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This paper is intended to encourage scholars to submit papers for a symposium and the next special issue of Medische Antropologie which will be on empirical studies of normative questions. We describe the 'empirical turn' in medical ethics. Medical ethics and bioethics in general have witnessed a move from applied ethics (the application of rules and principles to complex situations) to a renewed interest in practical, everyday ethical issues and the ways health care providers deal with them in practice. We highlight four forms of empirical research in ethics: studies about the effects of some form of institutionalized ethics in health care; studies about ethical views and practices in society; studies about ethical issues concerning medical innovations, and finally, studies about the normativity of care practices. We end the paper with an assessment of the function of empirical ethics research: to provide the building blocks for societal debate about health care.

[empirical ethics, medical ethics, health care, ethnography, anthropology]

The end of applied ethics?

The days that health care ethics was dominated by the four principles approach (autonomy, beneficence, nonmaleficence, and justice) seem over (Beauchamp 1999). Other approaches, such as care ethics (Tronto 1993) and virtue ethics (MacIntyre 1985) have obtained their legitimate spaces within the health care ethics community. Even so, within health care practices, there are countless other ways of doing good that are not covered by these largely theoretical approaches.

At the same time, health care ethics is threatened by bureaucratisation and a focus on applicability. Health care ethics threatens to become synonymous with ethical committees and ethical policy advice. So the answer to the question raised by Barry Hoffmaster in 1992, *Can ethnography save the life of medical ethics?* may be 'Yes', but it demands continuous empirical work. The up-coming symposium on 'Ethics, health care and anthropology' takes Hoffmaster's question as a starting point and intends to bring together and explore new ideas on the empirical study of the ethical dimensions of everyday practices of health care. This 'teaser' for the symposium hopes to inspire

colleagues to contribute to the discussion on ethics in health care. A call for papers can be found in the News section of this journal.

A lot of excellent anthropological and ethnographic work has been done on ethical issues in health care during the last decade, such as Gerrits' (2008) study of in vitro fertilization, or Pool's (2000) and The's (2008) studies on euthanasia, and Mol's (2008) work on ontologies of disease. Since it is not the aim of this piece to give a systematic overview, we will discuss a limited number of studies that we consider paradigmatic for a type of approach in the *empirical turn* in health care ethics – ranging from largely quantitative to detailed ethnographic studies. There is some partiality in our choice of examples: they are mainly from studies that the authors have been involved in.

Good care

Care practices are overflowing with different notions of what is good care. Everybody wants care to be good, but there is no agreement what this 'good' should look like. Like in practice, in health policy and the health sciences there are different, sometimes conflicting ways of conceptualising good care. Care can be good when its is just, effective, or ethically legitimated. It can be good when it is 'managed well', and uses public money sparingly. Care may be called 'good' when the patient is leading, and more than once a combination of goods is asked for. Philosopher Georg Henrik von Wright has argued that these *varieties of goodness* are not without significance (Von Wright 1993; Willems 2010). Empirical studies of how good care takes shape in various domains in health care are needed to map these varieties and learn about their workings. Such studies should not start from a pre-conceived idea of what the ultimate good is and what ethics is about, but should be sensitive to the goods that people involved in health care practices find important. How do health care providers (nurses, physicians, paramedics, relatives) and patients conceptualize what is good and how do they attempt to realize it in their daily practices? Also, the bureaucracies of ethics in health care may be studied. How do ethics committees in various forms work, how do they reach new conceptualizations of the good? Studies of ethics committees may analyse those that try to resolve ethical issues in patient care, but also those that concentrate on the ethics of *research* in medicine and health care. Anthropological studies of how research ethics committees evaluate anthropological forms of research might be especially interesting.

Another aspect of the kind of studies we are interested in is that they should be about everyday forms of good care, not, or at least not exclusively, about the big ethical issues we all know from the media. Daily ethics is – for instance – about the way a nurse helps a child with painful dressing changes, how a doctor breaks bad news to a patient, or how a physiotherapist encourages a demoralized patient to keep doing her exercises. Or even about how coffee is served on the ward (Pols 2008).

The changing face of health care ethics

Ask a doctor or a nurse *what* health care ethics is about and the majority will answer 'life-and-death'-issues. Some would add issues of justice; some the ethical problems surrounding the care for incompetent patients.

Ask a doctor and a nurse *where* health care ethics may be found, and they will probably answer: in committees such as hospital ethics committees, institutional review boards, in the ethical committees working for government and professional associations.

Ask them what people *do* when they do ethics. They will look at what such committees do, so they will probably answer that doing ethics means deliberating, clarifying, advising, or simply talk. Even though almost everybody thinks ethics is important to health care, quite a few professionals think that no decisive conclusions may be drawn about it, because ethics, in their view, remains a question of opinion or even of taste. These may be deeply entrenched opinions about what is of value, about whether it can ever be good to end a human life, about what constitutes human dignity – but they are opinions nonetheless.

In short, the standard image of health care ethics is that it is about the big issues, that it occurs in dedicated committees and that it is all about talk and opinions that will never converge. However, during the last decades, an 'empirical turn' has taken place in health care ethics. Empirical research is increasingly considered an essential part of ethics. Empirical ethics, in the words of G.E. Moore, is the "systematic examination of the good"(Moore 1903). In the words of Hoffmaster (1992: 1428), "[empirical ethics aims for] new understandings of theory and practice, in particular, understandings that locate theories *in* our practices rather than *underlying* them." In the Netherlands, this goal has been taken up by a government-sponsored research program called 'Ethics and Policy' (for a description of the role of empirical research in this program, see Van Delden et al. 2005). The 'empirical turn' means that not only the traditional hot topics in medical ethics (abortion, euthanasia, cost containment…), but also the daily groping for good care in various, sometimes completely unspectacular ways are topics of interest for empirical ethical studies.

Secondly, the empirical turn in health care ethics rejects the seemingly perennial descriptive-normative distinction we inherited from David Hume. This so called 'is-ought' distinction meant that there is no obvious relationship between what *is* and what *should* be, or between what people approve of and what is good. The idea was, for example, that even if everyone in a society thinks that euthanasia is permissible, it may still be morally unacceptable. In other words, the classic view was that descriptive research simply cannot tell us what is good to do and what is not. Descriptive ethics has long been performed to chart views and was considered a sub-field in sociology and anthropology, irrelevant for normative ethics

Scholars doing empirical work in ethics, especially anthropological studies, however, state that articulating the ethical content of practices is itself a way to be normative. For instance, the choice to study the way in which nurses in nursing homes deal with patients who refuse to eat, is a normative choice (Harbers et al. 2002). They point

out that the practices they study do not simply reflect *opinions* on the good, but show how participants invent and develop goods and activities to bring them about within those very practices. These are not *applications* of ethics in practices; they are normative inventions.

Forms of empirical ethics: From quantitative study to ethnography

Today, ethics research focuses on four types of goals:
– to establish the effectiveness of ethics as a practice;
– to act as a critique of normative views and responses;
– to act as a source of normative questions;
– to act as a source of normative views and responses.

These four different targets of 'empirical ethics' lead to different questions and thus to different forms of research. In what follows, we will try to sketch the landscape of empirical studies in ethics, starting from large-scale quantitative studies and ending in very detailed ethnographic accounts of the varieties of goodness invented in practices. Our examples are partial: at least one of us participated in three of the studies we mention. There is a lively discussion about the different ways in which ethics and empirical work may be combined (see e.g. Widdershoven et al. 2008; Borry et al. 2005 and the recent call for a special issue of Bioethics). This admittedly partial overview is meant as an encouragement to bring in new visions and examples of research in ethics. We will end with a modest prediction of future empirical research in health ethics.

Research into the effectiveness of ethics interventions in health care

Over the last 10-15 years, much attention has been devoted to the improvement of the ethical quality of care. Quality improvement initiatives abound in hospitals and other care facilities. The activities range from occasional hospital conferences on ethical issues to a structured and regular dialogue on ethical issues in practice in an official ethics committee. Many health care facilities now have such an ethics committee dealing with ethical questions.

For various reasons, often of a political and financial nature, the question is raised whether interventions really help. Is the patient better off because of the existence of an ethics committee or of 'moral deliberation' in the hospital? Is the work of care improving? Is staff better motivated when such deliberations are organised? Research into these questions has only tentatively begun. An example is a 2001 American study on the effects of ethics consultation on the prevention of major life-saving treatment in intensive care units (ICUs) in the last days of life of incurable patients (Schneiderman et al. 2003). An earlier exploratory study had shown that a relatively large number of patients on the ICU had undergone radical, 'heroic' treatment until the day of their death. Simply put, there was a reason to try to reduce misplaced heroism.

The study was designed as a randomized trial. In four of the seven intensive care units that participated, a monthly medical ethics discussion was organized during one year, coupled with the possibility to organize emergency consultations. During the deliberations, patients were discussed who, according to the attending physician, had a life expectancy of less than two weeks. The other three ICUs performed 'care as usual'. The outcome measure was the number of inappropriate, invasive, life-saving treatments on patients who died shortly after (this was determined retrospectively). Eventually, the study showed a significantly lower number of misplaced heroic treatments in the intervention group.

As a form of ethics research, this is marginal for several reasons. First, outcome measures will be liable to discussion as they become more measurable. In letters to the editor following the publication of the study, commentators almost always took issue with the suggestion that major, life-saving treatment just prior to death is always misplaced in the context of an intensive care unit. Secondly, it is almost impossible to prove that the effect has to do with the content of the discussions. It could equally well be that a long lunch break together, at which no ethical debate took place, had the desired effect. Third, the study was not really on an ethical issue, but about a meeting procedure. Even though it may have been important in its own right, the "systematic reflection on the good," to quote Moore again, has not advanced very much through this type of study.

Empirical study and criticism of normative views and responses

Another example of empirical research is intended, at least partly, to find out whether current rules based on normative views have the desired effect: the five-yearly Dutch research into euthanasia practices (Van der Wal et al. 2003). As these studies are intended to assess the effects of the Dutch regulations on euthanasia, one of the questions is the plausibility of the 'slippery slope' argument. This is a common argument in ethical debates, especially in the one about end of life within medical practice. The argument contends that if euthanasia is tolerated under strict conditions, this will inevitably lead to the extension and slackening of these conditions. For example, the fear was that if one allowed people to get euthanasia when they requested it specifically and in a well-considered way, this would eventually lead to allowing euthanasia without such explicit requests. Since this is an empirical hypothesis that can be subjected to a test, it was important that it has been repeatedly rejected in the above mentioned series of studies. This specific version of the 'slippery slope' argument appeared to be untenable (Van der Wal et al. 2003).

Does such research bring the "systematic study of the good" any further? More, probably, than the first form we discussed above. In any case, these studies weakened the slippery slope as an argument in the debate on the proper regulation of medical practices at the end of life. However, even though the study discusses the value of a given type of arguments in an ethical debate, it hardly says anything about what is good within the practice of euthanasia, except for 'adhering to the protocols'. Moore, we think, would still not be satisfied.

New ethical questions

There is empirical research that he would be more satisfied with, for instance, the type of studies that give insight into new normative questions raised by technological innovation in medicine. Such research could, for example, focus on questions that are raised by keeping alive very preterm children (see for example Vermeulen 2001). With what new ethical questions do changing opportunities in this area confront us?

An example of research that addresses new questions raised by innovation is a study of unexpected findings in prenatal diagnosis (Van Zwieten et al. 2006). The current technique of prenatal diagnosis to identify Down's syndrome consists of an analysis of all chromosomes. The problem with whole-chromosome analysis is that it yields not only the deviations that doctors and future parents are looking for, but also a high percentage of unsought abnormalities that are often difficult to interpret and do not always have severe consequences. Other techniques could be applied instead, techniques that are more selective and would only detect the abnormalities that were targeted, such as trisomy 21 (Down syndrome), or maybe a limited range of other abnormalities.

This ethical and empirical study used a combination of qualitative methods to identify the ethical questions the introduction of a selective research technique might raise. Ethnographic research using in-depth interviews with both professionals and pregnant couples yielded new insights into normative questions. It made abundantly clear that a renewed discussion is needed about the exact purpose of prenatal diagnosis: is the aim to enable pregnant women to terminate pregnancy in the presence of a few well defined abnormalities (that would be a reason to be as selective as possible), or also to prepare the parents for a child with a chance of a less dramatic disorder? In other words: will prenatal diagnosis remain linked to abortion or does it also have to serve other goals?

The purpose of studies such as the one by Van Zwieten et al. is usually not to test hypotheses, but to open up and nourish a debate on ethical issues, in this case about a particular technology and the consequences of its workings, as compared to the aims of a particular field of health care. It is in itself possible to formulate and test hypotheses based on this research, but that would overshoot its target. That target is sensitizing stakeholders for the normative questions that arise about prenatal diagnosis, and encouraging reflection about these.

Empirical ethical research as a source of normative views and responses

Another innovative form of research tries to bridge the Humean divide between the 'descriptive' and the 'normative'. An example is the investigation of one of us into forms of good care in psychiatry and care for the elderly (Pols 2004). In this study, nurses and patients were followed with ethnographic techniques. Apart from observations, interviews were conducted with key stakeholders on the question of whether they perceived their activities as good care or not, and why. Respondents were not directly asked for opinions ("What would you consider good care?"), but were in-

terviewed about their common and mundane everyday care activities. Issues such as washing patients and the organization of the meals were the subject of research and ethical reflection. The study found that nurses use at least five repertoires to describe and approach patients who are unwilling to wash (Pols 2006). Each of these repertoires had its own diagnosis of the unwillingness of patients, and its own views on how the refusal to wash should be dealt with.

Purpose of the study was to make everyday health care practice visible to those concerned, in a new way, by making existing ideals of care explicit and by showing possible frictions between these ideals. What ideals are important in these practices and how are those ideals connected with what the informants say about how the world works? Thus, this study examined the 'good' empirically, but it was normative in the sense that it focused on the good in everyday health care problems and that it placed them on the ethical agenda alongside the 'big ethical questions'. It was normative because it refused to designate a particular form of knowledge in advance as the 'truth'. The different repertoires were examined with a view on their implications for practice. The purpose of the study thus was to give actors materials for reflection and the design of possible improvement –another normative move, i.e. to stage the actors as the ethical experts, and by not privileging academic 'outsiders' as authorities in ethics. Ethicists have one voice among many.

Potential of empirical studies in ethics

Empirical ethics research can put normative questions at the heart of research in health care practice. It allows us to raise questions such as: What is the purpose of this study? Why are these tools and concepts used? What can they make visible and what do they make invisible? Rather than de-scriptions, as empirical research was thought to do, but also other than pre-scriptions that were thought to be the kind of results to be gained from ethical studies, empirical ethical studies aim for re-scriptions (term is from Harbers 2005).

Because the investigation of practices of good care is complex, qualitative research designs are often most appropriate to do this. Different types of research are possible: the analysis of documents (e.g. records or diaries), in-depth interviews, particularly suited to investigate attitudes and sometimes also to examine practices (e.g. with questions like "Tell me about your last case of euthanasia"). However, for the investigation of actual practices, ethnographic methods (observational studies) are usually more appropriate. This is certainly true for practices in which technical objects play an important normative role –as they do influence practices, but never talk about it.

Another example. If research on the use of advanced home care technology leads to new insights into the normative meaning of 'home', it will give rise to a better understanding about home, about care, about technology. Empirical ethics leads to other forms of insight and understanding than predictions and even if it does lead to predictions, testing these predictions is not always the most important way to evaluate the theory. There are other more suitable criteria, such as the extent to which new and

surprising concepts are introduced, unexpected connections are revealed, new ways of seeing and understanding are opened up and the extent to which it helps people to live with problems and dilemmas in health care.

Ethics as a companion to innovation

Empirical studies in bioethics will increasingly take the form of accompanying research following new developments, as is already happening around developments in genomics: ethical projects 'run along' with technical or medical-scientific research. But also matters of 'implementation' are of ethical interest (Pols & Willems 2010). How will new technologies be used, and how is this different from what policymakers intended? Technologies influence how people act, and – the other way around – people influence the way technologies act. It is hard to predict the shape these 'experimental' practices will take when new technologies enter. Rather than standard evaluation research that measures some pre-defined effects, ethnographic research may show what variables become relevant, how they develop, what shape the relations between humans and machines take, and what tot think about this. Indeed, a fruitful area for ethnographic research to enrich medical ethics.

Note

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