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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

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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 between 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 – caused 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.

Nevertheless, 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 unresolvable ethical dilemma.

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- (12) See reference (8): 51–52.

Table 1

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

Ethical principles				
Persons involved	Beneficence	Non-maleficence	Autonomy	Justice
1				
2				
3				
4				
5				

Table 2

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

No informed consent		Informed consent		
Persons involved	Beneficence	Autonomy	Beneficence	Autonomy
Exposed workers		Known costs		No costs
Future workers	Known benefits		Uncertain benefits	
Community at large	Known benefits		Uncertain benefits	
Nominal level				

Table 3

Psychological autopsies of suicide

Persons involved	Beneficence	Non-maleficence
Relatives of the deceased persons	Considerable benefits	Small costs
Persons with future suicidal risk	Moderate benefits	
Relatives of persons with future suicidal risk	Moderate benefits	
Investigating psychiatrists	Moderate benefits	Moderate costs
Ordinal level		

Table 4

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

Persons involved	Beneficence	Non-maleficence	Sum
Present intravenous drug-abusers	+8	-2	+6
Their sexual partners	+3	0	+3
Potential new abusers	0	-5	-5
Sum	+11	-7	+4
Interval level			