



## What is the role of empirical research in bioethical reflection and decision-making? An ethical analysis

Pascal Borry, Paul Schotsmans and Kris Dierickx

Center for Biomedical Ethics and Law, K.U. Leuven, Kapucijnenvoer 35/3, 3000 Leuven, Belgium  
(E-mail: Pascal.Borry@med.kuleuven.ac.be)

**Abstract.** The field of bioethics is increasingly coming into contact with empirical research findings. In this article, we ask what role empirical research can play in the process of ethical clarification and decision-making. Ethical reflection almost always proceeds in three steps: the description of the moral question, the assessment of the moral question and the evaluation of the decision-making. Empirical research can contribute to each step of this process. In the description of the moral object, first of all, empirical research has a role to play in the description of morally relevant facts. It plays a role in answering the “reality-revealing questions” (what, why, how, who, where and when), in assessing the consequences and in proposing alternative courses of action. Secondly, empirical research plays a role in assessing the moral question. It must be acknowledged that research possesses “the normative power of the factual,” which can also become normative by suppressing other norms. However, inductive normativity should always be balanced out by a deductive form of normativity. Thirdly, empirical research also has a role to play in evaluating the decision-making process. It can rule out certain moral choices by pointing out the occurrence of certain unexpected consequences or effects. It can also be useful, however, as a sociology of bioethics in which the discipline of bioethics itself becomes an object of research.

**Key words:** empirical ethics, empirical research, ethical methodology, medical ethics, meta-ethics

### Introduction

Anyone familiar with the scholarly literature in bioethics cannot avoid the observation that interest in empirical research has recently increased. Renowned bioethicists such as Callahan (1980) and Thomasma (1985) have made appeals to work together with social scientists, being convinced that their research findings could improve ethical decision-making. These appeals did not fall on deaf ears: various authors in the past decade have indicated that a novel form of scholarship in bioethics (Brody, 1990) or a “new form of ethics paper,” has appeared (Arnold and Forrow, 1993) and that bioethicists’ interest in empirical data continues to grow (Molewijk et al., 2003). A limited empirical study also showed that the number of empirical postings in the bioethics literature increased from 1.5% in 1980 to more than 5% in 1989 (Sugarman et al., 2001).

By a “new form of ethics paper” we mean the literature that is categorized as sociological (Fox and De Vries, 1998), empirical (Singer, 1990), or experimental (Thomasma, 1985), but also focuses on bioethical themes. This alternative bioethical literature has methodological roots in the social sciences and uses methods such as case studies, surveys, experiments, interviews, and participatory observation. The common objective is the gathering of qualitative and

quantitative data about ethical issues. Unlike studies of ethical dilemmas via *a priori* ethical theories, principles or rules, empirical studies focus on “ethics in action” (ten Have and Lelie, 1998, p. 269). The themes studied by means of empirical research vary from how theoretical concepts such as dignity and autonomy are interpreted in the respective contexts of terminal illness (Chochinov et al., 2002) or hospital practice (Schemer, 2001), to the norms and values that appear in relation to organ transplantation (Guttmann and Guttmann, 1993), informed consent and truth-telling (Dalla-Vorgia et al., 1992), end-of-life decisions (van Delden et al., 1993), persistent vegetative states (Dierickx et al., 1998), genetic testing and screening (Dierickx, 1999), etc. In addition to this, there is also empirical research that assesses the consequences of a particular action or decision (Taesdale and Kent, 1995). We consider the empirical field developed here to be an interdisciplinary one that benefits not only from the work of sociologists and social psychologists, but also from researchers in medicine and public health, epidemiologists, health economists, and physicians.

That the field of empirical research has appeared on the horizon of bioethics does not mean however that they are now suddenly hand-in-hand. Pragmatic, historical and meta-ethical factors have in the past soured relations between the two disciplines, and will

undoubtedly continue to do so in the future. Nevertheless, the epistemological climate is currently much more open to empirical research. The explanation for this lies in a dissatisfaction with a foundationalist interpretation of applied ethics, the development of clinical bioethics and the emergence of evidence-based medicine (Borry et al., 2005). Although various authors have stressed the importance of reflecting on the role of empirical research in bioethics, only a very few articles actually undertake such a meta-ethical reflection (Brody, 1993; Pearlman et al., 1993; Braddock, 1994; Haimes, 2002; van der Scheer et al., 2003). Empirical research in bioethics has increased greatly in the past two decades, but it remains unclear how this will affect bioethical reflection. This lingering uncertainty is the most controversial topic in the debate over the rise of the empirical approach in bioethics. The dialogue concerning its actual, concrete contribution is contentious. Many ethicists fear that the factual situation will dictate the way that we “ought” to behave (Pellegrino, 1995). We begin this article by presenting a concrete example of the decision-making process in withholding or withdrawing intensive invasive treatment in a neonatology ward (McHaffie et al., 2001). This example illustrates the need for reflection on the contribution of empirical research to ethical clarification and decision-making. We proceed to analyze the unique features of ethical problems and we examine what contribution empirical research might make to the ethical clarification and decision-making process. As a last remark we should make clear that the concept of ethics we are talking about, is concentrated on the treatment and resolution of ethical problems. This is a rather practical concept of ethics and we are fully aware that the field of ethics is much broader than this interpretation of ethics.

### An example

With the help of an example taken from neonatology, we will illustrate the urgency of reflecting on the contribution of empirical research to the ethical clarification and decision-making process. Decisions regarding withholding or withdrawing intensive invasive treatment in neonatology wards are ethically sensitive, and much philosophical thought has already been given to the issues (Yu, 1997). A set of guidelines has also been drafted (Royal College of Paediatrics and Child Health, 1997; British Medical Association, 1999). However, little was hitherto known about parental input in the decision-making process. A recent study (McHaffie et al., 2001) on the basis of in-depth interviews in Scotland with 176 medical and nursing staff and 108 parents of babies

where the withholding or withdrawing of treatment became an issue has shown that the majority of physicians and nurses believe that the final decision about the fate of the child does not lie with the child's parents. Because they believe this decision weighs too heavily on the parents, they state that the decision whether or not to withhold or withdraw treatment ultimately lies with the physician. The majority of physicians agree that an attempt should be made to find common ground in the decision-making process. From the point of view of the parents, however, the results are surprising and contradictory. Not only do the majority of parents indicate that they would like the opportunity to decide about treatment limitation, they also indicate that in most cases they are able to shoulder this responsibility. In 56% of cases, moreover, parents actually had the feeling that they had made the decision themselves, not someone on the medical staff.

The debate about the role of empirical research in bioethical decision-making arises when authors draw normative conclusions after having described the research findings (our italics):

It is evident *from our findings* that the majority of parents want to be included in decision making about treatment limitation, and they appear to have the capacity to take on the role of final arbiters without adverse sequelae. *It can be concluded* then that parents *ought to be given* the opportunity to take this responsibility even though a significant number of our respondents declined to do so, indicating that they should not be obliged to make the ultimate decision themselves. (McHaffie, 2001, p. 108)

What is striking is not so much that the parents' opinions are taken seriously and that a decision is made to give parents the chance to decide about the fate of their children; what is striking is that the impression is given that this only occurs on the basis of the results of empirical research, which means that the authors ignore the fact that values, norms and principles play a crucial role in adopting a position. Such a decision assigns enormous decision powers to the parents. This can only be a result of the belief that the parents' autonomy and responsibility for their children is so important that it overrules medical authority. We would like to explicate the value patterns underlying the article's conclusion, which that conclusion only reflects in an implicit manner. This brings us straight to the heart of the issue: How do empirical research findings implicitly embody certain norms and values? Can research findings help in resolving moral dilemmas? What is the value of empirical research for the ethical clarification and decision-making process? The first step in finding

an answer to these questions is to reflect on the task and methods of ethics.

### The identity of the ethical problem

In order to gain a clearer view of the way in which empirical research might have a role to play in the ethical clarification and decision-making process, it is important to get some idea of the identity of the ethical problem. What is the aim of ethics and what are the various stepping stones which are almost invariably present in an ethical process of reflection? Although various concepts of ethics have been proposed in the history of ethics, two questions have remained persistent: “what kind of life is best for the individual and how ought one to behave in regard to other individuals and society as a whole?” (Slote, 1995, p. 721). For bioethics, the goal is much the same, only the field of application is further specified. The next question we need to ask is how does a moral evaluation process take place? It should be clear that ethics implies a specific point of view, a particular way of looking at the moral problem. The ethical point of view is normative, anti-dogmatic, argumentative and it seeks consensus (van Willigenburg, 1993). By normative, we mean that an ethical problem expects to be answered in terms of good, evil, right or wrong. By anti-dogmatic, we mean that ethical dilemmas cannot be resolved by appealing to arguments from authority or absolute principles. Ethical decision-making is not a matter of absolutely right or absolutely wrong, but a careful weighing of relevant norms and values. Moral truth remains the goal, but is unattainable as such. By argumentative, we mean that moral decision-making can only be regarded as acceptable if the decision is supported by good arguments, since moral argumentation and decision-making cannot be merely a subjective matter. By consensus, we mean that in any moral judgement, the various moral viewpoints should be examined as thoroughly as possible. The interests and ideas of all parties must be taken into consideration when passing a moral judgement.

Now that we have a clear idea of the ethical point of view, we can explain how a moral problem should be dealt with. We describe here a plan for ethical reflection which indicates the different steps taken in an ethical clarification and decision-making procedure. The standpoint of this article is that, at each step, we will look at the way in which empirical research might be integrated. At the same time, we will indicate a number of limitations. The three conceptual steps are the following: 1) the definition and description of the moral question; 2) the assessment of the moral question; 3) the evaluation of the decision-making.

In the first step, the moral question is defined and described, which entails a close analysis of the action or choice one wishes to assess. An action cannot be assessed in isolation, but only at the moment when the circumstances in which the action takes place have been clearly described. Maguire (1984) claims that the following questions are relevant when describing the moral question: what, why, how, who, where and when. These are quite obvious but nevertheless essential questions, and a correct answer can often resolve moral conflicts (*Ibid.*, p. 66). If not all of these questions are answered, then there is a risk that the judgement will only be based on a partial reality. In addition to these reality-revealing questions, Maguire poses two other questions which are relevant to the description of the moral problem: What are the foreseeable effects? What are the existent viable alternatives? Only after these questions have been answered has the moral object been sufficiently described. By carrying out this analysis with great care, one gains insight into all the essential circumstances of the case. The second step is the assessment of the moral problem. This step in the analysis is the integration of principles, norms, virtues and values in a specific case. Ethics is not satisfied with merely observing and explaining the facts, it also wants to pass judgement on them. To this end, ethics can make use of its normative instruments. After it has been determined which norms, values, virtues or principles are relevant to a given ethical problem, an evaluation is carried out which will be the deciding factor in the ethical decision-making process. The ultimate result of the evaluation process is not fixed in advance. In a different moral case, different norms and values might have priority over others. The third step is the evaluation of the decision-making. This step is often neglected. Nevertheless it is important that decisions are subject to continual evaluation. In a concrete case, it is always possible to take the “wrong” decision. It is important to acknowledge this mistake and to take a different decision in analogous cases in the future. Evaluation involves not only assessing the effects but also introspection: how did I make this decision? What norms and values were invoked? To what extent is my decision determined by economic, cultural or socio-historical factors?

### How can empirical research contribute to ethical reflection and decision-making?

The example described above (II) is interesting because it also involves a meta-ethical reflection on the contribution of empirical research to ethics. The authors (McHaffie et al., 2001) distinguish seven functions fulfilled by this empirical research: 1) It

challenges authority and experience by showing how practice varies; 2) It illuminates understanding of the reality of ethical decision-making; 3) It raises awareness of the underlying important questions and ethical implications of various practices; 4) It explores the limits of tolerance and acceptance; 5) It gives insights into what constitutes a good process; 6) It provides a yardstick for what other parents think; 7) It offers a comprehensive picture. This analysis begins from the authors' research principles and offers a good overview of how they assess the moral value of their empirical work. We, however, would like to take the opposite approach: how does empirical research fit into the different steps of the ethical clarification and decision-making process? This means that the study design is not at the centre of our concerns. We do not deny that different research methods can have different meanings for ethical reflection, but neither is it the case that there is only one research methodology (e.g. ethnography or surveys) that leads to ethically relevant results. Many authors stress the value of ethnographic and qualitative research (Jennings, 1990; Hoffmaster, 1992; Gallagher et al., 1998), but others also point to the value of quantitative research for bioethics (Wertz, 1998). We assume that qualitative and quantitative approaches constitute alternative styles of viewing and interpreting the reality. Both perspectives are complementary and can make significant and positive contributions to ethics. In what follows, we examine the role empirical research plays in the three steps of the moral evaluation: 1) the description of the moral question; 2) the assessment of the moral question; 3) the evaluation of the decision-making.

### 1. *The description of the moral question*

Ethics does not exist in a vacuum, but in a concrete context. The first step in ethical reflection is the description of the moral question, since a moral judgement cannot be made without having some idea of the circumstances in which the choice or action takes place. Before examining the reality-revealing questions (what, why, how, who, where and when) and the question of consequences and alternatives, a few remarks should be made. First of all, not all questions are equally relevant in an analysis of a particular ethical question or in assessing a particular action. Secondly, these questions are open questions and they must be interpreted differently in each context. For instance, the question "who?" can refer to the physician, the patient, the nurse or other persons. So the cases presented here should be considered as exemplars. Thirdly, the questions are simply instruments. If certain relevant information cannot be entirely subsumed under a certain question, that is no reason

to ignore it. Finally, we would like to reiterate that the aim of this section is to illustrate the role of empirical research in describing the moral problem. It is only in a subsequent phase of the ethical process of reflection that the moral value of the research findings will be evaluated.

### *What?*

What is the issue? What is the ethical problem, the ethical question or the case that demands an ethical judgement? These appear to be basic questions but that is actually not the case. Moral problems do not simply lie in wait for us; they only become moral problems once they receive that status. Even though, from a Western standpoint, moral dilemmas often seem universal, in reality they are dependent on time and culture (Light and McGee, 1998, p. 9). "Morality is socially situated. The decision to become 'ethical' is not made in a vacuum: Ideas about right and wrong, proper and improper, are shaped by social context" (De Vries and Subedi, 1998, p. xi). Of course this does not mean that only customs that appear problematic in a certain context can become the object of ethical discussion. Ethical problems can be raised, studied and dealt with across the borders of particular traditions and customs. Respect for cultural and ethical diversity does not give a free hand to the moral norms of a particular context. That would run the risk of an ethical relativism in which everyone has their own truth. In such a case ethics becomes superfluous and is completely reduced to the moral norms of the context in question. An important premise therefore is that every action or every decision can become the object of ethical reflection. Ethical problems are not merely "conflicts of values" (Christie and Hoffmaster, 1986, p. xv), i.e. choices between two conflicting alternatives. Every action or situation can become the object of an ethical inquiry.

Empirical research can assist in identifying ethical problems that arise in the practice of medicine (Brody, 1990). It can help to outline rarely studied ethical problems (Braddock, 1994). Research can focus on new subjects deserving ethical reflection, such as evidence-based medicine, or problems that only receive minimal ethical consideration (Reiser, 1987; Fulford, 1994). For example, empirical research can point to the importance of reflection for choices that seem routine at first sight, but which are really quite fundamental, such as mealtimes for patients or daily hygiene. These are everyday decisions and actions with an enormous impact on patients. Fetters and Brody (1999) emphasize the benefits that epidemiology could bring to bioethics, by providing insight into the prevalence of bioethical topics. They begin from the idea that one cannot get an accurate representation

of ethical problems if one looks only at tertiary care settings. Epidemiological research has shown that the health problems arising in primary care are completely different from those in tertiary care. For instance, the prevalence of coronary artery disease with a similar medical history is 67% in tertiary care and only 21% in primary care (Sox et al., 1990). According to Fetters and Brody, the difference in setting is not only essential for the organization of health care or medical services but also for ethical questioning. They believe that bioethics concentrates too much on ethical problems in the hospital and tertiary care while ignoring the health encounters of primary care and non-medical settings, and this at a time when the ethical dilemmas, the moral agents, and the solutions to these dilemmas can be very diverse in the two contexts. They argue that the following ethical dilemmas are scarcely mentioned in bioethics: treatment refusals, financial conflicts of interests, time constraints, testing and treating because of legal concerns, difficult patients, falsifications of medical records, excessive regulation, etc. According to them, empirical research is needed primarily in order to provide a valuable population perspective to the field of bioethics. For these authors, empirical research can make a contribution to setting research priorities, raising funds for research and cost-cutting.

#### *Why?*

To grasp the real meaning of a certain action or choice, we must look at the subject's reasons or motivation. What reasons or subjective grounds would incite someone to take a particular action or choice? What significance does someone place on the action he carries out? Of course, there is no univocal answer to this question; a choice or action is often driven by many different conscious and unconscious motives. It is important to point out that motives should not always be interpreted individually. Every act is conditioned by social, cultural or geographical factors. From this it becomes clear that human action does not take place in a vacuum but in a concrete historical context. Empirical research is particularly well placed to describe this context and to provide models for explaining why someone came to carry out a certain behaviour. In the context of donor insemination (DI) for instance, the issue of confidentiality is an important field for ethical discussion. The question is whether it would be better to inform children of their DI origin or to keep this a secret. A central consideration in this respect is the question why parents decide to inform or not to inform their children about their genetic descent. Empirical research can survey the attitudes of parents as well as the motives underlying certain attitudes or choices of action. A systematic review bringing together the different research results can provide a

good summary of these motives. Brewaeys (1996) reviewed 23 studies between 1980 and 1995. The great majority of parents had not yet informed their children (range: 70%–100%) and were not planning to do so in the future (range: 47%–92%). Various reasons were given to legitimate the choice not to inform their children: worries about the well-being of the child, uncertainty about when and how to tell them, and fear that knowing would disturb the father-child relationship (Brewaeys, 2001). Empirical research can also provide insights into the influence of the historical context on ethical choices. Given the greater social openness regarding the application of DI to fertility problems, it would be interesting to know whether this new context has not altered parents' attitudes such that they are more inclined than in the past to inform their children of their genetic descent. However, a study carried out in the Netherlands comparing DI parents between 1980 and 1996 showed no difference. The number of parents who cling to donor anonymity and secrecy towards the children is the same over this period (van Berkel et al., 1999). Other studies have also shown that the majority continues to opt not to tell their children about the DI treatment (Golombok et al., 1996; Leiblum and Aviv, 1997; Nachtigall, 1998). That context is a determining factor in the ethical decisions made by parents is clearly demonstrated in a study from New Zealand where 94% of the respondents had been encouraged during their counselling to disclose to their children the circumstances of their conception. This clearly had an impact on the parents, since 30% told their children at a relatively young age and 77% of the remaining parents intended to tell their children at a later age (Rumball and Adair, 1999). The use of empirical research therefore enriches our knowledge of attitudes, the reasons underlying these attitudes, and the context in which these attitudes take shape. Empirical research can also bring to light differences between what people say they will do and what they actually end up doing (Bosk, 1999, p. 66).

#### *How?*

The next question that must be asked is the question regarding the concrete action. People can act on the basis of an ethically good attitude, but this is no guarantee that the action will be good: "What you might be doing may be good; why you are doing it may be excellent; but the action may fail morally by how you do it." (Maguire, 1984, p. 70) The choice one makes may be morally good, while the means used to fulfill the choice can make it immoral. This question, then, has much to do with the way in which something occurs. Here again, empirical research can play a role. For example, it can describe how concrete actions or decisions are made. The example of with-

holding or withdrawing intensive treatment in neonatal practice (McHaffie et al., 2001) is a good illustration of how empirical research can give us insight into a question. We have already said that physicians usually make the final decision because they think that parents cannot bear that responsibility. The study is interesting because the parents' perception is just the opposite: they believe that they are able to bear this responsibility and therefore would like the opportunity to make such a decision. This empirical research puts pressure on the moral deliberation and decision-making process as it currently takes place, and reorients the discussion to the way in which decisions about withholding and withdrawing intensive treatment should be taking place.

#### *Who?*

It should be clear that the question "who?" is open to differing interpretations. It might be the person who is expected to make the ethical decision or action, or the person who is the object of the decision or action. Moreover, it is not necessarily a single person: it might be a collective. Persons have an irreducible unicity and are characterized by various personal features. Groups also possess certain identity features, but these features do not always apply to individuals within the group, and vice versa. To do ethics is to take account of the identity and history of the person or group in question. Empirical research can assist in revealing the identity of an individual or group. Ethical reflection on the issue of fertility, for instance, entails the acquisition of knowledge about infertility or subfertility for the persons involved. It entails being clear about the stress generated by non-fulfilment of the wish for a child, stress generated by a situation of subfertility and the subfertility treatment (Demyttenaere, 2000). Empirical research can address the emotional pressures of subfertility (depression, anxiety, anger, marital and psychosexual dysfunction, social isolation, etc.). Research shows, for instance, that women have greater difficulty dealing with the discovery of their infertility, since they experience more intensely than men the resulting damage to their identity (Olshansky, 1987), feelings of imperfection (Valentine, 1987) and become more easily depressed (Wright et al., 1991). Moreover, they are quicker to avoid all contact with children or pregnant women (Sabatelli et al., 1988). Empirical research can also provide insight into the way in which treatment for subfertility is experienced. There exist studies that survey people's ideas about donor insemination after the birth of their child (Levie, 1976; Rosenkvist, 1981; Leeton and Blackwell, 1982; Milson and Bergman, 1982; Kremer et al., 1984). If it came to light that a significant number of people, for whatever reason, have regrets about their decision, then this would be

extremely relevant from an ethical viewpoint. The studies show, however, that in the majority of cases, DI is experienced as a positive choice, and this is equally relevant for ethical reflection. Parents generally experienced great happiness that their wish for a child was fulfilled, often undergoing the treatment a second time.

#### *Where?*

For a long time, ethics was thought to be a trans-cultural and trans-historical perspective on what humans consider to be desirable. It transcended all particular cultural conceptions and operated as the only standard of truth against which all practices and decisions could and should be tested. Ethics made universal claims in deciding what is good. The problem with this was that the historical, contextual and cultural aspects lost all value. Today, an ahistorical understanding of ethics is no longer plausible and attempts are being made within ethics to take cultural historicity into account. It is not only individuals who have a history; the community also has a history. For this reason, an ethical argument will need to take into account the culture of which it is a part, and this means that an ethical argument cannot simply be transplanted to a different cultural situation and history; it does not mean that particular customs are not open to criticism. Empirical research is a means of gaining insight into ethical decision-making in another historical and cultural context. This context can be further specified in terms of macro (sub-national, national and international), meso (institutions or associations) and micro (smaller units) levels. In the past, Wertz and Fletcher have made distinguished contributions to cross-cultural empirical studies in the field of genetics (1989, 1998). A recent example (2002) describes how the general responses to the cases proposed illustrate a shift away from population or eugenic concerns to a model of genetics focused on the individual. However, geographic differences remain: the trend to respect patient autonomy was greatest in the US and less evident in China and India.

#### *When?*

Just as in the previous cases, the question "when?" is a many-sided question which will receive a different answer in every ethical reflection process. And just as in the previous cases, there is a belief that this question, too, is not morally neutral. It makes an ethical difference to know when the patient or family members have been informed about a certain diagnosis, when termination of pregnancy occurs, when the patient's last living will was dated, and so on. Empirical research can provide information that will help to answer these and other questions. Research can also report on norm shifts in society. For instance, Wertz's research

findings (2002) demonstrate a trend toward increased respect for patient autonomy since an earlier survey in 1985.

*What are the foreseeable effects?*

Actions and choices do not take place in a vacuum; they bring about changes in reality. This is why it would be ethically irresponsible not to take account of the foreseeable effects of one's actions. Naturally, certain effects can escape our assessment, since it is impossible to attain complete clarity regarding all the consequences of an action or decision. However, this does not absolve us of our responsibility to outline the foreseeable effects and later to gauge them against the real effects. Consequentialism is a strong tendency in bioethics which bases its judgements on an analysis of the effects and considers an action good only to the extent that its consequences are interesting, useful or beneficial for the interests or welfare of the individual, group and/or society, irrespective of the motives underlying the action. The study of consequences is a necessary but not a sufficient condition for doing ethics. Nevertheless, studying effects is important and empirical research can assist in verifying or falsifying the foreseeable consequences of certain actions, or in detecting other possible consequences. One of the most important arguments used in ethical debates is the slippery slope argument. The fundamental idea behind this argument is that if we adopt a new practice in some specific area, which may initially seem innocent, we will eventually end up performing something morally reprehensible (Nils Holtug, 1993, p. 402). Van der Burg (1991) distinguishes a logical and an empirical version of the argument. According to the logical version, we are logically committed to allow B, once we have allowed A. According to the empirical version of the slippery slope, allowing A will causally lead to allowing B (or B happening), the undesirable outcome. The empirical version is particularly relevant for the purposes of this article, since empirical research can investigate whether or not certain consequentialistic claims are still defensible (Brody, 1993). "If an ethical claim is based on the assertion that a practice or arrangement is ethically questionable because it results in a particular outcome, then that claim is empirically testable" (Zussman, 2000, p. 9). The only problem is that such an empirical test can only be carried out retrospectively. In order to measure the consequences of an action, the action must first be carried out in practice. Of course, these empirical findings can then be used prospectively in other countries, though a certain degree of caution should be upheld: the results of research cannot simply be transplanted from one context to another without critical evaluation. When donor insemination was first intro-

duced, many ethical objections to the application of the technique were raised, objections which were based on the possible consequences of the technique's use. There was concern that there would be problems in the relationship between father and child (Brewaays, 1993; Englert, 1994) since the father would not be the genetic father. The argument was also put forward that keeping the child's genetic origins secret would undermine the family's relationship of trust. It would be a constant blemish on the relationship between parents and children, exercising a negative influence (Adair and Purdie, 1996). It could also be a heavy burden on the relationship between the parents, leading to an increase in the number of divorces. It was also argued that this would influence the child's psychological development. Generally these objections have not been empirically tested. They usually go no further than pointing out the risks. However, empirical research can control these claims retrospectively: it can confirm or deny that these risks were prevented in reality. For instance, it turns out that the fear of disrupted relations between fathers and children as a result of DI is unfounded. Fathers claim that they feel they are the real fathers, and that their relationship with their children is not affected by the fact that they are not the genetic fathers (Kremer et al., 1984). Secrecy often appears to weigh heavily on parents (Berger et al., 1986). Nevertheless, research shows that it does not negatively influence the relations between parents and children. The mothers of DI children even exhibit greater involvement and emotional bonds with their children than naturally conceived children, and the quality of the parent-child interaction seems to be higher among DI parents (Cook et al., 1997; Golombok et al., 1995; Golombok et al., 1996). The claim that DI upsets the stability of relationships and leads to a higher incidence of divorce also turns out to be false (Amuzu, 1990; Nielsen et al., 1995), nor does genetic descent have any effect on the psychological development of the child. There is no distinction between DI children and naturally conceived children of heterosexual couples in terms of their emotional development, behaviour patterns, relationships or image of the family (Golombok et al., 1995; Golombok et al., 1996).

*What are the existent viable alternatives?*

In assessing an action or decision, the question arises whether other actions or decisions might have been pursued which would have responded better to the basic ethical choices, and led to fewer deleterious consequences. In posing this question, the implication is that a perfect ethical choice does not exist and that ethical choices cannot be made once and for all, but must be continually re-assessed. The search for

alternatives also sensitizes us to the pluralistic context and multiplicity of viewpoints that can co-exist in society. Empirical research is able to sketch a picture of this multiplicity. By portraying how ethical problems are dealt with in practice, it also becomes possible to outline alternative solutions or underline the need for them. Here, one could refer to the example of the neonatological setting (McHaffie, 2001), where a description of the decision-making process throws this practice into question and demands greater thought about treatment alternatives.

### *Practical problems*

Including empirical research in the description of the moral object also requires a focus on two concrete practical problems: selection and statistical validity. If the ethicist wishes to take account of the facts generated by the empirical sciences, then he or she must realize first of all that the empirical sciences generate an enormous number of evidence. This will raise the question whether this evidence is actually relevant for ethical reflection. In any case, a selection of this evidence is legitimate. To argue in favour of giving empirical research a place in ethical reflection does not mean that all research findings are equally useful for the ethical clarification and decision-making process. Of course, such a selection must be done with great care, since a well chosen selection can drive the ethical decision-making. Consequently, it will be a significant ethical challenge to collect in an honest manner empirical research which is relevant for the ethical issue under consideration. Secondly, it is particularly important to have an idea of the value of an empirical study. We will not attempt to survey everything that could go wrong when setting up an empirical study, but a certain degree of vigilance must nevertheless be exercised with respect to the methodology of any empirical study. With surveys, for instance, questions arise regarding the representativity of the samples, whether the non-response rate is too high, whether what is being measured is really what was intended, whether the respondents do not simply provide socially acceptable answers, whether the respondents have understood the questions, whether the statistical processing took place properly, whether the findings lend themselves to interpretation, or whether a repeat study would yield analogous results. If one bears in mind all the things that could go wrong in a study, it is a legitimate concern to ensure that the study yields quality results before using them in the ethical clarification and decision-making process. For most ethicists, this is an especially difficult task because they are usually not trained in the methodology of empirical research. Questions and problems could be resolved through greater cooperation with epidemiologists, statisticians

or other empirical scientists (ten Have and Lelie, 1998, p. 269).

### *2. Assessing the moral object*

The description of the moral object as we described it in the first section is more than simply a descriptive activity. There is also an ethical dimension to it: the demand of lucidity (Burggraeve, 1992, p. 21) or the requirement to attain as much honesty and insight as possible, with oneself and with reality. By excluding empirical research from ethical analysis, this demand for lucidity is left unfulfilled. Yet the ethical clarification and decision-making process does not end with the presentation of research results. Ethical inquiry, therefore, is an exchange between the moral meaning found in the empirical context, and the moral meaning found in the several norms contending for application in this concrete case. From this perspective, research results turn out to be more than merely facts, they also embody normativity. One could speak here of the "normative force of the factual" (Korff, 1968, p. 13) or of "statistical normativity" (Burggraeve, 1989, p. 422). Empirical results describe a piece of factual behaviour and usually also claim to be doing nothing other than giving a pure and objective presentation of research data. However, the publication of research results gives rise to standpoints and influences decisions which, in turn, can alter the normative structures of the reality of action. Sociologically described facts can repress existing norms and introduce new ones. A good example of this are the studies of withdrawing or withholding invasive treatment in neonatological practice (McHaffie, 2001). In carrying out their research, the scientists came to the belief that parents are too often shut out of the ethical decision-making about the fate of their children. The research results influenced their thinking to such an extent that they ended up rejecting the existing norm and arguing for a new one. We cannot deny that this is one of the ways in which norms can change. The problem with this example is that it does not take account of the fact that this is only acceptable under certain conditions. A practice that deviates from the norm can itself become a normative rule if it is felt to be more correct and undergirded with arguments. This means that the action acquires the necessary moral legitimacy. What happens then is that moral justification is granted to a certain argumentation and conclusion, which amounts to "presenting sufficient ground for it" (Beauchamp and Childress, 2001, p. 385).

In our view, moral legitimacy cannot be granted on the basis of an inductive bottom-up perspective alone. Empirical research cannot by itself determine what is good or evil, right or wrong. The inductive



approach runs the risk of lacking a critical attitude and assigning a sacred meaning to the facts without testing them against normative principles and theories. This focus on facts run to such an extreme that one believes it is possible to derive what ought to be done from the facts alone, without taking values and norms into account. In moral debates where a consensus cannot be reached, there is often a hope that the bare facts will somehow indicate how we ought to behave. There is then a temptation to raise statistical normality to the only source of ethical normativity, even though this remains implicit, unrecognized and poorly clarified (Burggraeve, 1989, p. 422). The same thing occurs in the example discussed at the beginning of this article (McHaffie, 2001). The authors derive moral justification from their research results. The existing norm (physicians take the final decision) is set aside on the basis of parents' beliefs. At this point the authors commit a methodological error since they neglect to explain which norms and values lie at the basis of this decision. Persuasive argumentation cannot only be based on empirical data, it must also explain and critically evaluate the values or ethical theories that are being presupposed (Nilstun, 2000, p. 114). This does not mean that we are questioning the authors' conclusions, only the manner in which they reached them. Empirical research demonstrates that parents would always like to have the opportunity to become involved in the decision-making process. But the decision to actually do this presupposes that the belief in parental responsibility is so important that it trumps medical authority. This research not only provided the facts indicating there was a problem in practice, it also proposed an alternative course of action by granting parents greater responsibility. It is clear that empirical research does more than simply provide facts: it also embodies normativity. However, this normativity has to acquire ethical legitimacy and justification, and this can only be done by introducing norms and values of a different order than the "normativity of the factual."

The risk associated with an inductive ethical justification is that there could be too little critical distance with regard to the facts provided. We would like to demonstrate this with the help of some of the examples discussed in the description of the moral object (III.1), without denying that empirical research can play an important role in the ethical clarification and decision-making process.

#### *Example 1 – What?*

Clearly empirical research can play a role in drawing the attention of bioethicists to the everyday practice of care, for instance. Bioethicists tend to be too focused on the ethical dilemmas taking place in hospitals and

tertiary care institutions. But we should be wary of expecting too much from this. At this level, empirical research is often as set in its ways as normative ethics, because research often merely reflects the ethical problems that are raised in normative discussions. This has also been underscored by Fetters and Brody (1999, p. 108, our emphasis): "The vast preponderance of philosophical inquiry *and empirical research* focuses on dilemmas arising in hospitals and tertiary care institutions." Empirical research has limited its scope to the problems most often studied by bioethics. Moreover, the identification of ethical problems must also be linked to a discussion of norms and values. It is not because something is measured as an ethical problem that it actually is an ethical problem, and vice versa. It would be a mistake to think that describing ethical problems leads to a prioritization of ethical reflection, as Fetters and Brody (1999) propose. Priorities are not only established on the basis of the prevalence of a specific problem. That is a significant argument, perhaps the most significant, but there are other criteria such as the urgency of a problem, the novelty of a problem or the extent of a problem. By itself, empirical research cannot provide these criteria.

#### *Example 2 – Who?*

In ethics, it is of great importance to study personal history, cultural determination, individual aspirations, personal complaints, wishes and motives. This does not mean, however, that every motive and behaviour is ethically acceptable. Judging an action on the basis of its motive alone fails to take account of the consequences of the action for oneself or for others: "The subject – the who – constitutes part of the objective reality to be evaluated. Note what is not being said here: this does not mean that what Lola wants is good for Lola. It does not mean that an arbitrary subjectivism where everyone does their own normless thing is being suggested. It merely means that if you do not know the who with all their hopes, needs, and personal possibilities, you do not know what you are judging" (Maguire, 1984, pp. 71–72). For instance, the emotional stress associated with subfertility (depression, anxiety, anger, marital and psychosexual dysfunction, social isolation, etc.) can weigh heavily on the person in question, but this does not mean that an obstinate medical persistence is legitimized in helping a couple get pregnant.

Since a purely inductive moral justification in ethics has been rejected since at least the time of David Hume's *Treatise of Human Nature* (1740), ethicists have usually chosen a deductive method of problem solving. This method adheres to the principle that moral justification occurs by applying general prin-

principles, ideals, rights and rules to concrete situations. However, this top-down approach to moral justification has come in for sharp criticism because it was too far removed from clinical reality, insensitive to the peculiarities of specific situations, and unable adequately to consider the nature of diseases and the clinical contexts in which clinicians and patients were confronted with ethical problems (Sider and Clements, 1985; Clouser and Gert, 1990). For this reason, nowadays more integrated models are usually defended, where the inductive and deductive approaches are brought together. The idea is that neither general principles nor concrete situations can grant sufficient legitimacy to a moral judgement. Reflective equilibrium is one example of this. This model seeks a balance between theory and practice (Rawls, 1972; Daniels, 1979; Van Willigenburg and Heeger, 1989; Van der Burg and Van Willigenburg, 1998): among the various elements (morally relevant facts, moral judgements, principles and theories) a sort of coherence is sought, without any one of the elements receiving a special epistemological position.

### 3. *Evaluating the decision-making*

Since moral truth cannot be fixed once and for all, moral choices must continually be subject to question and, in some cases, adapted. Evaluation includes, for example, evaluating the effect of an action. In an ethical decision-making process one always tries to estimate the possible outcomes of an action, opting if necessary for the lesser evil. The estimation can be wrong, however, and adjustments may be required. Unforeseen effects or consequences may occur. At the same time a degree of introspection about the course of the decision-making process is also required: How did I come to this decision? What facts did I integrate into my decision-making process? Are any essential elements lacking? Have any relevant facts recently come to light? What norms and values were involved in the decision-making process? Are they still defensible? To what extent has the decision been determined by economic, cultural or socio-historical factors? What is important, then, is a moral evaluation of the moral evaluation.

Here, too, there is a place for empirical research. This evaluation can show that empirical claims still need to be verified through empirical research. Up to now, we have mainly discussed the movement from empirical research to ethics, but here we could invoke a new movement from ethics to empirical research. In other words, ethics must not only collect empirical evidence but also play a more active role in designing empirical research. The relation between ethics and empirical research could be much more dynamic.

Empirical research can help us get an idea of the cultural specificity of bioethics and bioethical reflection. Sociological research can shed some light on “the who, what, where, and when of bioethics: who are bioethicists? What are they saying? Where are they working? When are they called upon?” (De Vries and Subedi, 1998, p. xiii) Sociological research can help in detecting the social, cultural and historical influences on ethical thought. “How do the trends within bioethics reflect the larger culture of which they are a part? What ideological leanings do the moral theories undergirding bioethics openly or implicitly manifest?” (Fox, 1990) The book by De Vries Subedi (1998) collects a number of examples of empirical research in bioethics.

## Conclusions

The rise of empirical research in the field of bioethics has led us to ask the question regarding the possible contribution of empirical research to the ethical clarification and decision-making process. This in turn led us to an analysis of the aim and methods of ethics, and to the development of a three-step plan that describes the phases almost every process of ethical reflection will go through: description of the moral question, assessment of the moral question, and evaluation of the decision-making. The focus was on determining what contribution empirical research can make to the thought processes in ethics. At every step, empirical research has a contribution to make. In describing the moral object, firstly, empirical research can play a role in the description of the morally relevant facts. It also plays a role in answering the reality-revealing questions (what, why, how, who, where and when), in measuring the consequences, and in proposing alternative courses of action.

Secondly, empirical research plays a role in assessing the moral question. Collecting data is one of the most important tasks of research, but it would be misleading to state that research does nothing more than provide the data that the ethicist must then judge. Empirical research is also value-laden, involving not merely “is” but also “ought.” Empirical research must be recognized as the “normativity of the factual,” which can also become the factual normativity by repressing other norms. However, facts by themselves lack sufficient legitimation to determine what is good, evil, right or wrong. Before facts can become the norm, they must acquire a moral justification. In the example of withdrawing or withholding of invasive treatment in the neonatological setting (McHaffie, 2001), the facts are value-laden. Parents are not systematically given the chance to decide about the fate of their own children. The authors believe this is an attack on the

parents' responsibility, and they argue for change on the basis of their empirical research. Here, empirical research reveals a difficulty in the decision-making process, but is a bit too hasty with the moral judgement since it forgets to bring together the inductive and deductive approaches and provide moral justification for its claim. Both inductive and deductive approaches must point in the same direction if their claim is to receive sufficient legitimacy. In assessing the moral question, therefore, a critical attitude should be adopted with respect to research results being described. In the examples provided, we illustrated how problematic it can be if this is forgotten. This means that ethics does not always have to simply accept what empirical research produces, but at the same time ethics bears a heavy burden of proof if it proposes a different view. Applying this to our example, if ethics cannot permit the final decision to be left in the parents' hands, then it must address two major problems: 1) it needs to provide support for the argument that being given a chance to decide is not an absolute right; 2) it must demonstrate that all parents are mistaken on this point. Yet if ethics is to remain ethics, it must always retain this critical reflex, otherwise it risks abandoning its very identity. A critical attitude on the part of ethics towards the empirical field also benefits the latter: "The social sciences (...) have at least as much to gain from this collaboration as does bioethics (...). Furthermore, it would not harm our own efforts at disciplinary self-reflection if ethicists, and particularly the analytic philosophers among them, were to function as critical observers of our assumptions and intellectual procedures" (Weisz, 1990, Introduction, p. 6).

Thirdly, empirical research plays a role in evaluating the decision-making process. It can demand a modification of some moral choices if certain unforeseen consequences or effects ensue. However, it can also function as a sociology of bioethics, where the discipline of bioethics becomes an object of sociological research. In such cases, it provides greater clarity about how bioethical decision-making is itself influenced by the context.

At the beginning of this article, we posed the question regarding the precise content of the ethical problem. It seems that the task of ethics is to answer the questions "what kind of life is best for the individual and how one ought to behave in regard to other individuals and society as a whole (Slote, 1995, p. 721)." In answering these questions, ethics has usually excluded empirical research. In the course of this article, we have attempted to show that there is indeed a place for empirical research in the different stages of the ethical process: in describing the moral question, in assessing the moral question, and in eval-

uating the decision-making. We have made only a minimal contribution at the level of theory formation and development in ethics, but we do provide an analysis of how empirical research can make a concrete contribution to ethical clarification and decision-making. It should be clear that empirical data as such cannot generate normativity or determine what is good or evil, right or wrong. Nevertheless, the classical gap between is and ought is not absolute: ethical theory, ethical norms and values are nurtured and shaped by empirical knowledge.

## References

- Adair, V. and A. Purdie: 1996, 'Donor Insemination Programs with Personal Donors: Issues of Secrecy', *Human Reproduction* 11 (12), 2558–2563.
- Amuzu, B. et al.: 1990, 'Pregnancy Outcome, Health of Children and Family Adjustment of Children after Donor Insemination', *Journal of Obstetrics and Gynaecology* 75 (6), 899–905.
- Arnold, R. and L. Farrow: 1993, 'Empirical Research in Medical Ethics: An Introduction', *Theoretical Medicine* 14 (3), 195–196.
- Beauchamp, T.L. and J.F. Childress: 2001<sup>5</sup>, *Principles of Biomedical Ethics*. New York: Oxford University Press.
- Berger, D. et al.: 1986, 'Psychological Patterns in Donor Insemination Couples', *Canadian Journal of Psychiatry* 31, 818–823.
- Borry, P., P. Schotmans and K. Dierickx: 2005, 'The Birth of the Empirical Turn in Bioethics', *Bioethics* 19 (to be published).
- Bosk, C.L.: 1999, 'Professional Ethicist Available: Logical, Secular, Friendly', *Daedalus* 128 (4), 47–68.
- Brewaeys, A. et al.: 1993, 'Children from Anonymous Donors: An Inquiry into Homosexual and Heterosexual Parents Attitudes', *Journal of Psychosomatic Obstetrics and Gynaecology* 14 (Suppl.), 23–35.
- Brewaeys, A.: 1996, 'Review. Donor Insemination: The Impact on Child and Family Development', *Journal of Psychosomatic Obstetrics and Gynaecology* 17 (1), 1–17.
- Brewaeys, A.: 2001, 'Review: Parent-Child Relationships and Child Development in Donor Insemination Families', *Human Reproduction Update* 7 (1), 38–46.
- British Medical Association: 1999, *Withholding and Withdrawing Life-Prolonging Treatment, Guidance for Decision Making*. London: BMA.
- Brody, B.A.: 1990, 'Quality of Scholarship in Bioethics', *Journal of Medicine and Philosophy* 15 (2), 161–178.
- Brody, B.A.: 1993, 'Assessing Empirical Research in Bioethics', *Theoretical Medicine* 14 (3), 211–219.
- Burggraeve, R.: 1989, 'Grondlijnen van een ethische methodologie in pastoraal perspectief', *Collationes* 19 (4), 404–431.
- Burggraeve, R.: 1992, *Zinvol seksueel leven onderweg, concrete probleemvelden en belevingswijzen*. Leuven: Acco.
- Callahan, D.: 1980, 'Shattuck Lecture – Contemporary Biomedical Ethics', *The New England Journal of Medicine* 302 (22), 1228–1233.

- Chochinov, H.M. et al.: 2002, 'Dignity in the Terminally Ill, A Developing Empirical Model', *Social Science and Medicine* 54 (3), 433–443.
- Christie, R.J. and C.B. Hoffmaster: 1986, *Ethical Issues in Family Medicine*. New York: Oxford University Press.
- Clements, C.D.: 1985, 'Bioethical Essentialism and Scientific Population Thinking', *Perspectives in Biology and Medicine* 28 (2), 188–207.
- Clouser, K.D. and B. Gert: 1990, 'A Critique of Principlism', *Journal of Medicine and Philosophy* 15 (2), 219–236.
- Cook, D.J.: 1997, 'Health Professional Decision-Making in the ICU, A Review of the Evidence', *New Horizons* 5 (1), 15–19.
- Cook, R. et al.: 1995, 'Disclosure of Donor Insemination: Parental Attitudes', *American Journal of Orthopsychiatry* 65 (4), 549–559.
- Dalla-Vorgia, P. et al.: 1992, 'Attitudes of a Mediterranean Population to the Truth-telling Issue', *Journal of Medical Ethics* 18 (2), 67–74.
- Daniels, N.: 1979, 'Wide Reflective Equilibrium and Theory Acceptance in Ethics', *Journal of Philosophy* 76, 256–282.
- Demyttenaere, K.: 2000, 'Anxiety and Depression in Subfertility', in: M. Steiner, K.A. Yonkers and E. Eriksson (eds.), *Mood Disorders in Women*. London: Martin Dunitz, pp. 371–382.
- De Vries, R. and J. Subedi (eds.): 1998, *Bioethics and Society. Constructing the Ethical Enterprise*. New Jersey: Prentice Hall.
- Dierickx, K.: 1999, 'Adolescents and Carrier Testing: Attitudes and Ethical Presuppositions', in: A. Thompson and R. Chadwick (eds.), *Genetic Information: Acquisition, Access and Control*. New York: Kluwer Academic Publishers, pp. 175–182.
- Dierickx, K. and P. Schotsmans et al.: 1998, 'Belgian Doctors' Attitudes on the Management of Patients in Persistent Vegetative State (PVS), Ethical and Regulatory Aspects', *Acta Neurochirurgica* 140 (5), 481–489.
- Englert, Y.: 1994, 'Artificial Insemination of Single and Lesbian Women with Donor Semen', *Human Reproduction* 9 (11), 1969–1971.
- Evans, J.H.: 2001, *Playing God? Human Genetic Engineering and the Rationalization of Public Bioethical Debate*. Chicago and London: University of Chicago Press.
- Fetters, M.D. and H. Brody: 1999, 'The Epidemiology of Bioethics', *The Journal of Clinical Ethics* 10 (2), 107–115.
- Fox, R.C. and J.P. Swazey: 1984, 'Medical Morality Is not Bioethics – Medical Ethics in China and the United States', *Perspectives in Biology and Medicine* 27 (3), 336–360.
- Fox, R.C.: 1990, *The Sociology of Medicine, A Participant Observer's View*. New Jersey: Prentice Hall.
- Fox, R.C. and R. De Vries: 1998, 'Afterword: The Sociology of Bioethics', in: R. De Vries and J. Subedi (eds.), *Bioethics and Society. Constructing the Ethical Enterprise*. New Jersey: Prentice Hall, pp. 270–276.
- Fulford, K.W.M.: 1989, *Moral Theory and Medical Practice*. Cambridge: Cambridge University Press.
- Gallagher, E.B. et al.: 1998, 'To Enrich Bioethics, Add One Part Social to One Part Clinical', in: R. De Vries and J. Subedi (eds.), *Bioethics and Society. Constructing the Ethical Enterprise*. New Jersey: Prentice Hall, pp. 166–191.
- Golombok, S. et al.: 1995, 'Families Created by the New Reproductive Technologies: Qualities of Parenting, Social, and Emotional Development of the Children', *Child Development* 66 (2), 285–298.
- Golombok, S. et al.: 1996, 'The European Study of Assisted Reproduction Families: Family Functioning and Child Development', *Human Reproduction* 11 (10), 2324–2331.
- Guttmann A. and R.D. Guttmann: 1993, 'Attitudes of Healthcare Professionals and the Public towards the Sale of Kidneys for Transplantation', *Journal of Medical Ethics* 19 (3), 148–153.
- Hoffmaster, B.: 1992, 'Can Ethnography Save the Life of Medical Ethics?', *Social Science and Medicine* 35 (12), 1421–1431.
- Holstug, Nils: 1993, 'Human Gene Therapy: Down the Slippery Slope?', *Bioethics* 7 (5), 402–419.
- Hope, T.: 1999, 'Empirical Medical Ethics', *Journal of Medical Ethics* 25 (3), 219–220.
- Jennings, B.: 1990, 'Ethics and Ethnography in Neonatal Intensive Care', in: G. Weisz (ed.), *Social Sciences Perspectives on Medical Ethics*. Philadelphia: University of Pennsylvania Press, pp. 261–272.
- Korff, W.: 1968, 'Empirische Sociologie en Moraal', *Concilium* 4 (4), 8–24.
- Kremer, J. et al.: 1984, 'Psychosocial Aspects of Parenthood by Artificial Insemination Donor', *Lancet* 8377, 628.
- Leiblum, S. and A. Aviv: 1997, 'Disclosure Issues and Decisions of Couples who Conceived via Donor Insemination', *Journal of Psychosomatic Obstetrics and Gynaecology* 18 (4), 292–300.
- Light, D.W. and G. McGee: 1998, 'On the Social Embeddedness of Bioethics', in: R. De Vries and J. Subedi (eds.), *Bioethics and Society. Constructing the Ethical Enterprise*. New Jersey: Prentice Hall, pp. 1–15.
- Maguire, D.: 1984<sup>2</sup>, 1973, *Death by Choice*. New York: Doubleday & Company/Garden City.
- McHaffie, H.E. et al.: 2001, 'Deciding for Imperilled Newborns: Medical Authority or Parental Autonomy?', *Journal of Medical Ethics* 27 (2), 104–109.
- Molewijk, A.C. et al.: 2003, 'Implicit Normativity in Evidence-Based Medicine. A Plea for Empirical Ethics Research', *Health Care Analysis* 11 (1), 69–91.
- Nachtigall, R. et al.: 1998, 'The Disclosure Decision: Concerns and Issues of Parents of Children Conceived through Donor Insemination', *American Journal of Obstetrics and Gynecology* 178 (6), 1165–1170.
- Nielsen, A. et al.: 1995, 'Psychological Aspects of Donor Insemination', *Acta Obstetrica et Gynecologica Scandinavica* 74, 45–50.
- Olshansky, E.F.: 1987, 'Identity of Self as Infertile: An Example of Theory-Generating Research', *Advances in Nursing Science* 9, 54–63.
- Pellegrino, E.: 1995, 'The Limitation of Empirical Research in Ethics', *Journal of Clinical Ethics* 6 (2), 161–162.
- Rawls, J.: 1972, *A Theory of Justice*. Oxford: Clarendon.
- Reiser, S.J. et al.: 1987, *Divided Selves: A Case Approach to Mental Health Ethics*. Cambridge: Cambridge University Press.
- Richter, J. et al.: 2001, 'Doctors' Authoritarianism in End-of-Life Treatment Decisions. A Comparison between Russia,

- Sweden and Germany', *Journal of Medical Ethics* 27 (3), 186–191.
- Royal College of Paediatrics and Child Health: 1997, *Withholding of Withdrawing Life Saving Treatment in Children. A Framework for Practice*. London: RCPCH.
- Rumbal, A. and V. Adair: 1999, 'Telling the Story: Parents' Scripts for Donor Offspring', *Human Reproduction* 14 (5), 1392–1399.
- Sabatelli, R.M. et al.: 1988, 'Factors Mediating the Adjustment to Involuntary Childlessness', *Family Relations* 37, 338–343.
- Schemer, M.: 2001, *The Different Faces of Autonomy, A Study on Patient Autonomy in Ethical Theory and Hospital Practice*. Doctoral dissertation, University of Amsterdam, The Netherlands.
- Sider, R.C. and C.D. Clements: 1985, 'The New Medical Ethics: A Second Opinion', *Archives of Internal Medicine* 145 (12), 2169–2179.
- Singer, P. et al.: 1990, 'Research in Clinical Ethics', *Journal of Clinical Ethics* 1 (2), 95–99.
- Slote, M.: 1995, 'The Task of Ethics', in: W. Reich (ed.), *The Encyclopedia of Bioethics*. New York: Simon & Schuster, pp. 720–727.
- Sox, H.C. et al.: 1990, 'Using the Patient's History to Estimate the Probability of Coronary Artery Disease: A Comparison of Primary Care and Referral Practices', *American Journal of Medicine* 89, 7–14.
- Sugarman, J. et al.: 2001, 'A Decade of Empirical Research in Medical Ethics', in: J. Sugarman and D. Sulmasy (eds.), *Methods in Medical Ethics*. Washington DC: Georgetown University Press, pp. 19–28.
- Taesdale, K. and G. Kent: 1995, 'The Use of Deception in Nursing', *Journal of Medical Ethics* 21 (2), 77–81.
- ten Have, H. and A. Lelie: 1998, 'Medical Ethics Research between Theory and Practice', *Theoretical Medicine and Bioethics* 19 (3), 263–276.
- Thomasma, D.C.: 1985, 'Empirical Methodology in Medical Ethics', *Journal of the American Geriatrics Society* 33 (5), 313–314.
- Valentine, D.: 1986, 'Psychological Impact of Infertility: Identifying Issues and Needs', *Social Work in Health Care* 11 (4), 61–69.
- van Berkel, D. et al.: 1999, 'Difference in the Attitudes of Couples whose Children Were Conceived Through Artificial Insemination by Donor in 1980 and in 1996', *Fertility and Sterility* 71 (2), 226–231.
- van Delden, J.M. et al.: 1993, 'Deciding not to Resuscitate in Dutch Hospitals', *Journal of Medical Ethics* 19 (4), 200–205.
- van Delden, J.J.M. and G.J.M.W. van Thiel: 1998, 'Reflective Equilibrium as a Normative-Empirical Model in Bioethics', in: W. van der Burg and T. van Willigenburg (eds.), *Reflective Equilibrium*. Dordrecht: Kluwer Academic Publishers, pp. 251–259.
- van der Burg, W.: 1992, 'The Slippery Slope Argument', *Journal of Clinical Ethics* 3 (4), 256–268.
- van der Burg, W. and T. van Willigenburg: 1998, *Reflective Equilibrium, Essays in Honour of Robert Heeger*. Dordrecht: Kluwer Academic Publishers.
- van der Scheer, Lieke, Ghislaine van Thiel, Johannes van Delden and Guy Widdershoven: 2003, 'Theory and Methodology of Empirical Ethics', in: Soren Holm and Monique Jonas (eds.), *Engaging the World: The Use of Empirical Research in Bioethics and The Regulation of Biotechnology*. The Netherlands: IOS Press, forthcoming.
- van Willigenburg, T. and F.R. Heeger: 1989, 'Justification of Moral Judgments: A Network Model', in: M. Otte (ed.), *Societas Ethica*. Jahresbericht. Hannover: Societas Ethica.
- van Willigenburg, T.: 1993, *Ethiek in praktijk*. Assen: Van Gorcum.
- Weisz, G. (ed.): 1990, *Social Sciences Perspectives on Medical Ethics*. Philadelphia: University of Pennsylvania Press.
- Wertz, D.C. and J.C. Fletcher: 1985, *Ethics and Human Genetics: A Cross-Cultural Perspective*. Heidelberg: Springer-Verlag.
- Wertz, D.C. and J.C. Fletcher: 1998, 'Ethical and Social Issues in Prenatal Sex Selection: A Survey of Geneticists in 37 Nations', *Social Sciences and Medicine* 46 (1), 255–273.
- Wertz, D.C.: 1998, 'International Research in Bioethics: The Challenges of Cross-Cultural Interpretation', in: R. De Vries and J. Subedi (eds.), *Bioethics and Society. Constructing the Ethical Enterprise*. New Jersey: Prentice Hall, pp. 145–165.
- Wertz, D.C. et al.: 2002, 'Has Patient Autonomy Gone Too Far? Geneticists' Views in 36 Nations', *The American Journal of Bioethics* (2) 4, In Focus, 1–25.
- Wright, J. et al.: 1991, 'Psychosocial Distress and Infertility: Men and Women Respond Differently', *Fertility and Sterility* 55 (1), 100–108.
- Yu, V.Y.: 1997, 'Ethical Decision-Making in Newborn Infants', *Acta Medica Portuguesa* 10 (2–3), 197–204.

