GROUNDED THEORY REVIEW
An international journal

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March/June 2010

Grounded Theory Review, Vol 9 (Issue #3), 51-56

The online version of this article can be found at:

https://groundedtheoryreview.org

Originally published by Sociology Press

https://sociologypress.com/

Archived by the Institute for Research and Theory Methodologies

https://www.mentoringresearchers.org/

A Swedish perspective on research ethics review

Hans Thulesius, M.D., G.P., Ph.D.

I have participated in writing ethical approval applications for research projects in Sweden a dozen times. I am also since some years a member of the local ethics advisory board in a mostly rural area serving 180.000 people. From that position I advise on what types of local project applications will have to be sent further to the regional ethics committee, REPN in Sweden. With that background I will try to give a brief Swedish perspective on research ethics reviews in general and regarding CGT (classic grounded theory) studies using qualitative data in particular.

The most famous Swedish example of unethical research is the 1947-1951 Vipeholm sugar trial (Krasse, 2001). Several hundred intellectually and mentally challenged persons at the Vipeholm institution were for years given an excess amount of sugar, mostly in the shape of candy. This resulted in caries that totally ruined the teeth of 50 persons. Of course participants did not give informed consent. Yet, at the time the research was not considered unethical. At least there was no debate about it.

In Sweden there are 6 REPNs each with a population base of around 1.5 million people. Above the REPN is a central research ethics committee – CEPN – to which one can appeal the decisions of the REPNs (http://www.epn.se/start/startpage.aspx). The REPN consists of one judge as a chairman, 5 scientifically competent persons and 5 laymen, all ordained by the Swedish government. In order to get the REPN to even look at an application there is a fee of 5000 SEK (700 USD) to be paid by the applicant; 16000 SEK for collaborative projects involving more than one Swedish region. Yet, student projects below the Ph.D. level are not requested to apply for REPN approval although they can get advisory statements from the REPN that also require a fee. As a consequence local ethics advisory boards have sprung up to supply the need for research ethics advice in a context where the respect for personal autonomy becomes more and more important and research ethics increasingly politically correct.

The EPNs are guided by research ethics principles that can be formulated in a number of rules. These research ethics rules deal with four different requirements: information, consent, confidentiality, and use. In brief: 1. The person potentially being researched should receive adequate information from the researcher about the aims, risks, advantages and costs of the research project as well as conditions for participating. 2. The person has the right to self decide about participation or non-participation at any time even after the project has begun. 3. The person should be guaranteed anonymity and that research data is kept safe and secret. 4. The data from the research may not be used outside of the research project.

Ethical review boards, both regional and local, deal with research methodology apart from looking at the direct ethical integrity aspects of research. It is often emphasized that research projects with a questionable methodology are unethical since they will eventually fail to produce useful results and thus they represent a waste of, mostly public, resources. This part of the research review can actually be very useful to the researcher in order to refine the study protocol that may prove valuable when applying for grants and for publishing the study.

There was a time in Sweden when projects that could be defined as societal/behavioral from a research ethics perspective were treated differently, read less critically, than projects with a more biomedical approach. This has changed since a few years so all research involving humans exposed to approaches where their integrity could be challenged in any way have to pass some sort of ethical scrutiny. To apply for ethics approval is for many researchers a red tape issue, something you try to avoid as much as possible. Yet, it is becoming increasingly difficult to do so in Sweden. A review of Swedish nursing dissertations from 1987 to 2007 show that while the early Ph.D. students avoided ethical discussions 63 out of 64 theses in 2007 had a section on research ethics. And 39 dissertations discussed ethical issues concerning methodology (Kjellström & Fridlund, 2010).

Since the experience of research methods that derail from the mainstream is still limited for the ethical review boards it is evident that CGT studies are difficult to assess from an ethical perspective. However, it is probably useful to load the ethics application with CGT jargon and to give a short explanation to it. Also, one may have to make up an interview protocol and to give

an exact number of interviewees for a CGT study in order to please the committee. Another possible strategy is in my view a more ethical (!) way to have a CGT study pass the scrutiny: Do a couple of pilot interviews, present results of a preliminary analysis and how the interviews were conducted, and eventually discuss the reaction of the respondents. This reaction is normally very positive since most people like to talk about what concerns them, ie the CGT goal of successful interview data.

What is most important for an ethics research application to get through is to write the information to the participants according to a preformed default standard. By doing that the project has tackled the fundamental challenge of satisfying the committee members' urge for a mainstream application. Something they recognize as right. So it is very useful to borrow information from projects that have passed the scrutiny before. What is difficult sometimes is to figure out when an interview study does not require an REPN approval. In Sweden, this is normally the case with research that does not impose something on someone, and research that does not try to influence another person, or does not deal with sensitive issues such as that person's health.

In a CGT study of detabooing/ tabooing I have been working on for some years, I analyze what healthy people think of euthanasia and assisted suicide. Secondary analysis of data from a postal survey that did not require REPN approval in Sweden is a vital part of the study (Helgesson, Lindblad, Thulesius & Lynöe, 2009). However, since many scientific journals (but not all) require a study to be ethically reviewed and approved to get published, the study protocol was given an CEPN advisory endorsement. As for the part of the study where data is my talks to healthy people, including participants at CGT seminars (!) and internet forum postings, we have not asked for ethical approval. Consequently, me and my two coworkers in the study, a medical ethics professor and a professor of practical philosophy, are discussing if it is OK to publish an article without having EPN approval for all the data. Funny enough one sentence in our paper goes, "To question informed consent procedures has become difficult – another indication of a new taboo under development." We will eventually submit the manuscript to a suitable journal, read a journal that normally accepts manuscripts without formal ethics approval, and see what the reviewers think. Wish us luck!

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