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NEW ANGLES AND TANGLES IN THE ETHICS REVIEW OF RESEARCH

ABSTRACT. This articles considers the larger, external and the micro, internal forces that impinge on the nature and impact of contemporary research-ethics codes. The larger forces that shape the impact of codes involve the increase in public and governmental concern with privacy protection, changes within disciplines, and the rise of research entrepreneurship. In terms of micro-level forces, the article explores the continuing problems associated with the bio-medical approach to research-ethics, on-going instability for some types of social research, slippages between REBs and researchers, and variability of local interpretations of ethics codes. A number of ethics-review fads also produce instability in the ethics regime.

KEY WORDS: changes in ethics regimes, ethics fads, ethics in research

In the passage of time, nothing stands still when it comes to the dynamics of research-ethics review. While complaints of researchers about national research-ethics policies are commonplace (some complaints are justified and some are not), they are rapidly overtaken by developments outside and inside the research-ethics regime. As a consequence, some complaints now take on an archaic character in light of these new developments. Any well-founded, constructive critique of national research-ethics codes must take into account the rapidly shifting sands of change.

This articles considers the larger (external) and the micro (internal) forces that impinge on the nature and impact of contemporary research-ethics codes. The larger forces that shape the impact of codes involve the increase in public and governmental concern with privacy protection, changes within disciplines themselves, and the rise of research entrepreneurship. In terms of micro-level forces, the article explores the continuing problems associated with the bio-medical approach to research-ethics, on-going instability for some types of social research, slippages between REBs and researchers, and variability of local interpretations of ethics codes. A number of research-ethics fads also produce instability in the ethics regime.

THE LARGER FORCES THAT SHAPE THE RESEARCH-ETHICS REGIMES

Of note, there are at least three areas in research-ethics regimes that are currently reshaping the relationship between research-ethics review and

research, namely (1) the increase in privacy protection, (2) changes in the disciplines themselves, and (3) the proliferation of the consumerist, capital-intensive model of research.

Increase in Privacy Protection

Whether one assigns nefarious goals of institutions to promulgate policies and laws that enhance the protection of privacy (such as to counter public accountability), or whether one sees them as merely the logical consequences of society that prides itself on a heightened sense of individualism, it is clear that contemporary concerns about privacy and confidentiality play an increasing role in research-ethics. This augmented importance of privacy and confidentiality has led the Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC, 2006) to devote a sizeable study to consider its implications for ethics in research. While this study speaks about the right of privacy from researchers, its central argument revolves around the relationship between law and ethics that have issued forth from Protection of Privacy legislations. The struggle between privacy rights and concerns regarding security or such hidden problems as child and sexual abuse has become more apparent and has cast ethics in research in a new, sometime political dimension. The conflict between law and research-ethics has become more prominent, involving criminal prosecutions and civil litigation, unanticipated "heinous discovery," and mandatory reporting laws (SSHWC, 2006: 15).

Within the Disciplines Themselves

The forces that are transforming research-ethics codes not only come from the public at large, as noted above), but also entail fundamental changes in the way various disciplines have come to practice their craft. One notes in particular the rise of qualitative research in a dozen disciplines, including educational research, nursing, social work, geron-tology, kinesiology, and even history. (Anthropology and sociology were already engaged in "qualitative" research, although it was more widely known as "field work," of "ethnographic" research). Qualitative research involves many research strategies, such as life-history, interviews, focus group, and field work (a.k.a., ethnographic research), to name a few. Over the past 10 years, however, the mixture of research-ethics review and of qualitative research and field work has produced a distinctive style of research: the interview. At the same time, there has been a substantial drop in research using field work.

   In its more traditional format, field work involves the researcher's immersion in a culture or group. Given the social nature of the

individual, it stands to reason that qualitative researchers must submerge themselves in "field work" as a means of understanding people within their social settings. Field work, however, has proven to pose a major challenge in terms of contemporary research-ethics codes. In light of this challenge and despite their promise to gain a fuller grasp of the human condition, fewer and fewer studies bear the stamp of field work. This decline is especially tragic given the venerable and rich history of field research. Van den Hoonaard and Connolly (2006) provide a summary of field work (or ethnographic or field research) which is,

> closely identified with anthropology for nearly 100 years. In its ideal form, it stands for complete immersion in a culture, learning enough about the culture to understand the native's interpretations of behaviour....What distinguishes ethnographic research from other forms of research is the close interaction between researcher and research participant or informant (not "subject"), and the gradual emergence of issues and questions to be pursued as the research moves on. "Protocols" are quite unfamiliar to ethnographers as strategies and techniques of research only become obvious once one enters the field. Anthropologists were adept at "hanging out" as one of their chief means of gathering data. The usual requirements for consent forms or even for verbal consent are based on the medical model in which the subject learns exactly what is to be done, which does not fit the ethnographic model. (van den Hoonaard & Connolly, 2006: 62)

In Canada, field research has suffered a significant decline over the past 10 years. In sociology alone, the proportion of Master's theses using research participants has dropped from 57% in 1995, in to close to 42% in 2004 (van den Hoonaard, 2006a).[1] Still more significant is the drop of field work in Master's theses in sociology from an average of 21% per year for all theses before the introduction of national research-ethics codes, to an annual average of 5.5% after the adoption of the code in 2001. Indeed, as if to reinforce the finding that field-work-based theses are in the decline, a researcher from a large Ontario university (Presentor R16)[2] had noted there has been an immense decline at the Qualitative Analysis Conferences (which has a high attendance of graduate students) of subcultural research. This is partly due to ethics review and due to decline of participant observation research as a research tool (Notes on Presentations, 14 May 2004).[3]

In anthropology, Anita Connolly and I (van den Hoonaard & Connolly, 2006) discovered that Canadian Master's theses have

increasingly come to rely on interviews as the *sole* data-gathering technique, namely 47.9% (in 2004 – the latest with available data), rather than field work. In conventional field work, interviews were *not* a main component of research, although conversations, chats, and the like were then more common than they are now. There are, of course, many advantages to relying on interviews, but the problem is compounded when no advanced analysis is performed on the interview data, i.e., without bothering with concepts or generic social processes, or when the data are still analytically attached to each individual, on an individual-by-individual basis.

In any event, these observations have underscored the process of the homogenization of methods – a research situation where several disciplines have adopted one data-gathering technique, i.e., the interview method. If interdisciplinary research is the goal, then surely it involves the integration of the plurality of methods, not the creation of a similar goal. The advent of interview-based research would lead one to conclude that we are also witnessing a pauperization of the disciplines: history, society, and culture are pushed to the background; the "voice" of the *individual* participant is privileged. For sure, it is important to hear these voices, but without placing them in a historical and social context, even these voices will carry less power.

The "interview" as the mediated exchange between research-ethics codes and the various disciplines is an interesting issue. One may well see the interview as a convenient congruence between one form of qualitative-research method with one of the most referred to method in national research-ethics codes given their source and tone in biomedical research. The "interview" has come to occupy a dominant position in contemporary methodology because it approximates an approach that medical researchers are more familiar with than with any other social-science method.

A Consumerist, Capital-intensive Model of Research as the Basis
of Research Entrepreneurship

One cannot lay the blame entirely on mandatory research-ethics codes to explain the changing nature of research. Aside from the previously mentioned larger processes that are influencing the changing relationship between ethics and research, one must also point to the consumerist, capital-intensive model of research – the basis of research entrepreneurship – as the other purveyor of change. The "ready-made" style of research not only involves interviews, but is also predicated on the use of computer coding, large samples, signed consent, protocols, and the employment of many

research assistants. This style of research speaks to a variety of discourses. It carries the patina of technology-friendly research, the language of quantitative research ("large samples"), the formality of widely accepted ethics models ("signed consent," "protocols"), and a capital-intensive approach to research ("many research assistants"). Gone are the shoe-box operations of traditional qualitative research; we now welcome the arrival of competitively well-funded research in the pursuit of practical goals for universities and groups. From the perspective of the new entrepreneurs–researchers this style of research is not an aberration; rather it fulfills the well-articulated goals of what it means to be a successful researcher. It also poses no dilemma to the current ethics regime, due to its "ready-made" style of research.

The On-Going, Small-Scale Aspects

Medical Model of Ethics is Overwhelming Social Sciences

It is now a commonly heard phrase that the current packages of national research-ethics codes are biomedical in nature. What stands out in international and national codes is their origins in medicine. The history of these codes are familiar to most readers, namely the Nuremberg Code (1947) in the aftermath of human experimentation in Nazi camps in World War II, followed by the Declaration of Helsinki in 1964, which the World Medical Association subsequently amended. The Council for International Organizations of Medical Sciences (CIOMS) and the World Health Organisation followed suit. This international concern about experiments on humans (the use of the current more neutral terms, "studies,""trials," or "research" point to the lingering worries about experimentation) penetrated national research-ethics codes and have subsequently shaped ethics codes that also govern social research, not just medical research.

The protest of social researchers against the application of such codes to their research has been well documented (e.g., van den Hoonaard, 2002). The move around the world to set up and enforce research-ethics codes echoes the Western, deductive template. Structurally, these policies produce a dislocation of the research enterprise in the social sciences. Kellner (2002) avers that the implementation of these ethics codes may "bring natural science even closer to us than it has been before the new policy came into effect."

As strange as it may seem, the biomedical basis of national research-ethics codes is even overwhelming medical research on health. The conventional biomedical concept of the "human subject," as found in

ethics codes, is out of step with WHO's own holistic definition of health, which involves "a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity"(Üstün & Jakob, 2005: 802). The "human subject" in international and national research-ethics policies is a highly individualistic, autonomous person, in contrast to WHO's holistic definition of the healthy person (van den Hoonaard, 2006b).

On-Going Instability of the Research-Ethics Enterprise

I thus aver that formal research-ethics review procedures in national codes have induced inadvertent changes in the way social scientists and researchers in the humanities conduct their research. The changes have affected their methodology, methods, and choice of research topics. While on the surface it is the social sciences that have been most strongly affected by current ethics codes, we should also include researchers in the humanities. It is fair to say that when humanities research is subject to ethics review, the research often shares its methodology with the social sciences. The choice of methodology and research topic is not impervious to research-ethics review. The impacts can be quite pervasive. There are many of such impacts, but I wish to highlight only those that are most centrally implicated in these shifts.

"*Hanging Out.*" Research-ethics review has cut a swath through traditional and major research approaches, as well as a number of more contemporary research strategies. "Hanging out" (or "mucking around"), a favourite approach in ethnographic research, is becoming a thing of the past. Hanging out was (and still is) not only quite necessary to see what interesting topics would emerge from the research, but also useful to see what research techniques might evolve that are best suited to the situation. The emergence of research questions constitutes the strength of ethnographic or inductive research. This approach requires the researcher to become more familiar with a setting, rather than starting out with foregone conclusions. As mentioned above, this research practice is on the wane.

Participatory observation is thus still experiencing difficulties. One researcher speaks of how an Institutional Review Board (IRB) "shot down" "a purely observational study," since the principal investigator could not get consent from everyone (i.e., thousands of consent forms) in a study on football-fan behaviour (SSSI Listserv, 26 Jan. 2004). Linguists apparently always face such research-ethics "problems:" an

important methodology consists in asking people their opinions about expressions in their language. They sometimes ask native speakers about basic grammaticality judgments. Linguists find these speakers in class-rooms, conferences, etc. As several linguists mentioned, a "strict literal interpretation of current guidelines can thus have a particularly chilling effect on the initial stages of research" (SSHWC, 2004).

Much research grows out of serendipity and "of the moment." While research hardly proceeds without serendipity (and hard work, presum-ably), it is difficult to ascertain when a research interest moves from the informal, serendipitous stage, to the more formal stage of enquiry. It is not at all uncommon for researchers to take advantage of serendipitous pre-research discovery to explore a topic further, entailing discussions with "research participants" and "hanging out." These research musings form an integral part of one's work as a researcher, but at what point do we declare the start of a project? Private musings are one thing, but when such musings start to involve others as co-discussants, at what stage do we formally declare these musings as research? Does one approach the REBs after all the ducks are in place? Or long before then?[4]

Journal Entries.   A genuine research-ethics problem, from the perspective of an REB, occurs when something starts as an curious observation, but then finds its way into publication. REBs also treat journal entries and diaries as research when they involve notes about one's research activities. But "what happens during dissemination," says the same researcher, "if you have not been through review?" She describes how a friend's paper was rejected from a journal not too long ago because her data – which began as informally kept journal entries for personal use and then became more systematic – was not gathered with informed consent in place and the approval of a board (SSSI Listserv, 26 Jan. 2004).

Natural Disasters Research.   The frequent occurrence of contemporary disasters should stimulate important research, but can it? Electrical blackouts, floods, and large medical emergencies (such as S.A.R.S.) preclude research because it is not usually possible to pull together ethics approval for such research in the allotted time.[5] Haggerty (2003) refers to *Everything in its Path*, Kai[6] Erikson's award-winning book about a West Virginia community destroyed by a flood (Erikson, 1976). With interviews, Erikson collected memories of that flood, with the gratitude of the interview participants. The study of such "adverse reactions" might be a pipe-dream today. In the same vein, researchers now see informal or exploratory conversations or discussions with research participants as being limited. The constraint imposed by REBs limits

initial research conversations with agency employees and spokespeople (SSHWC, 2004).

Researching Safer Topics. Particular research topics are disappearing, the engine that drives research curiosity and have become devalued, or there is an affirmation of "safe" topics of research. One researcher had this reaction when she learned of European research projects that generally do not require ethics review:

> I know that the presence of the IRB and the necessity of getting through review constrains how I even think of topics and research. I did not realize this until years ago in Spain, when I was at a conference of doctoral candidates and many of them were describing fascinating studies that made my mouth water....I had never even thought of many of their research tactics (or topics) as possible – perhaps since they weren't in my world, and I knew that there was *no* way I could ever get such a thing passed [through ethics review]. I have also steered students away from certain ideas and topics that I feel have little chance of passing a quick review. (SSSI Listserv, 26 Jan. 2004)

As another example, research on under-age children in schools seems to be waning, according to Rogers (2001). He reports that three active researchers in his Department of Educational Psychology are no longer doing research in schools and he says that "[w]e have run into too many logistics problems that is increasing our cost of doing research" (SSHWC, 2004). Similarly, there are times when delays in ethics review might prevent timely research. One REB in Eastern Canada, for example, does not meet between the end of April to the third week in September (SSHWC, 2004). Research involving schools are disadvantaged by the delays caused by such an approach.

Retroactive Approvals of Research. As it has been over 5 years since the formal introduction of research-ethics review in Canada, we now can see a number of unintended slippages between REBs and research. While no REB theoretically issues retroactive approvals of research, I have found numerous instances in my ethnographic research on REBs that such approvals are, in fact, not uncommon. For example, it may involve a student who started research before the Canadian *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* (TCPS) (MRC. et al, 1998) was implemented or when due to an oversight of a

supervisor (and no prior ethics consent for the research had been given), a student is about to graduate. REBs have also given retroactive approval when, inside a research project, the researcher finds he or she has to go back and get consent for an informal conversation, when an adjustment in the research strategy is too minor to go back to the REB, when a researcher omits doing a particular research strategy (maybe out of a choice of proposed strategies that were submitted earlier to the REB) (On-Going Research Observations, 1 Feb. 2006).[7] And do researchers go back to REB with any "significant" change in research? What constitutes a "significant" change?

Variability of Local Interpretations

It is also becomes evident that national ethics codes are not entirely to blame. In fact, as an example, the early portions of the TCPS express the need for a genuine support of the diversity of research paradigms. Researchers explain that it is the Research-Ethics Boards (REBs)[8] who configure largely in the obstacles that researchers face (see, e.g., Johnson & Altheide, 2002; Ward et al., 2004). There is a great variability among REBs who give more emphasis to ethics review than to education of researchers about ethics (Anthony, 2004). REBS, moreover, according to researchers, follow the dictum of "better safe than sorry" when assessing research proposals. Researchers, themselves, exclaim, "Don't give REBs cause to worry" and find that the whole process has a dismaying, chilling effect on research (Adler & Adler, 2002). REBs, moreover, according to some researchers foster "ethics drift" which encapsulates more and more areas of review, beyond what is necessary (Fitzgerald, 2004; Haggerty, 2003). To circumvent the "vagaries and inconsistencies" of REBs, Dolan (1999: 1010) found that qualitative researchers in Britain are now calling their studies "audits, rather than "research."

Ethics-Review Fads

Some of the instability is driven by changing concerns in research-ethics review. Ethics conferences, listservs, and emails seem to drive these "fads." The scope and intensity vary. They can involve research in the classroom, quality-assurance studies, and confidentiality of focus groups. Worries about researching closed settings where research participants know each other can also beset an REB. Another REB worry relates to snowball samples-used in settings where acquaintances are only known by word-and-mouth. This technique allows members of the researched community to configure the chain of acquaintances who researchers have used to acquire data. Most recently, the dangers of off-shore research and

harms to researchers have become a particular concern of REBs (see, e.g., National Centre for Research Methods, 2006). As an example of such concern, one religious-studies scholar reported to me that her REB created obstacles in her research (on food prepared in the kitchen by Muslim women) because it wanted her to certify that she will not be speaking with Muslim "fundamentalists" or "fanatics" – all quite unrelated to her topic on Muslim food preparation (Fieldnotes, 3 January 2005). The REB was concerned for her safety while doing research in a Balkan country.

CONCLUSION

This article has traced the shifting nature of both external and internal forces that are shaping the current status and debate on ethics review of research. The larger forces involve the increase in public and governmental concern with privacy protection, changes within disciplines, and the rise of research entrepreneurship. In terms of micro-level forces, the article explores the continuing problems associated with the bio-medical approach to research-ethics, on-going instability for some types of social research, slippages between REBs and researchers, and variability of local interpretations of ethics codes. A number of ethics-review fads also produce instability in the ethics regime.

Currently standing at the cusp of governments' internationalizing research-ethics codes, we can already discern a number of features that stand to leave a mark on the future of research in the world. First, as alluded to above, the formal research-ethics codes are so extensively based on biomedical research that they have disenfranchised many other forms of research, or at least made it more problematic for those who wish to pass ethics review. There are, however, moves underway by the trustees of these research-ethics regimes to find ways to make room for social researchers. They envision structural and textual changes in the codes.

In Canada, the Interagency Advisory Panel on Research Ethics created in 2003 the Social Sciences and Humanities Research Ethics Special Working Committee to work on such changes. It has already produced two reports (SSHWC, 2004, 2006) and another one is on its way (SSHWC, 2007).

Australia is producing discussion papers that speaks clearly about the need to integrate the social sciences in its current policy on research-ethics, in a manner that speaks more clearly to the needs of social scientists (NHMRC et al., 2006). Significantly, the statement acknowl-

edges, "the independent development of ethical codes in other disciplines, especially in the social sciences and humanities. It reflects not only the great diversity of research techniques employed within institutions but also the fact that many of these techniques have closer analogies in everyday life than in medical research practice."

In the United States, the University of Illinois at Urbana–Champaign (Center for Advanced Study Project Steering Committee, 2005) produced a white paper arguing that the ethics regime in crisis. The paper offers a number of insights on how to stem "mission creep" which focusses on the procedures of ethics approval rather than the substance of difficult ethical decisions.

As the fourth example, in the United Kingdom, efforts are underway to revisit the ethics regime. No doubt, the work undertaken by the ESRC Research Ethics Framework at the University of York and Oxford Brookes University (see e.g., ESRC, 2004) will prove useful in that regard.

While all efforts to make the ethics regime more responsive to the needs of social researchers are of course welcome, the process of this change is so very slow. Attempts to initiate the original ethics regime (that favoured the bio-medical approach over the social-sciences) were put into place without due consultation with the community of social scientists (let alone researchers in the humanities), contemporary efforts in changing the ethics regime seems to have gone in the other direction: a deliberately slow process to ensure that all parties are consulted. During the current consultative phase, however, REBs have grown accustomed to their role in the prevailing ethics regime. In the end, it might be excessively difficult to bring about the much-needed change in practice.

At the same time, moreover, one must not discount the influence of the American approach to research-ethics review which, at its heart, is strikingly different than elsewhere. Canadian research-ethics administrators annually attend large research-ethics symposia in the United States, such as F.O.C.U.S., and bring back American-inspired ideals. Even international organizations are susceptible to such influence. The Society of Research Administrators International, for example, includes only workshops that specifically address the American approach to research-ethics review, even though the 2006 meeting, for example, was held outside of the United States (SRA, 2006).

The issues facing researchers in the social sciences and the humanities are far from resolved even though the research-ethics setting is dynamic. The dynamism involves processes both external to the ethics regime and internal. What might frustrate changes in the regime that would benefit

researchers in the social sciences and humanities is the slow progress of planned changes, the increasing entrenchment of REB roles and functions, and the pervasive influence of American research-ethics review ideals and practices.

ACKNOWLEDGMENTS

NOTES

[1] During my tenure as Sociology Book-Review Editor of the *Canadian Review of Sociology and Anthropology*, May 2002–May 2004, some 200 titles passed my desk; only 27 (14%) actually involved research participants.

[2] Since 2003 I have interviewed, held discussions with, or listened to nearly 170 academics talk about the impact of research ethics on research.

[3] "Notes on Presentations" refers to the field notes I have taken during some 70 public and academic presentations on ethics in research.

[4] My suggestion would be for the researcher to initiate the immediate research on disaster, but would submit his research for REB approval once he has firmed up his or her research plans, also demonstrate to the REB that he or she has followed ethical principles of research, such as confidentiality, respect for the person, anonymity, etc.

[5] On the fateful day of 11 September 2001 after terrorists struck down the World-Trade Towers in New York City, a colleague poked her head into my office to announce the imminent collapse of the Towers. Throughout the rest of the day I took notes of conversations among students, support staff, and faculty in the hallways, and was fascinated by how news travels, urban legends in the making. For example, when I emerged from a class at 11:30 A.M., I overheard a story of how a student's uncle who worked in the Towers, was not feeling well that day and had stayed home. It was remarkable that an event taking place in a city some 13 h of a drive away and within 1 h had produced an intimate account of someone's life. It would be quite impossible to continue with that sort of research, where one's "research-self" got the better of one's personal curiosity. Did I violate ethical norms by publishing this account even in this footnote?

[6] SSSI stands for the Society for the Study of Symbolic Interactionism

[7] I noticed there was already a poster on bulletin boards at a university's seeking volunteers for a research project, but a member of an REB told me that the REB has not yet considered the application. Is this an example of a research's being jumpstarted (Fieldnote, 9 Feb. 2006) later needing retro-active approval?

[8] I use the Canadian term "Research Ethics Boards." These boards carry different names in other countries. In the United States, "Institutional Review Boards" (IRBs) is commonly used, while in the United Kingdom, the term is "local research ethics committees" (LRECs).

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