurriedly, certainly without ever 'suppressing findings' (Who has the luxury?) stem in part from a profound and eminently defensible commitment to academic freedom. Paradoxically, however, this very commitment to the freedom of researchers may spawn rules facilitating disdain for respondents' autonomy as persons. In given sociohistorical and

sociopolitical contexts, the release of controversial findings may fuel policies researchers know carry a high probability of causing significant harm to the population studied, if not to individual respondents.

Among the reasons for setting such considerations aside are the enormous potential professional costs to the researcher. example, the entire data set which provided the preamble to this article remained intentionally unaddressed for months. I waited until after the U.S. presidential election, in the hope that the Administration would acquire a newfound sensitivity to key HIV/AIDS-pertinent issues. Should that occur, I expected that findings resulting from that research would be less likely to fuel further oppressive, restrictive, arcane policies meant to impress the 'Moral Majority.' The data from the interview itself will not be published during the respondent's lifetime, unless dramatic changes in law ensure his safety from prosecution.

These decisions are grounded in theoretical assumptions which underlie my thinking.

#### Theoretical Assumptions

Although the label of 'applied' social science seems to allow an ever-greater multitude of theoretically disembodied publications, epistemological concerns about truth and authenticity [ought to] precede data collection8. Such foundational components of disciplinarity draw in part from ethics, but also from the theoretical underpinnings of one's work. For Symbolic Interactionists, the most fundamental divergence between the Chicago and the Iowa schools remains the methodological implications of the interminable opposition between 'humanistic' and 'scientific' viewpoints (Kuhn, 1964). Blumer argues for a distinctive methodology in the study of human beings, while Kuhn urges the recognition of commonality of method in all scientific disciplines. Blumer thus seeks to make modern man intelligible, an idiographic function. This is contrary to Kuhn's position, which promotes the search for universal predictions of social conduct - a nomothetic function some critics view as an unrealistic endeavor (Meltzer & Petras, 1970).

My own commitment to the Chicago school rests largely on its allowing the explicit

integration of theory and ethics. The articulation of one's understanding of truth is contingent upon researcher self-awareness not only qua researcher, but also qua fellow person. Particularly convincing arguments urging recognition of the ethical requirements of interaction reside in feminist scholarship, which offers transformational or emancipatory power resting upon feminist epistemology. This details the difficulties inherent to the dissociative processes of so-called objective research. Jaggar points out that perspective is necessarily determined by standpoint, which she defines as "a position in society from which certain features of reality come into prominence and from which others are obscured" (1983, p. 382).

This argument should carry weight for positivists, since it is both based upon and generalizable to the natural sciences. The widespread acceptance of the post-crisis stage in physics - residing in its admission of the relativity of traditional definitions of 'truth' - ought to grant the notion of 'standpoint' or 'perspective' increasing acceptability among social scientists. In physics, the current popularity of conformity and chaos theories -

offering two sides of the same coin - highlights the fluidity of even the corporeal world. Physics, as a maturing science, now admits that everything is amorphous and distinctions are merely perceptual foils easing human functioning in an indefinitely complex universe. Establishing differences is the human way of managing despite an acute shortage of the synapses needed to take in the 'true' (read 'objective') nature of being. Physical sciences now admit that 80 percent of the universe's mass is constituted of 'dark matter' (thus named because it remains neither defined nor understood). As humans studying humans,

".. [we] remember and cogitate about what was or is relevant or convenient to our own feelings. Our opponents' views differ ... not because [they] are any less true, but because their 10 percent of perception concentrates on different things and places them in a different context . . . It is quite possible that viewpoint is all there is "(Callahan, 1993:14).

Standpoint highlights the need for awareness of and consciousness about our social location and its relationship to our lived experience. From that recognition stems awareness of the different realities coexisting within one experiential context. Perceptual relativism also emphasizes individuals' different relationships to experience, as reflections of their sociopolitical and psychosocial standpoints in that experience:

The challenge to social scientists for a redefinition of the basic problem has been raised in terms of the "colonial analogy." It has been argued that the relationship between the researcher and his subjects, by definition, resembles that of the oppressor and the oppressed. [In both cases, the oppressor] defines the problem, the nature of the research, and . . the quality of interaction between him and his subjects. This . . . neo-colonialism . . . prevents most social researchers from being able accurately to observe and analyze . . . life and culture and the impact [of] oppression. . . The basic concepts and tools of white Western society are permeated by this partiality to the conceptual framework of the oppressor" (Ladner, 1987, p. 77; author's emphasis).

Even when both are physicians who historically

perceived clinical reality in much the same way, the person with HIV/AIDS and her physician, however 'objective' both try to be, necessarily live shared encounters differently. Their perspectives vary, by virtue of their differing social, economic, political, emotional, personal, interactional and experiential standpoints concerning the diagnosis. Adding a social scientist to the equation only complicates matters: we have yet one (and potentially several) other standpoints: theoretical, experiential, emotional, perceptual, gender, race-, culture-, age- and health-based 'angles,' (to name a few) each of which subtly but definitely alter perspectives.

Because sociologists as members of a profession have ignored standpoint, we lack insight into how experiential and perceptual differences in general alter perceptions in fundamental ways transcending individual awareness. Thus, we know little concerning how they permeate our reflexive commentaries as researchers, and 'theirs' as respondents. Only by acknowledging 'standpoint' can we underscore the troublesome dimensions of several assumptions underlying 'objectivity': the interchangeability of data

sources, the scientific detachment of researchers, and the intrinsically problem-denying dimensions of empirical analysis, among others. No doubt, standpoint perspective carried to its logical extreme has problematic consequences similar to those of extreme skeptical postmodernism: ".. the implication ... is that the greater the oppression, the broader or more inclusive one's potential knowledge. . . . a conclusion that few scholars can [endorse]" (McCarl Nielsen, 1992, p. 25). That extreme, however, is not necessary to the empirical applications of 'standpoint.' Even while acknowledged theoretically, standpoint need not interfere with its application to understanding individuality.

Paraphrasing Sandra Harding's argument about feminist scholarship, issues of overt ambiguity and ambivalence in our theorizing and traditional notions of 'good theory' should remain frustratingly unresolvable, because both have a great deal to offer future theories and practices (1987). I retain the notion of standpoint - ambiguous though it may be - as an acknowledgement of the individual's specific social and interactional place within the various

power dimensions relevant to an empirical enquiry. I also stress how standpoint applies to the researcher as well as the respondent. As a medical social-psychologist involved in academic and community AIDS-related activities, I depend on formal support through the academic institution where I work evidenced by the grant which sponsored the research which, in turn, facilitated the articulation of these ideas. I also depend on the host institution(s) facilitating research, several community agencies, professional societies, health care providers, and much of the apparatus of social control attendant to contemporary inner city life. Most of all, I depend in many ways upon the kindness, the openheartedness and the willingness to trust that respondents have invested in our relationship.

Therefore, I stand at a particular juncture, which unavoidably influences not only the ways in which I interact while conducting research, but also the very facts I count as data . . . and those of which I remain unaware. That I follow up an 'admission' of a particular behavior with "would you want to tell me more?" rather than with "could we now turn to your other experiences .

.." stems from how I define what is important. It also specifies what I know! I rely on intellectual and psychosocial support from likeminded (or, at least, open-minded) colleagues, supportive friends and family, and, to an amazing extent, from respondents and AIDS-community members, whose ability to relate to my interpretations validates my work in ways both different, and, on a fundamental level, more important than, collegial understanding.

Standpoint thus becomes *intrinsically ethical*; its recognition is a precondition of our sensitivity to our potential for evoking oppressive social authority vis-a-vis disempowered respondents. By definition, when we concur as sociologists that persons are unequal in power and autonomy, and that perspective participates in situation<sup>9</sup>, we are admitting that there can be no objective perspective. Furthermore, citing MacKinnon:

"... objectivity - the nonsituated, universal standpoint, whether claimed or aspired to - is a denial of the existence or potency of ... inequality that tacitly participates in constructing reality from the dominant point of view. Objectivity, as the

epistemological stance of which objectification is the social process, creates the reality it apprehends by defining as knowledge the reality it creates through its way of apprehending it. . . . The solipsism of this approach does not undercut its sincerity, but it is interest that precedes method" (1991, p. 181; my emphasis)

Another important element within feminist analyses of experience is the unavoidability of dialectic: oppositions, tensions, dilemmas and discontinuities form part of women's lived reality as 'Other' in a patriarchy (Westkott, 1979). By extension, some elements of this dialectic - and some unique facets of social reality - form part of any minority's lived experience in a society dominated by healthy white male perceptions, authority and vision:

"The category of the *Other* is as primordial as consciousness itself. In the most primitive societies, . . , one finds the expression of duality -- that of the Self and the Other . . .

We find in consciousness itself a fundamental hostility toward every other consciousness; the subject . . . sets himself up as the essential, as opposed to the other, the inessential, the object.

volunteer to become the object, the inessential; it is not the Other who, in defining himself as the Other, establishes the One. The Other is posed as such by the One in defining himself as the One" . (de Beauvoir, 1952:xvii-xviii; my emphasis))

By extension, whether one is 'Self' or 'Other' has unavoidable consequences for standpoint. My being a 40-year old white French-Canadian who has been 'Other' as a woman, a member of an ethnic and linguistic minority in her country. a visible minority while living in Harlem (New York), a member of the academy, and currently an 'alien10' in the United States, contributes to my very particular standpoint - my having and being a 'Self' - in ways I cannot detail . . . but must acknowledge and account for, if I am to understand the perspective of respondents. I concur with Abraham that "[e]xperiences happen to individuals and therefore sometimes are to be regarded as idiosyncratic; but these very same occurrences might, under other circumstances, be usefully regarded as typical" (1986, p.49).

These arguments contest the euro-, ando- and health-centric properties of traditional sociological practices, which subdue the lived actualities of people's experience to the discourses of ruling (Smith, 1990), alienating and occluding the experiential standpoints of the vulnerable and the oppressed, and replacing them by interpretations in support of the status quo. The practice of sociology as a purportedly objective, scientific enterprise self-perpetuates disengaged, insensitive and often ethically questionable research. By neglecting standpoint, researchers diminish the urgencies - and undermine the decision-making processes - of those whose very lives are grist for their mills.

From this perspective, it follows that all research unavoidably implies standpoint. Consequently, political undertones shape underlying theory, selection of methods, the nature and wording of questions, the perception of meaningful data on which the focus of analysis hinges, . . . Thus, standpoint challenges objectivity claims: "research is plagued with all the emotionality and uncertainty of any human behavior" (Ronai, 1992, p. 103). Every researcher alters 'absolute or objective'

traits of the data through reflection and contemplation, analysis and authorship, layering and restructuring, emotion and ideation. Ethics unavoidably overlay these occurrences - whether the researcher articulates ethical principles implicitly or explicitly, appropriately or not.

# Empirical Manifestations of Standpoint: Implementing Advocacy in HIV/AIDS Research

Queries about my research usually seek to know who? why? and how? My commitment to the area started nine years ago, so 'who' has changed over the years, and the 'why' is altered by imperatives of participants and place. Because as a Canadian, I consider health care a fundamental right, and disease the ultimate definer of one's disempowerment in a society that so casually denies access to it, I have chosen - and continue to choose - research participants who reside in the inner-city, whose resources are sorely depleted.

In part, this is a conscious decision to provide an ear to people who cannot afford to 'rent' one<sup>11</sup>. Because I believe in Civil Rights first, my commitment in the U.S. is to work among socioeconomically deprived minority persons in particular.

The 'how' is in line with these two breaches of objectivity: I try to provide a context within which matters relevant in some way to the research area and important to respondents can be voiced. I listen to people's stories, no matter how well or badly they fit any preexisting theory . . . because few of the theories to date are about real, everyday life in the inner-city (Dalton, 1992). I meet people at times and places of their choice . . . including squatter basement apartments and shooting galleries as well as hospital rooms and renovated townhouses. First, I do this because I am well aware of my dependency upon respondents, and of the unlikeliness of my providing them with tangible benefits in compensation for participation. Therefore, I must minimize inconvenience. Secondly, I also know that the choice of place is often a test of my commitment: I do not expect respondents to trust me unless I show in some ways that I am trustworthy.

The Pandora's box effect, which I define as the negative emotional, psychological or interactional consequences of participating in research requesting the sharing of intimate information without providing suitable outlets, is always a preeminent concern. I ensure the accessibility of a therapist, nurse, social worker or other mental health worker during the interviews. Respondents have my telephone numbers and are encouraged to contact me both during the course of the research and subsequently. In my experience, most respondents elect to remain in touch. These occurrences cause me to question the effectiveness of mechanisms when researchers only ensure access to support during the research process. I know the difficulties of being 'on call,' . . . but, through my respondents, I know the hell of living with HIV/AIDS. My understanding of ethics includes obligations to remaining available after asking difficult questions about life-wrenching experiences. Those whose goal-orientation inhibits this approach might note that, from a scientific perspective, this allows ongoing exposure to respondents' changing social reality.

## **Drawing Out Inferences: Conclusion**

Researchers shape knowledge and central tenets of science recognize that knowledge is power: neither contention is controversial. Why, then, do social scientists limit this awareness to discussions about the power elements of relationships between persons and social authorities/structures? Arguing in favor of knowledge for knowledge's sake - the very argument used to shore up commitments to absolutist positions about the non suppression of findings - is only authentic when we allow the importance of knowledge as power for the very persons who make that knowledge possible!

If (1) researchers owe their most significant debt to vulnerable respondents; (2) social scientists shape knowledge; and (3) knowledge is power, an obvious conclusion follows: researchers owe knowledge primarily to those who lack power and yet, who made the research possible. Those are the people who have most to gain from empowerment -- and yet, who are paradoxically thought of as 'subjects.' Any manifestation of the Pandora's Box Syndrome morally accrues to the researcher both as an individual and as a member of a profession. My response is to

adopt the clinical commitment to nonmaleficence, although neither my profession nor the laws of the land recognize it as a viable commitment for a social scientist.

My epistemological position - which I hope the self-evidently problematic data I shared help explain - is that my first obligation is to the respondents who allow me into their lives. Because consent is ephemeral at best, and volatile in times of stress, I define it narrowly. Unless respondents specifically permit the management of findings in ways that may place them at political risks, I do not take those risks on their behalf.

Boorse and Sorensen argue that "Ducking Harm" is, at best, cause for skepticism concerning the ethics of the duck (1988, pp. 77-91, in Fischer and Ravizza, 1991) . . . reminding us that "certainty, intent and motive are relevant" in any assessment of the morality of behavior. Obviously, we need to distinguish between professional codes as mechanisms of professional self-policing, and philosophically grounded ethics as principle-driven sets of moral obligations (Frankena, 1973)<sup>12</sup>. Too often, the

former are worded - or, equally importantly, interpreted - so as to serve merely as apologia for researcher 'autonomy.' While the ethical standards applied in professional codes are sets of normative rules, their grounding serves far broader interests than the notion of 'ethics as morality' (Serafini, 1989). Professional codes are too often rooted in self-promotion and concerns with potential lawsuits.

When this leads to realistic appraisals of risks and the resulting adoption of respondent- and self-oriented protection mechanisms such as professional liability insurance, awareness of risks is no doubt helpful. The situation is much different when researcher self-protection receives greater prominence than the welfare of powerless respondents (unlikely to retaliate if we should conduct ourselves inappropriately, since they neither read professional journals, nor know what constitutes 'appropriate' academic research!).

Clearly, the decisions I take are mine; I alone bear responsibility for them. Just as clearly, colleagues who decide to ignore the social context of information release must be prepared for the different consequences of their actions. Is my strategy acceptable? To me, it obviously is - although more than one colleague equates it with suppression. Who should decide? Does motivation count?

As an ethnographer collecting all her own data, I can accurately anticipate findings before completing the analysis. I have no statistical hiding places. I know the trends as respondents formulate them. Must I stop research when I become aware of tendencies to behavior a particular administration seeks to criminalize? Am I a political hired gun, ferreting out the information governing officials want just so they can punish those who consent to trust me? Am I entitled to decide what poses significant social risk? to weigh my obligations to respondents against my responsibilities as a member of society? Is it sufficient to assess consequences in light of context and circumstances, against a backdrop of commitments to research participants? I was trained to assume responsibility as an ethnographer for the wellbeing of all those involved in my work: respondents first, other researchers second, society next, and my own well-being and that of the discipline last. Are there compelling professional reasons to alter these priorities? Caught between the politics of AIDS and the welfare of both individual respondents and the population to which they belong, can I ever hope to find a 'neutral corner?'

### NOTES

- 1. The language in this article was carefully chosen. While I understand the etiology of the term 'research subject,' I refuse to use it, and discourage students from the practice. I fear that we underplay the importance of the words fueling our thinking about persons who let us into their lives, and that this allows us in subtle ways to objectly them.
- 2. While true in its most important constituent parts (including the dialogue), this scenario represents a collage of circumstances, physical and environmental attributes, all of which have been linked with this research at different points in time. The respondent's name is of course fictional.
- 3. See two recent edited volumes [Berg and Kenwyn (1991) and Ellis and Flaherty (1992)] for insights into empathy as a research tool. Taylor (1991) provides a brilliant articulation of the importance of authenticity in every endeavor, and more particularly in attempts at creativity.
- 4. Lowest Publishable Units allow researchers to generate literally dozens of "peer-refereed articles" from a single research project, by devoting their attention to the data, piecemeal. AIDS research has been particularly (though by no means exclusively) vulnerable to that approach. The emphasis is on each variable, which becomes the subtitle for its own article. The sense of perspective, the overarching scheme of the project is forever lost. But the resumes look good!
- 5. As of this writing, a court order temporarily inhibits enforcement of the Michigan law banning assisting anyone committing suicide. Defined as a "break" for Dr. Kevorkian, this decision may have consequences that are difficult to anticipate. Despite the ultra-conservative tendencies of the Governor, the Michigan electorate has been repeatedly found to agree that Dr. Kevorkian ought to be allowed to help patients who wish to die.
- 6. Sources have asked to remain anonymous. However, four current or past chairs of HSIRB's at various universities have concurred. Interestingly, each one is a social scientist. Philosophers in similar positions have expressed strenuous disagreement.
- 7. This problem recurs throughout the sciences. The number of scientists who have been found to have committed ethical faux pas only to be rewarded with early tenure and promotion for their

academic productivity is amply documented (Tourigny, 1992). . and suggest to all of us who worry about respondent welfare that we have a long, uphill struggle ahead!

- 8. The opportunity to teach Ethical and Philosophical Foundations in Research at the Graduate level certainly confirmed the widespread failure of social scientists to articulate their own ethical voices as a component of writing about research. Graduate students seeking models found them almost exclusively in Feminist Epistemology, although other areas such as the undercover investigation of crimes cried out for similar detailing of ethical underpinnings.
- 9. Much of the work of sociology lies in explaining how "perspective" (identified as poverty, minority status, education, race, ethnicity, age, etc., etc.) alters life chances. Therefore, a sociologist who denies the importance of standpoint needs to recognize the severity of the challenge to the very discipline this "objective" view is intended to serve!
- 10. This charming term is a very politically telling statement about the formal consideration received by those born outside this country. This is one more reminder of the ways in which labels can and do serve to keep us aware of our power vis-à-vis another!
- 11. Recently, a fifteen year old daughter whose mother is dying of AIDS, sister of two healthy siblings and two with AIDS phoned me, asking to help her find someone who could help her cope. I tried to accelerate the process to find her a psychoanalyst, a social worker, a psychiatric nurse, or anyone else. Four months later, she is still on a waiting list: she is part of a population which officially does not exist: the daughter of someone with HIV/AIDS. She is also part of a population many wish would not exist: the poor-poor, African-American, inner-city resident. . . the ones about which a police officer told me " . . with any luck, they're all killing each other off . ."
- 12. Each of the four principles of ethics autonomy, beneficence, justice, and non-maleficence warrants consideration for inclusion in every research design. I contend that autonomy as understood in the current conceptualization of informed consent can only be maintained if political risks are clearly articulated to respondents. Further, non-maleficence, requiring that we "first do no harm" is currently inferred by vulnerable respondents, and that this is promoted by researchers seeking high response rates. Justice, stipulating that

people who are equal in all relevant respects ought to be treated equally, while those who differ in said respects should be treated differently.ly, conflicts at least potentially ly with the suppression rules. Lastly, beneficence, or the commitment to removing existing g harm, cannot be considered as a potential guiding principle when the requirement of non-suppression governs a research-orientedted profession.

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