Empirical Ethics: The Case of Dignity in End-of-Life Decisions

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ABSTRACT. The actual rise of empirical contributions in bioethics questions – at a fundamental level – the place bioethics will reserve for empirical approaches in its field. This article aims to discuss the relationship between empirical research and normative evaluations and to apply this to the use of the concept of dignity in end-of-life research. It describes five possible ways in which empirical research can be related to normative ethics: prescriptive applied ethics, theorist ethics, critical applied ethics, particularist ethics and integrated empirical ethics. In this article, we elaborate on the critical applied ethics perspective and present it as a five stage process comprising a) the determination of the problem, b) the description of the problem, c) the study of effects and alternatives, d) normative weighing and e) the evaluation of the effects of a decision. At each stage, we explore the perspective from both the empirical and the normative poles and apply it to the case of dignity in end-of-life decisions.

KEYWORDS. Empirical, methodology, bioethics, theory, dignity, end-of-life decisions

I. INTRODUCTION

Working in the field of bioethics one cannot fail to notice recent interest in empirical research on bioethical questions. In the past decades, scholars and researchers from different disciplines have addressed the question as to how the empirical is related to the normative (Borry *et al.* 2004, 2005). The actual rise of empirical contributions in bioethics questions the place bioethics intends to reserve for empirical contributions at a fundamental level. A puzzle thus emerges concerning the possibility of integrating attempts to understand what *is* the case and attempts

to justify what *should be* the case. This concerns the complementarity of approaches that try to explain and understand reality, and other approaches that normatively judge reality. As Tony Hope sharply articulates: “Is this empirical work unfortunate, taking medical ethics away from its true intellectual base in philosophy and leading to mediocre studies of little interest or significance? Is it a worthwhile activity, but not medical ethics? Or is it a healthy development in the maturing subject of medical ethics?” (Hope 1999, 219)

In the present contribution we will sketch our own position with regard to the relationship between empirical research and normative evaluations and illustrate this on the basis of a single example: the use of the concept of dignity in end-of-life research. Before this, however, we will take a step backwards and briefly review the differences between normative and non-normative approaches in bioethics and the development of empirical approaches.

II. BACKGROUND: RECENT INTEREST IN EMPIRICAL ETHICS

The field of ethics is usually divided into normative and non-normative approaches. *Normative approaches in ethics* (more succinctly designated as normative ethics) set out to answer in a rational, coherent, anti-dogmatic and argumentative way what people should do (Van Willigenburg 1993). With such an aim, normative ethics concentrates on the development of ethical theory (e.g. deontological, teleological or utilitarian models) and ethical norms, principles or rules. In addition to normative approaches in ethics, meta-ethics and descriptive ethics are depicted as *non-normative approaches in ethics*. *Meta-ethics* is the branch of ethical inquiry that studies the assumptions of normative approaches. This includes questions as to whether – and if so how – we know what is right and good, whether moral values are objective, and how ethical attitudes motivate us. Furthermore it “investigates the meaning of moral terms, the logic and linguistics of moral

reasoning, and the fundamental questions of moral ontology, epistemology, and justification” (Sulmasy and Sugarman 2001, 3). *Descriptive ethics* is the factual investigation of moral conduct and beliefs. It aims at describing temporal values, rules, preferences, norms, and actions living and occurring in society or in specific groups. It is the domain *par excellence* in which sociology, anthropology, psychology, and epidemiology contribute to ethics.

The dichotomy between normative and non-normative approaches reflects the important *caesura* between *is* and *ought*, which functions in the field of ethics. “Descriptive ethics and meta-ethics are grouped together as non-normative because their objective is to establish what factually or conceptually is the case, not what ethically ought to be the case” (Beauchamp and Childress 2001, 2). In this view, empirical research provides “just the facts” (Lindemann Nelson 2000, 13), while normative ethics does the difficult and important work of resolving value questions by defining concepts, building valid arguments, and reaching practical conclusions. In this vision of bioethics, empirical research deserves only a marginal position: moral justification occurs by the rational and deductive application of norms, theories, and principles, not by the description of social worlds.

Recent initiatives, however, have urged bioethics and social sciences to go beyond the ‘false’ separation between facts and values and to reflect upon the necessary relationship between empirical and normative approaches (Haimes 2002). The best evidence of this new effort to integrate the empirical and the normative in bioethics is offered by a number of international and national research projects funded over the past decade.¹ As a result of these projects and other, individual initiatives, (bio-)ethicists, academic nurses, physicians, ethnographers, social scientists, economists, philosophers and theologians have been searching for better ways to integrate the empirical and the normative in bioethics.

By empirical research in bioethics (Sugarman 2004) – or the synonyms empirical-ethical research (van der Scheer *et al.* 2003), social sciences

perspectives on bioethics (Weisz 1990), and ethics-related empirical research (Miller 2002) – we mean the systematic investigation of a particular problem in the field of bioethics by using a research methodology (such as a qualitative or a quantitative approach) that has methodological roots in the social sciences with a view to generating, analysing and interpreting reliable and valid information or data about the total experience of all members of the society or the group under study.

The interest in empirical research on bioethical questions has yet to reveal a specific method for combining the empirical and the normative, but it has yielded a number of approaches to integrating empirical and normative bioethics. Review of these approaches allows us to assess the value of different methods of empirical/normative integration and to examine whether this offers new and useful ways to resolve moral problems.

III. OUR OWN POSITION SITUATED

In a paper published in 2004, Molewijk *et al.* distinguished five possible ways in which empirical research can be related to normative ethics: prescriptive applied ethics, theorist ethics, critical applied ethics, particularist ethics and integrated empirical ethics. A short description of Molewijk's continuum would be helpful in situating our own position among other possible ways of establishing a relationship between the empirical and the normative.²

The first position Molewijk distinguishes is *prescriptive applied ethics*. Those who hold this position are interested in moral practices, but consider moral theory to be the final arbiter. The fit between moral theory and a given social practice is not relevant for deciding what is right or wrong. Empirical data have no bearing on moral theory: data are useful only as a measure of the extent to which people are behaving properly. This approach, in fact, does nothing to integrate the empirical and the

normative; furthermore it suffers from the problem of paternalism, giving outsiders authority to determine what is morally wrong and right in the practice of a given culture.

The second position is occupied by ethicists characterized as *theorists*. Like prescriptive applied ethics, theorists begin with moral theory, but unlike advocates of the first position, they allow theory to be *improved* by data from empirical research. The relationship between empirical data and normative theories is instrumental and one-way. Empirical data can help refine moral theory, but only to a certain extent. Theorists are more interested in the perfection of their theory than in the practices that require moral judgment.

The third position described by Molewijk and his colleagues is *critical applied ethics*. This position allows for a two-way relationship between empirical data and normative theories: a social practice can and should be judged by both the gathering of empirical data and by normative ethics. Both methods of looking at a social practice are open to readjustment and refinement and each can perform this role for the other. Our own position is a more developed version of this way of integrating the empirical and the normative.

The fourth position on Molewijk's continuum is held by the *particularists*. These researchers are interested only in the empirical study of behaviour; they are not interested in relating their data to ethical theory. Particularists view morality as intrinsically related to the particular situation of a practice. Their work begins and ends with the provision of a solid empirical description of reality. In opposition to the first position – prescriptive applied ethics – particularists give so much weight to *social context* that *moral theory* no longer performs a critical role. General acceptance of a practice by a community suffices as ethical justification of that practice.

The fifth position described by Molewijk and his colleagues is their preferred position. Labelled *integrated empirical ethics* (IEE), it is an intensified version of *critical applied ethics*, an ongoing dialogue between descriptive social scientists and ethicists in which the distinction between fact

and value eventually disappears. As Molewijk rightly points out, facts always contain and generate values, and values are based on facts.³ In their view, this sociological truth demands a theoretical hybridization of the normative and empirical disciplines, in which the cores of the two disciplines are combined to form a new field of research.

IV. OUR OWN POSITION DESCRIBED

The third position in the work of Molewijk has the advantage of continuing to distinguish the normative and the empirical as two independent entities, which are intrinsically linked to each other. In order to describe the interaction between both poles we present our *critical applied ethics* approach as a five stage process comprising a) the determination of the problem, b) the description of the problem, c) the study of effects and alternatives, d) normative weighing and e) the evaluation of the effects of a decision. At each stage, we explore the perspective from both the empirical and the normative poles. In our view, one pole is not subservient to the other; rather both serve to establish a mutually critical and clarifying perspective.

Determining the Problem

What is the ethical problem, the ethical question or the case that demands an ethical judgment? While these appear to be simple and unproblematic questions, the opposite is in fact the case. Moral problems do not simply lie and wait for us: they only become moral problems once they receive such a status. “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, xi). 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, i.e. choices between two conflicting alternatives. Every action or situation can become the object of an ethical inquiry.

From a normative approach, norms or ethical concepts (such as the concept of dignity we will discuss below) can sometimes perform the critical function of bringing a sensitivity to moral issues that is not felt by the majority of society's members. In other situations, they may help to give voice to moral intuitions that are felt by a group in society that is not able to articulate or defend its case. Moral theory can inspire a fresh perspective on the morality of a society when it is able to offer a new vision of practices that are, or may be, ethically problematic.

From an empirical approach, empirical research, whether done using qualitative or quantitative methods, can contribute to the identification of ethical issues. It can help to outline rarely studied ethical problems (Braddock 1994). Research can focus on new subjects deserving ethical reflection or problems that only receive minimal ethical consideration (Fulford *et al.* 1994). It can focus bioethicists on concrete ethical problems that require more normative reflection (Brody 1993). Empirical research can also make a critical contribution to theoretical ethics by demonstrating how ethical norms are embedded in culture and by revealing the ways society can conceal ethically questionable practices. For its part, moral theory can help empirical science discover implicit and otherwise invisible moral values present in their work. Feters and Brody (1999) emphasize the benefits that epidemiology could bring to bioethics, by providing insight into the prevalence of bioethical topics.

Where this five stage process begins, either in normative ethics or empirical research, is not an important question in our model. What is important is that the identification of moral problems by normative ethics is critically followed by empirical research and vice versa. In this way neither empirical research nor normative ethics are subservient to the other. Both are equally important and both co-determine the process without either approach being blurred or fused.

Describing the Problem

The description of a moral problem begins, but does not end, with its identification. The role of the social sciences in the description of the problem is more extensive. Social scientists have the skills to discover the motives that drive people's actions, underlying intentions, the nature of moral deliberation, how relevant actors experience a practice, and the impact of the place and time of a given practice. Their research can help to solve questions such as: what reasons or subjective grounds would incite someone to take a particular action or choice? what significance does someone place in the action he or she carries out? how and under which circumstances have concrete actions or decisions been made? Apart from helping with the description of the moral problem, social sciences can also perform a critical function by situating both ethical concepts and ethical problems in their broad social context (Fox and De Vries 1998; Ackerman 1980). Many bioethicists have the habit of using a variety of cognitive techniques to create distance between an ethical dilemma and its setting. This serves to reduce the complexity and ambiguity of a moral problem. While this limits the number and type of morally relevant factors to be juggled with, it also diminishes the value of moral advice (Fox and Swazey 1984).

Normativity is consistently socially situated. Interesting studies have revealed that governing ethical concepts such as 'informed consent', which are embedded in law and bioethics, do not always function in clinical practice or research (Corrigan 2003; Conti *et al.* 2004; Hamvas *et al.* 2004). This research has shown that people have problems with processing information about risks and correct estimation of potential benefits, and that these problems may lead to distortions in the assessment of risks when making choices. The concept of informed consent originates from respect for the autonomy of the person, from the ethical right the patient enjoys to direct what happens to his or her body, and from the ethical duty of the physician to involve the patient. Informed

consent is a standard of conduct in a medical setting. However, empirical research has shown repeatedly that the conditions for informed consent are often not met and are sometimes difficult to fulfil in practice. According to Musschenga (1999), this raises the question whether the doctrine of informed consent has to be rejected because of the limits of patients' actual capacity to understand information and to assess risks. Should ethical theories be rejected because they fail to be converted into practice? How should a normative principle or theory be affected by empirical research, demonstrating that the principle or theory fails to be implemented in a certain context?

Effects and Alternatives

Actions and choices do not take place in a vacuum, rather 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. This does not absolve us of our responsibility to outline foreseeable effects, however, and later to gauge them against real effects. Empirical research can provide an overview of the consequences of a decision or policy. Brody points out that "even if one is not a consequentialist, one can at least agree that consequences are morally relevant and are part of the basis for evaluating policies. In this way, then, discoveries about what *is* the case are relevant for deciding what *ought* to be the case" (Brody 1993, 211-212). He continues: "Moreover, [empirical research] can contribute to that normative analysis by discovering relevant consequences which become the consequentialist component of that normative analysis" (212). Empirical research can also test important aspects of normative arguments. Perhaps the best example of this is the idea of the 'slippery slope'. Researchers can test when and where 'slippery slopes' actually occur (and when and where they do not) and they can explore the factors

that encourage and discourage the creation of such dangerous and slippery slopes. Further, empirical studies can identify possible alternative solutions to moral problems.

However, there is a limit to the role of empirical data. Empirical data about consequences of actions is especially helpful for those who favour a consequentialist ethics. As Brody notes: “When the moral issues are fundamentally non-consequentialist, empirical data will largely be irrelevant and may even confuse the discussion by drawing attention to the wrong issues” (218). Consequentialism is an approach in bioethics that bases its judgments 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. It is at this juncture that theoretical ethics must point to the fact that deontological approaches are sometimes helpful. Not only can normative ethicists offer a critical appraisal of the causal relations assumed in the description of a given case, they can also point to the disjunction between moralities supported by data and those supported by (deontological) ethical theory. A consequentialist may claim, for example, that the death penalty is morally indefensible because, empirically, it does nothing to deter crime, provoke remorse, or save the state money. To someone whose moral evaluation of capital punishment is based on the notion that life is *so* precious that those who unjustly take a life must forfeit their own life, however, data about deterrence and costs is irrelevant.

Normative Weighing

We enter the very heart of normative ethics with the phase of normative weighing. Nevertheless, here too we see critical reciprocity between the empirical and the normative. Ethical inquiry is thus an exchange between the moral meaning found in the empirical context, and the moral meaning

found in the various norms contending for application in a concrete discussion. 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” (Burggraeve 1989, 422). Empirical results describe a piece of factual behaviour and usually also claim to be doing nothing more than providing an unadulterated and objective presentation of research data. However, the publication of research results gives rise to standpoints and influences decisions that, in turn, can alter the normative structures of the reality of an action. Sociologically described facts can repress existing norms and introduce new ones. A well-known example of this is the way in which euthanasia was legalized in the Netherlands after extensive national surveys that mapped out actual practice and how it was supported by the population. In this way, the social scientific examination and analysis of bioethics (e.g., bioethics committees, research ethics committees, ethical decision making, allocation choices) by non-bioethicists will foster the critical self-reflection necessary for the intellectual development of the field (Weisz 1990; De Vries and Conrad 1998).

The most important contribution of theoretical ethics is to make sure that the normative power of the factual is given its proper place. When a practice is described and analyzed, discovered to be widespread and judged as morally acceptable by a majority of the members of a society, statistical normativity begins to work. Normative theory stands over and against the simple idea that the majority creates the moral rules: in the end ethical theory (empirically informed) renders moral judgment. This means that a certain suggested course of action or moral judgement should acquire the necessary moral legitimacy. What happens then is that moral justification is granted to a certain argumentation and conclusion, which amounts to presenting sufficient grounds to support it (Beauchamp and Childress 2001). In our view, moral legitimacy cannot be granted on the basis of an inductive, bottom-up perspective alone. Empirical research cannot determine what is good or evil, right or wrong, by itself. 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. Persuasive argumentation must not only be based on empirical data, it must also explain and critically evaluate the values or ethical theories that are being presupposed (Nilstun 2000; Nilstun and Sjökvist 2001).

Since our critical applied ethics is a model in which theoretical ethics and empirical research provide us with a double (and mutually clarifying) critical perspective on the moral issue at stake, normative weighing is preceded by three stages in which already normative judgments have been made. A normative position is established from the very moment a problem has been identified and described, or rather: the implicit normativity of the identification and description is brought to light. As such, researchers already take a normative position, even when their position is one of non-judgmental clarification. Once again, this phase of normative weighing does not ascribe a secondary, supportive role to either empirical research or normative ethics. By clarifying one's own moral position a transparency is achieved on both the normative ethical theory that is chosen and the social position and motives of the researchers involved. Even in its most normative phase, therefore, our model of critical applied ethics honours both poles of the ellipse, achieving choice and critical clarification thereof at one and the same time.

Evaluating the Effects of a Decision

Since moral truth cannot be fixed once and for all, moral choices must be subject to continual question and, in some cases, adapted. Bioethics is a never ending process of evaluation and re-evaluation. Once a decision has been made, it is the moral responsibility of the decision-makers to be sure that the decision has no unforeseen and unintended effects or side-effects. The critical function of theoretical ethics here is to make sure that attention to effects does not, in the end, result in a victory for consequentialism (if this is not the appropriate moral theory). Empirical researchers

must map out the actual effects of a decision and provide data that can foster further ethical reflection.

V. THE CASE OF DIGNITY

In order to illustrate how our theoretical position functions in the field of bioethics we will focus on the way the concept of dignity is used in a specific bioethical discussion regarding end-of-life issues. In the Netherlands and Belgium, a specific group of patients who have made a free and long-standing request to have their suffering brought to an end can ask for euthanasia. It was observed in the case of the Netherlands that the term dignity was appearing with increasing frequency in the reports of the regional review committees. Research has shown that of the 123 euthanasia requests reported by physicians in 2002 no less than 63% were inspired by a perceived loss of dignity (Rietjens *et al.* 2006). This observation had already been described elsewhere (Haverkate *et al.* 2000; Chin *et al.* 1999; Morita *et al.* 2002). The self-chosen death of Hugo Claus, a renowned Belgium writer who was suffering from the initial stages of Alzheimer's disease, raised the discussion as to whether patients like him should have the right to die. *Right to Die-NL*⁴ is an association numbering more than 104,000 members that plays a major role in the public debate.⁵ The association has started a research project in order to find out whether irreversible loss of dignity can be a criterion for those who suffer from unbearable suffering. How would our five stage version of *critical applied ethics* deal with this case?

The first stage concerns the determination of the problem. In this case the discussion about dignity is already ongoing and does not need to be identified from a theoretical point of departure. It remains important, nevertheless, that we examine how and in what context the problem was empirically determined as such. From the resulting description, we learn that the discussion can be understood as having been inspired in part by

political motives. Research on dignity was thus initiated by a political party that had a specific goal in mind: more individual freedom when it comes to end-of-life issues.

From the perspective of normative ethics, a first critical question might be raised concerning the central concept of dignity. Dignity is a notoriously confusing concept (Griffin-Heslin 2005). As Richard Horton framed it: “Human dignity is a linguistic currency that will buy a basketful of extraordinary meanings” (2004, 1081). In the end-of-life discussion, for example, the concept is used both by those who argue in favour of assisted death and euthanasia and those who are firmly against. In the case of the research of *Right to Die-NL*, a specific meaning of dignity is used: the self-reported and self-attributed dignity of patients. Both in the public discussion and the research project, the choice for dignity as a focus is claimed to be the appropriate answer to a public desire. This may be an empirically valid claim, but from a theoretical and normative perspective one can ask whether dignity-talk is not the effect of another, hidden problem, i.e. the real problem. *Right to Die-NL*’s research claims that the formulation of the problem was done democratically and had a solid empirical foundation. But how deep does the self-analysis of the general public tend to go? How ethical is the power of statistical normativity? And what are the motives of those who support this discussion? *Right to Die-NL* is very clear about this: they use the empirical call for dignity as a means to promote more personal and individual freedom in end-of-life choices. In other words: the empirical is used in a normative way.

The second stage, which is related to the first, concerns the description of the problem. Empirical research can be helpful in order to expose the experiences, motives and intentions of those involved in end-of-life issues. The *Right to Die-NL* project was inspired by the research venture associated with the Canadian psychiatrist Harvey Chochinov (Chochinov *et al.* 2002; Chochinov 2002), which focuses on the self-appreciation of dignity of terminally ill people. Chochinov discovered a strong link

between the undermining of dignity on the one hand, and depression, anxiety, the desire for death, hopelessness, the feeling of being a burden on others and a generally poorer quality of life on the other. He thus proposes dignity therapy for patients near the end of life, consisting of therapeutic sessions in which people talk about the most important events of their life. The outcome of these sessions is reshaped and edited into a narrative. Chochinov reports good results and has presented an empirical model for understanding dignity at the end of life, distinguishing between illness related concerns, a dignity preserving repertoire (perspectives and practices) and a social dignity inventory.

Building on the findings of authors like Chochinov, the Dutch research of *Right to Die-NL* tries to establish a list of criteria that help clarify the extent to which people experience dignity at the close of life. From the perspective of empirical research, one might argue that the description of the problem is based on the empirical finding that dignity seems to present itself as both a problematic *and* a useful category for addressing the needs of patients at the end of life.

From a theoretical and normative perspective, however, one can ask some serious questions with respect to the way the question is framed. In the first place, by focusing on dignity and choosing one particular meaning for the concept, a considerable number of presuppositions are introduced and taken for granted. It is presupposed that focusing on dignity is the best way to frame the problem at hand and we will return to this presupposition below. Nevertheless, even when one chooses for dignity, it remains important from a theoretical perspective to bring to light the different ways in which dignity can be understood in this phase. A brief survey of the history of Western thought and an analysis of the concept in question gives rise to three potential meanings.

In the first place, we can speak of the subjective dignity that is experienced by the person who is dying. This is the meaning of the word upon which the research is based. The positive element here is the focus on the experience of the dying person as an important basis for the ability

to bear suffering. But there is a danger that we limit our focus to this subjective dignity alone. People can be wrong about what they feel. As we know from people who are sick, they may feel they are a burden to their family, but their family may not agree. The same is true for people suffering from anorexia who consider themselves fat while their BMI is far below the acceptable level for someone in good health.

A second meaning of dignity has its roots in ancient Stoic philosophy and is based on the importance of someone else attributing dignity to a person. Dignity in this sense was originally associated with a public position that was highly esteemed. As such it was a social phenomenon that we shall call ‘social’ or ‘relational’ dignity. There are various versions of this kind of dignity. Apart from its aforementioned social form, attributed by members of a society at large, dignity can also be established in interpersonal relationships (Van Heijst 2005). The positive dimension of this meaning is that it makes clear that dignity can never be taken for granted. Dignity in this sense needs continuous establishment. Dignity, in other words, is a verb that requires continuous implementation. Once again, however, it would be risky to place all our eggs in one basket and support only this meaning of dignity: societies and people can stop attributing dignity to people. They can even structurally deny dignity to them, as the examples of women, homosexuals and persons of colour in many societies reveal.

There is a third meaning of dignity, which is not mentioned in the research carried out by *Right-to-Die-NL*, a meaning that understands dignity as an intrinsic quality, irreversibly linked to being human. The best known examples of this ‘intrinsic’ dignity are those promoted by the declaration of human rights of the United Nations and the Roman Catholic Church. Dignity in this sense has Stoic roots and is often associated with people’s rational human nature and free will. Sharing human nature is sufficient to be attributed this kind of dignity. As such, it can be a counterfactual predicate with a strong heuristic ethical impact. There are risks involved when we support this kind of dignity alone, however. In the first place, while the attribution of intrinsic dignity appears at first

sight to be a particularly solid way of protecting people, it can remain an empty word. One can declare that human beings are intrinsically ‘dignus’ and subsequently do whatever one likes, because this can never take away the dignity that is intrinsically linked to human nature. Secondly, the very fact of being attributed this sense of dignity can become very uncomfortable when one does not sense any dignity oneself (first meaning), and it is not attributed in interpersonal or societal relationships (second meaning). One can be left alone with one’s dignity and cut off from possibilities that may be considered compassionate from the perspective of, for example, *Right-to-Die-NL*.

What we discover from this theoretical exercise is that the meaning of dignity can be very different, resulting in different ways of framing the question. This will have considerable impact on the fourth stage of our model, which deals with normative weighing.

The third stage concerns the determination of effects and alternatives. Alternatives in the case of dignity, alternative ways of framing the problem, may result in different strategies and effects, and this is the place in which we must map out what we expect. Empirical research can help at this juncture to outline what the consequences of a given activity might be. What will happen when dignity becomes a new keyword and criterion in the end-of-life debate? Theoretical ethics might help to specify different types of possible harm related to the physical, psychological, social or spiritual. Empirical ethics might help to expose the impact of this development on the general public; how much respect will be given to those who experience no dignity themselves? Empirical ethics may also help to answer the question whether there is a possible danger of a logical or empirical slippery slope at this juncture. Normative ethics might focus on the limits of the consequentialist approach that is favoured when the effects of the dignity-research are given all the credit.

In the fourth stage a normative weighing takes place. Here one is naturally obliged to adopt a position with respect to the different meanings of dignity and the way they are brought into relation with one another.

One is also obliged at this juncture to adopt a position on the normative consequences of choosing one meaning of dignity or another, or one particular constellation of the three meanings. Any ethical position on end-of-life issues can also be read as an expression of a certain way of life, including (and excluding) certain experiences. This shapes the way one addresses this topic and contributes to a definition of a reality that is always value-loaded. In the case of dignity in relation to end-of-life issues, it will make a serious difference whether the normative weighing is done from the perspective of either one of the concept's three potential meanings as a most fundamental category. Being aware of this fact and communicating it in a transparent way is a methodological and ethical choice that is at the heart of our critical applied ethics.

Finally, the last stage of the research process consists of an evaluation of the effects of a decision. In the case of dignity, there is a clearly intended effect. The interest in dignity by *Right to Die-NL* has an important focus: it is meant to enable more autonomy in end-of-life decisions. The question remains, however: what is the real effect on the quality of end-of-life decisions? As we have seen, there is a danger of focusing merely on the subjective idea of dignity, which might contribute to a culture of subjectivism that is not counterbalanced by relational dignity. For this reason, according to our model, it is essential to build in an evaluation of the research results.

VI. CONCLUSION

Empirical research has an important role to play in bioethics. In our view, this role is best developed in a critical interaction with normative ethics. In the present contribution, we have described our position in terms of a revised critical applied ethics against the background of different possible ways in which empirical research can be related to normative ethics. We have developed our position as a five stage model, in which the

empirical and the normative are distinguished as two independent entities that interact in a critical way. Our position was applied to a recent example of research in which both empirical and normative elements are mixed so as to demonstrate that our critical applied ethics has the capacity to expose presuppositions and hidden normative views. To what normative conclusion this will lead in the case of the dignity research is still an open question. By using our model, however, we expect to be able to answer it in a clear and systematic way.⁶

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NOTES

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2. For a more critical and detailed discussion of the five positions and the development of our own view we refer to: Leget *et al.* 2009. The present contribution is partly based on this article in *Bioethics*.

3. We will come back to this more explicitly below when we deal with the second step of our own five stage model, namely ‘the description of the problem’.

4. Nederlandse Vereniging voor Vrijwillig Levensende or NVVE.

5. More information on: <http://www.nvve.nl/nvve2/pagina.asp?pagkey=72083> [accessed January 7, 2009].

6. We thank Charlie Camosy for correcting and Eva Leget for editing our manuscript.