Symposium on ethics and public health

Epidemiology and moral philosophy

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 Authors’ abstract

To an increasing extent ethical controversies affect and sometimes obstruct public health work and epidemiological research. In order to improve communication between the concerned parties a model for identification and analysis of ethical conflicts in individual-based research has been worked out in co-operation between epidemiologists and moral philosophers.

The model has two dimensions. One dimension specifies relevant ethical principles (as beneficence, non-maleficence, autonomy and justice). The other dimension specifies the groups of persons involved in the conflict under consideration (for example: the study-population, individuals who may benefit from the results, the researchers and their personnel, the community at large).

The model has been applied to the problem of legitimacy of case-register research and to problems in psychiatric health services research as well as epidemiological research.

Introduction

It is the experience of epidemiologists in many countries that, to an increasing extent, ethical controversies affect and even obstruct public health work and epidemiological research. Such controversies may concern to what extent case-registers and record-linkage may infringe on personal autonomy and privacy, to what extent sensitive questions in surveys may cause harm to individuals etc. The controversies depend to some extent on different personal values and different perceptions of benefits and costs. But they seem also to ensue from poor communication between the concerned parties.

In order to improve this communication a simple model is introduced and applied to three ethical conflicts in individual-related research. The model has been developed in co-operation between epidemiologists and moral philosophers (1). To avoid misunderstanding we would like to stress that the model is here used as a checklist, an instrument for identification and analysis of ethical conflicts, not as a decision-model. The purpose of the paper is to show how ethical judgements can be structured and communicated. Our purpose is not to defend these judgements.

The model

The model combines ideas from Hermerén (2) and Francoeur (3) and consists of two dimensions (Table 1). In the first dimension, different groups of the persons involved in the conflict under consideration are identified, for example, the studied subjects, other citizens and the community at large.

In the second dimension the relevant ethical principles are identified. For the present analysis we have chosen the principles of beneficence, non-maleficence, autonomy and justice, but other sets of principles may be used.

The principle of beneficence implies that all persons have some moral obligation to benefit others. The ultimate aim of scientific research and public work should be benefits to society and its citizens.

The principle of non-maleficence implies that all persons have a moral obligation not to harm each other. The infliction or risk of harm to others can only be justified by the pursuit of some other value of moral relevance, principally benefits to those involved, sufficient to outweigh the harm.

The principle of autonomy implies that all persons have a moral obligation to respect each other insofar as such respect is compatible with the autonomy of all affected. The principle requires respect for the deliberated choices of those involved, their dignity and privacy.

The principle of justice implies that all persons have a moral obligation to act fairly to others. Epidemiologists have a particular obligation to do so when distributing the benefits and burdens of research.

Case-register research

The first project to be elucidated by the model concerns an investigation of potential health risks at a Swedish plant, a copper-smelter, refining ore containing different metals (4,5). It was carried out by Wall and Taube on already existing medical records and registers, including almost 4,000 men who altogether contributed 50,000 years of work. The results showed a general excess mortality among the

Key words

Epidemiology; research ethics; methods of analysis.
studied workers, especially in death from cancer and
diseases of the circulatory system and among workers
in the roaster-and-arsenic department. As a result of
the study considerable improvements in the working
environment have been instituted and the high-risk
areas of work have been closed.

This example allows for a comparison of ethical costs
and benefits between two different study-designs with
and without informed consent (Table 2).

The actual study was conducted without the
informed consent of the studied workers. This design
reduced the attrition rate to almost zero, an important
contribution to the scientific validity of the study. The
benefits of the results will irrefutably be gained by
future workers but to some extent also by exposed
workers, particularly those who continue to work in
the plant for several years. Improved health status of
future workers also, through decreased medical-care
costs, implies benefits for the community at large. On
the other hand, the absence of informed consent from
the study subjects when collecting data from records
and registers entails autonomy costs.

Correspondingly, no such costs may be recorded in
an alternative hypothetical design, which would
include the demand for informed consent from 4,000
exposed workers. In such a design, however,
substantial attrition may be expected, reducing the
scientific value of the results and thus the potential
benefits.

In this example the model demonstrates the typical
dilemma of public-health research – valid scientific
information may not be obtained without some
infringement of personal autonomy. It also makes clear
that relevant ethical considerations may include the
interests of concerned groups other than the studied
subjects and also conflicts of interest other than
toetween these subjects and ‘the community’.

Psychological autopsies of suicides

The next example concerns a recent Swedish study of
psychological autopsies after suicide (6). The design
and methodology were conventional for this kind of
research. Relatives or others close to the persons who
had committed suicide were interviewed by a
psychiatrist some months after the suicide to get
information about the pre-suicidal conditions. Ethical
considerations regarding the study are particularly
interesting, as a member of an ethical review
committee tried to stop the project, stating that it
would be unethical to trouble the relatives with
interviews.

The risk for such costs was investigated in the study.
A social worker contacted the study-subjects some
time after the psychiatrists’ interviews and asked for
their reactions. These proved to be overwhelmingly
positive. Emotional benefits were reported by 65 per
cent, often such benefits were said to be great, while
nine per cent stated they would rather not have
participated. These negative emotional reactions,
however, seem to have been rather weak.

Applying our model and limiting the account to the
most obviously relevant ethical principles, in this case
beneficence and non-maleficence (Table 3), the
outcome for the interviewed relatives may be rated as
very positive with respect to the principle of
beneficence with slight violation of the principle of
non-maleficence. Regarding other persons involved,
the research results indicate at least moderate benefits
for future suicidal risks and their relatives and for the
participating psychiatrist. Ethical costs which became
very clear, when using the model as a kind of screening
instrument, were reports about marked emotional
stress on the part of the investigating psychiatrists –
carried by the seriousness of the subject and the
ambition to meet the relatives in a psychiatrically
adequate and responsible way.

In this case the comparison between the alternatives,
to carry out a study of psychological autopsies or not,
can be expressed not only at the nominal level of the
earlier example but at an ordinal level. The benefits for
the primary group concerned, the relatives of those
who committed suicide, seemed to be much greater
than the costs.

Nevertheles, the ethical analysis makes it obvious
that further efforts are needed to attempt to reduce the
costs observed for some relatives and for the
researchers.

An HIV-prevention project

The two examples presented so far have in principle
aimed at qualitative comparisons. In the third
example, the moral philosopher in our group (TN), has
taken yet another step, aiming at quantitative
assessment of relevant ethical costs and benefits (7).
The problem to be analysed concerns a very
controversial public-health issue in Sweden: whether it
is morally justifiable to distribute clean syringes and
injection needles among intravenous drug-users. In
this case the goal of preventing HIV-infections may be
opposed to the goal of reducing intravenous drug
abuse.

In this case the assessments have been restricted to
the principle of beneficence and non-maleficence for
three concerned groups:

- present intravenous drug-abusers,
- their sexual partners,
- potential new abusers, recruited by the syringe-
distribution programme.

The official Swedish health policy has given strong
priority to the goal of reducing drug-abuse. Hence an
increased recruitment of new drug-abusers may be
defined as ethical costs concerning the principle of
non-maleficence. Correspondingly, if this Swedish
health policy implies an increase in the rate of HIV-
infected individuals, this may also be defined as ethical
costs.

Now, when applying an interval scale to the existing
empirical evidence (Table 4), the continuation of the traditional health policy may be defined as a baseline, a zero alternative. This can be compared with the outcome of an experimental situation in the south of Sweden, where the doctors in charge have deviated from the Swedish official policy and implemented a syringe-distribution programme. There are as yet no indications of recruitment of new abusers, the most serious potential ethical cost of the programme, but future risks do exist. These risks are given the arbitrary value of minus five by Nilstun. The interval thus obtained between the value zero, no programme, and -5, the estimated value of risk for recruiting new abusers, will set the standard for the rating scale. Results from social surveys indicate that the sharing of syringes and needles was considerably less common after the programme was introduced. These indications are given the value +8. The probable benefits for the sexual partners of the abusers are, cautiously, given the value of +3. Finally, the potential risk of increased intravenous drug-abuse among the established abusers, who get the clean syringes, is given the value of -2.

Summarising the costs and benefits results in the net value of +4. (In order fully to understand this use of the model the reader is strongly recommended to make his or her own assessments.) It may seem provocative, even presumptuous, to put numbers on ethical values in this way.

However, it must be emphasised that there is no pretension to present ‘the objective ethical costs and benefits’ of the HIV-prevention programme. We believe that there are no such objective costs and benefits to be found. Other judges may, because of different values or different assessment of obtainable facts, arrive at other figures.

The purpose of this attempt to quantify ethical costs and benefits is to compel the disputing parties to ‘come out’ and consider the available empirical evidence in the light of their explicit ethical values.

**Discussion**

In this paper we have used the model as a checklist, as an instrument for identification and analysis of ethical conflicts, not as a decision-model. We have illustrated how ethical judgements can be structured and communicated. But we have not defended these judgements.

To defend a particular ethical decision further requirements must be satisfied. First, the choice of principles is in need of justification. Inspired by Beauchamp and Childress (8) we have used the principles of beneficence, non-maleficence, autonomy and justice. Examples of other value premises are Mill’s utilitarianism (9), Rawls’s theory of justice (10) and Nozick’s liberal theory (11). Second, the chosen principles should be made more precise. In this paper the principles have been used more as structural concepts in our presentation than substantial guidelines for assessment of costs and benefits. Third, a method for balancing the countervailing claims of different principles is needed. We have done this balancing in a rather intuitive way.

Several decision-making methods in ethics requiring quantification have been worked out, many of which are described and applied in (3). We are aware of the controversial nature of such methods but are convinced that (something like) quantification is often presupposed in ethical reasoning. We agree with Beauchamp and Childress (12) when they write that one’s

‘... actual duty is ... determined by the balance of the respective weights of the competing prima facie duties in the situation. One might say that the prima facie duties count even when they do not win.’

Some of our students in postgraduate education have found the use of interval data to be a fruitful exercise which forced them to make their values explicit – but for others, we admit, the experience has been rather frustrating. Though controversial, the use of numbers to express and communicate personal conceptions of costs and benefits should not be excluded as a tool in the analysis of ethical conflicts.

Though the model may be used as a decision-model, we believe that its main value is heuristic. In our experience it has stimulated a more comprehensive identification of ethical issues and more distinct arguments. It gives a common basis and structure for the much needed empirical studies of ethical problems and provides an incentive to re-examine the situation, the alterations and their probable consequences. The understanding provided by the model is also helpful in overcoming the paralysing feeling of facing an unsolvable ethical dilemma.

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**References**


### Table 1

A model for description and analysis of ethical conflicts in epidemiological research

<table>
<thead>
<tr>
<th>Ethical principles</th>
<th>Persons involved</th>
<th>Beneficence</th>
<th>Non-maleficence</th>
<th>Autonomy</th>
<th>Justice</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

### Table 2

Potential health risks at a Swedish plant – comparison of alternative designs

<table>
<thead>
<tr>
<th>No informed consent</th>
<th>Informed consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons involved</td>
<td>Beneficence</td>
</tr>
<tr>
<td>Exposed workers</td>
<td>Known costs</td>
</tr>
<tr>
<td>Future workers</td>
<td>Known benefits</td>
</tr>
<tr>
<td>Community at large</td>
<td>Known benefits</td>
</tr>
<tr>
<td>Nominal level</td>
<td></td>
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</tbody>
</table>

### Table 3

Psychological autopsies of suicide

<table>
<thead>
<tr>
<th>Persons involved</th>
<th>Beneficence</th>
<th>Non-maleficence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatives of the deceased persons</td>
<td>Considerable benefits</td>
<td>Small costs</td>
</tr>
<tr>
<td>Persons with future suicidal risk</td>
<td>Moderate benefits</td>
<td></td>
</tr>
<tr>
<td>Relatives of persons with future suicidal risk</td>
<td>Moderate benefits</td>
<td></td>
</tr>
<tr>
<td>Investigating psychiatrists</td>
<td>Moderate benefits</td>
<td>Moderate costs</td>
</tr>
<tr>
<td>Ordinal level</td>
<td></td>
<td></td>
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</tbody>
</table>

### Table 4

An HIV-prevention project – comparison between a syringe-distribution programme and traditional Swedish health policy with no such distribution (baseline)

<table>
<thead>
<tr>
<th>Persons involved</th>
<th>Beneficence</th>
<th>Non-maleficence</th>
<th>Sum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present intravenous drug-abusers</td>
<td>+8</td>
<td>-2</td>
<td>+6</td>
</tr>
<tr>
<td>Their sexual partners</td>
<td>+3</td>
<td>0</td>
<td>+3</td>
</tr>
<tr>
<td>Potential new abusers</td>
<td>0</td>
<td>-5</td>
<td>-5</td>
</tr>
<tr>
<td>Sum</td>
<td>+11</td>
<td>-7</td>
<td>+4</td>
</tr>
<tr>
<td>Interval level</td>
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<td></td>
<td></td>
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</table>