Health care ethics and health law in the Dutch discussion on end-of-life decisions: a historical analysis of the dynamics and development of both disciplines

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Abstract

Over the past three or four decades, the concept of medical ethics has changed from a limited set of standards to a broad field of debate and research. We define medical ethics as an arena of moral issues in medicine, rather than a specific discipline. This paper examines how the disciplines of health care ethics and health care law have developed and operated within this arena. Our framework highlights the aspects of jurisdiction (Abbott) and the assignment of responsibilities (Gusfield). This theoretical framework prompted us to study definitions and changing responsibilities in order to describe the development and interaction of health care ethics and health law. We have opted for the context of the Dutch debate about end-of-life decisions as a relevant case study. We argue that the specific Dutch definition of euthanasia as 'intentionally taking the life of another person by a physician, upon that person's request' can be seen as the result of the complex jurisdictional process. This illustrates the more general

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conclusion that the Dutch debate on end-of-life decisions and the development of the two disciplines must be understood in terms of mutual interaction.

1. Introduction

Within the span of just a few decades we have seen dramatic change in the way moral issues in medicine are regarded and addressed. Up until the 1960s, medical ethics remained largely a matter of professional moral codes; today medical ethics has been swallowed up by bioethics, a new and broad field of societal debate engaging lawyers, ethicists, theologians, social workers and others. The "veto" on bioethical matters is now the shared professional property of many disciplines. How did this transformation take place and what are its implications for the way bioethical problems are framed and resolved?

In an effort to explore this change, most analysts have looked at the social context and cultural meaning of medical ethics (Weisz, 1990; De Vries, 1995; De Vries & Subedi, 1998); they have studied *why* and *how* medical ethics developed and became bioethics (Rothman, 1991; Jonson, 1998). For example, in his analysis of experiments with humans and the development of medical ethics, Rothman focuses on the *social* context of the transformation of medical ethics. He posits that in The United States—a society concerned with 'underdogs'—we would *expect* special interest in the rights of research subjects to emerge. Rothman goes on to show how the concern with medical experiments involving human beings served to attract many 'outsiders' to the field of medical research, including jurists and ethicists.

In contrast to Rothman and other similar studies, we study bioethics as a developing field of several disciplines, in this case health care ethics and health law. We explore the relation *between* these two disciplines as they develop rather than between disciplines and society. We consider bioethics as an arena of actors from different disciplines who create boundaries between 'good' and 'bad'. In particular we are interested in the way the interaction between the many disciplines of bioethics has shaped both the field and the way moral problems come to be defined. Our focus is on health care ethicists and health lawyers in the Netherlands. Using the Dutch euthanasia debate as a case study,[1] we look at how these two disciplines/professions

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[1] We will not pay proportional attention to the role of the medical profession in this debate, although we admit that the Dutch medical association KNMG has taken an active part in the euthanasia debate. First, we are interested in the development of health care ethics and health law instead of euthanasia or the medical profession. Second, the combination of our analytical framework and a case-study is not appropriate to study the medical profession as one homogeneous *discipline*. Claims about the significant role of the medical profession in the Dutch debate about end-of-life decisions can be found in Griffiths (2000).

managed their competing claims of competence and show how a particular moral issue interacts with the development of professions within bioethics.

The transformation from physician control of normative problems to shared control of these problems by the professions of bioethics can be understood as a contest over jurisdictional boundaries between professions. Abbott's model for a comparative and historical study of relations between professions presupposes that jurisdictional boundaries between professions are perpetually in dispute (Abbott, 1988). The concept of jurisdiction—defined as the link between an occupation and its work—is an instrument to analyse professions as functioning in an interdependent system. Since one profession can pre-empt another's work, the histories of professions are inevitably interdependent.

2. Theoretical perspective

Our research shows that the definition of euthanasia in the Netherlands is inextricably linked to the fates of the competing professions of health care ethics and health law.[2] The two professions are still considered 'independent' disciplines with separate chairs, journals and professional associations (Roscam Abbing, 1985), and the relation between the two has been cause for comment and concern in the Netherlands (Van der Burg & Ippel, 1994; Dillmann, 1997; Schuyt, 1997). Some claim that ethical work is hindered because each has its own vocabulary and methodology; others fear that, like siamese twins, health care ethics and health law might be too intertwined with one another (Van der Burg & Ippel, 1994). We do not plan to engage this debate; rather we use the competition between these disciplines to gain insight into the development of problems in bioethics.

In order to analyse the complex interaction between these professions, we use Abbott's (1988) notion of jurisdiction. Abbott initiated the idea of studying occupations from an *ecological* perspective, from the perspective of a 'system of professions'. According to Abbott, the history of profession(s) is a history of jurisdictional disputes. Professions grow when there are *niches* for them to grow into; they change when other professions threaten their control of particular kinds of work. Technology, for example, can reshape professional work. New technologies create opportunities for jurisdiction. Professions establish, defend and exercise claims of jurisdiction. Professions are not shaped according to a certain model, since their dynamics are conditioned by the circumstances of their operations, especially the activities of other professional disciplines. Because we are interested in the evolution of health care ethics and health law and in the way their efforts to control the debate over euthanasia shaped their knowledge and skills, Abbott's ideas are well suited to our study. We will not attempt to answer the question from what time and on which

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[2] Our focus on the Netherlands offers the added benefit of lifting the study of bioethics out of its largely Anglo-American context.

criteria Health Care Ethics and Health Law have become robust or at least recognized disciplines, since this would require a much broader analysis.

We also use Gusfield's (1981) ideas about the dynamics of public problems as a supportive heuristic device. He explores the link between the 'ownership' of a public problem and the delegation of responsibilities to the actors involved. According to Gusfield, social problems—like euthanasia, or in Gusfield's case, drunken driving—generate jurisdictional disputes. Concerned groups struggle for influence, power and authority over the problem. Unlike Abbott, however, Gusfield suggests that the analysis of jurisdictional disputes should begin from the *problem*, not from the *professions* involved. He introduces the metaphor of 'ownership' and—in his case-study of drunken driving—shows that the owner of a problem has the major voice in its definition, and hence in the framework used to discuss the problem.

When a group controls the definition of a problem, it controls the assignment of causal and political responsibility for that problem. The professional struggle for ownership of a problem is a struggle for the distribution of causal and political responsibility. Gusfield illustrates his theory by looking at the consequences of medical control over drunken driving. When drunken driving is conceived as a medical problem it becomes a problem of the effect of alcohol intake on the individual's driving capacity. In this (apparently neutral) problem definition, the individual drunken driver is blamed (causal responsibility) and the political responsibility is relegated to those public agencies that are supposed to influence the individual's behaviour (preventive campaigns and law enforcement). This constellation of the problem effectively shifts attention away from the possible causal and political responsibility of alcohol manufacturers and distributors, car producers and road constructors, as well as the political responsibility of the public agencies responsible for those actors.

Our study blends the ideas of Abbott and Gusfield. In the dispute over the definition of euthanasia in the Netherlands we see medicine losing control over the moral problems in health care, while health care ethics and health law gain control. We also see these two professions struggling for jurisdiction over definitions, solutions, and the assignment of responsibilities concerning euthanasia. Abbott's analysis of the system of professions is restricted to *work related* problems; we extend his analytic framework to *social* problems.

Our case study gives us the opportunity to study professions in action. We are interested in a debate instead of handbooks and other declamations of professional identity, because it is in a debate that jurisdiction comes alive. Euthanasia is an ideal subject for a case study. Not only has it been a prominent subject for debate in the Netherlands since the late sixties, it is also considered to be one of the most important arenas for the transformation of medical ethics. Furthermore, the debate about euthanasia has been broad, intense and ongoing since the sixties, giving us a great amount of empirical material from both disciplines for the period we studied (1960–1994). Our analysis of this jurisdictional dispute is based on literature from the *professional* debate about end-of-life decisions, mainly from scientific journals. We do this for pragmatic reasons and because we presuppose this is the prime, though not exclusive, arena of the professional struggle for jurisdiction. It is remarkable that the Nazi

practice of euthanasia have never played a serious role in the professional debate or even in the public debate on end-of-life decisions (Kennedy, 2002).

3. Questions about life and death in the sixties

The literature about euthanasia in the Netherlands is divided about when the debate over the practice actually began. Ethicists tend to argue it started with the well-known and tremendously well-sold publication in 1969 from the psychiatrist Van den Berg, a critical monograph about the consequences of the new technical power of medicine for medical ethics (Zwart, 1998). Others, especially lawyers, mention the first famous lawsuit on euthanasia in 1973 (Legemaate, 1998; Legemaate & Dillmann, 1998). We start our analysis before these two well-acknowledged events, focussing on a period instead of a certain moment. This also implies that the term 'euthanasia' must be read with some caution. To define which part of the broader category of medical decisions at the end of life should properly be called euthanasia is one of the core issues of the debate itself. The rise and development of resuscitation and transplantation techniques, in the fifties and sixties, induced radical change in the medical context of life and death. Until then, medical ethics was a matter of etiquette for physicians. End-of-life matters were left to the prudence and conscience of physicians.

The new medical technology engendered serious uncertainties for the medical profession (Houtepen, 1998). Such a period of uncertainty offers opportunities for changes in jurisdiction. This is the reason to describe the debate from here on, despite occasional earlier publications on euthanasia. In the sixties, medicine was confronted with a new type of problem: decisions in the murky area between life and death. Until then the principle of 'absolute respect for life' had always been the only legitimate foundation for ethically sound decisions. But in the twilight area between life and death, this guideline was not much help. Prolonging life did not seem to be the right decision in every attempt for resuscitation.

The medical profession immediately tried to gain possession of the new problem of decisions about life and death. Early on, however, a professor of law cautiously claimed some jurisdiction in this matter. Although he didn't offer a solution, he proposed that 'deliberation between a physician and a lawyer' should be the proper way to handle such problems (Kooyman, 1960). It was not clear how he envisaged this co-operation. Jurisdiction was not settled in advance, neither regarding the relation between physicians and lawyers, nor in the broader context of medical ethics. A presentation at the yearly congress of the Protestant–Christian organisation of physicians illustrates the precarious nature of the initial opening up of the arena of medical ethics. Den Otter, professor in surgery, acknowledged the doubts and questions concerning resuscitation attempts: when to start and when to quit? But he was not convinced of the need for advice from non-medical professionals in this niche, as some of his colleagues suggested. In his opinion there was no need for a new medical ethics and even less necessity for debates with 'upset and anxious theologians, philosophers and lawyers' (Den Otter, 1963, p. 183). The acknowledgement

of a new type of problem was commonly shared, but there was no agreement on the sort of framework in which these questions should be handled.

Theologians and philosophers, later to be called ethicists, also began to assert their claims on the questions raised by the new medical technology. Although not all physicians appreciated their advice, they gained access to several medical magazines. For example, the Catholic theological ethicist Sporken approached the issue from the perspective of philosophical anthropology. He emphasised the joint responsibility of the physician and patient for new questions concerning life and death. The physician should regard the patient as a human and not only as a (biological) body. As a consequence, the ethical principle or guideline for medical practice should be: will this treatment be of true service for this particular human being, who—together with his fellow-men—is on his way to his destination according to God's mission? (Sporken, 1965, p. 377). This can be interpreted as follows: will this particular patient benefit, as a human being, from this particular treatment? Sporken explicitly introduced the patient as a discussion partner in important medical decisions. It became clear that from several angles—legal, medical and ethical—the absolute interpretation of respect for life, which had traditionally been the guiding principle in medicine, was now a matter for discussion. This was perceived as no less than a revolution in medical ethics (Kortbeek, 1968).

The psychiatrist Van den Berg synthesised many of these observations in a monograph on 'medical power and medical ethics' (Van den Berg, 1969). Medical power refers to the increased use of medical technology. Nearly all contributors to the debate agreed this was the main cause of the end-of-life questions. In order to illustrate the normative impact of this new medical technology, Van den Berg described certain patients as victims of the medical-technical power. A new medical ethics was required to set limits to the new medical power. Van den Berg argued that in some situations the patient should be regarded as a discussion partner. Like Sporken, Van den Berg relegated political responsibility to improved communication between physician and patient. Unlike Sporken, Van den Berg explicitly included active euthanasia as a relevant issue for discussion.

In a review of this controversial monograph, the physician and lawyer Schuurmans Stekhoven fully agreed with Van den Berg's plea for active (lethal injection) and passive (ceasing life-saving treatment) euthanasia. He even constructed a hierarchy in the discussion of what he labelled as a medical–ethical and medical–juridical problem, claiming medical–juridical ownership of this issue. His argument was that law bore much more importance in deciding upon the border between life and death than ethics (Schuurmans Stekhoven, 1969). Sporken argued exactly the other way around. According to him legalising active euthanasia was not indicated as long as ethics was still far away from a concluding position concerning euthanasia, since law ought to follow ethics (Sporken, 1969, p. 225). Notice the effort to introduce time-order. This is a way to create hierarchy: making clear what comes first and what comes next is an important element in claiming jurisdiction.

Thus, new developments in medical technology confronted the medical profession of the sixties with new questions and problems in end-of-life decisions. There was a niche and also a supply of other potential experts in the context of changed social

conditions. The arena of medical ethics, once the province of doctors, was now open to other professionals, especially lawyers and ethicists. On the legal side, jurisdiction was claimed next to and joining the medical perspective. The claims brought in from the ethical side, on the other hand, were much broader and relatively vague or still undecided. It was not yet clear from whence the guidelines that physicians wanted should come.

4. A broad category of problems

In the 1970s, the consequences of this 'crisis' in medical ethics became apparent. The idea of a crisis in medical ethics spread unchecked and opened an area of jurisdiction for medical ethics. Lawyers and ethicists transformed the medical ethics of end-of-life decisions. In the debate about these decisions, the meaning of the term euthanasia was still very broad. It could either refer to direct action, indirect action, refraining from action, action with or without request from the patient or even knowledge by the patient, physician or lay action. Before all this was sorted out, people from diverse professional backgrounds with competing claims had their say in it.

In the early seventies it was not clear who was allowed to say what about ethics and end-of-life decisions. This is illustrated by the General Meeting of the Royal Association of Physicians in 1970. Medical ethics was the first topic on the agenda. 'There is an evolution going on in medical ethics', as the chairman pointed out (Vander Drift, 1970, p. 413). Medical ethics as a matter solely for physicians had vanished. Medicine could not deny the crisis in medical ethics; there was a shift in moral values and attitudes. The chairman's statement meant that the door to official jurisdiction over medical ethics was ajar. In the context of end-of-life decisions the chairman called attention to the insufficiency of the principle of 'respect for life'. Instead of using this principle as a solution to each and every problem, as had always been the case in medical ethics, it should be used as a point of departure. A new approach to medical ethics was called for: a multiform medical ethics with a multi-disciplinary approach (Van der Drift, 1970). But what this new medical ethics should look like was not yet clear.

The ethicist Sporken was invited to give a lecture about medical ethics to this general meeting. Apparently he was considered a non-medical delegate of medical ethics. Sporken accentuated the evolution in medical ethics and pleaded for a medical–social ethics. He claimed more attention for anthropology and terminal care in medical education. There should be openness about the lethal character of some diseases and attention for the patient's experience, for example of fear and loneliness. Doctors should meditate on the status of their patients and themselves as persons and on the social and cultural nature of their relationship. In short, according to Sporken, there should be a serious dialogue between physician and patient (Sporken, 1970, p. 423). Sporken left unsettled who should take care of terminal care, indicating this could very well be done by a pastor (Hoofdbestuur, 1970, p. 962).

By defining terminal care in this particular (social) way, Sporken claimed jurisdiction in end-of-life matters for non-medical expertise. The philosopher Klever put it

even more sharply and potentially threatening for the medical profession: according to him, euthanasia (in the broad sense) was a technical question. Why should it necessarily have to be a physician who carries all the responsibility, he seriously wondered (Klever, 1972, p. 303). A few years later the ethicist Dupuis stated in her thesis that medical ethics was not the private property of the medical profession any more. She argued that medical ethics, because of its personal character, was a *case for everyone* (Dupuis, 1976). The personal and probing character of medical ethical issues legitimated a broader jurisdiction, according to Dupuis. All these comments from the ethical side of the debate explicitly disputed the medical jurisdiction concerning medical ethics and decisions in end-of-life matters.

From the juridical side, medical ethics was questioned too, but less threateningly for the medical profession. In the early seventies the lawyer Van Till asserted that the current medical ethics was no longer sufficient for the new type of problems. This was not very surprising, she stated, as current medical ethics was only dealing with a limited range of problems (VanTill-d'Aulnis de Bourouill, 1970). She argued that the question whether a life-sustaining treatment should be stopped or not was too complex to be answered solely by the medical profession. The medical profession should be *assisted* in this matter by law and ethics. Law should give guidelines on the basis of current ethics. Van Till aimed at supplying the medical profession with legal guidelines to show them a way out of this problem. In contrast with her ethical colleagues, she did *not* question the role of the physician in this process.

In the second half of the seventies her colleague, the lawyer Leenen, approached the problem of euthanasia from two perspectives. On the one hand he stated firmly that nobody but the patient himself could judge on the life of the patient. According to him it was obvious that the patient's wish was the main element in considering euthanasia. Leenen agreed with Van den Berg and most authors that the development of medical technology was responsible for the problem of euthanasia. In line with this statement he considered the medical profession to be primarily responsible for a solution. On the other hand he attributed the increase in patient requests for euthanasia to the development in human rights which had, according to him, gained force in the context of health care (Leenen, 1977: 74). This legitimated a *legal* approach for the problem of euthanasia, departing from the will of the patient. This patient-aspect became clear in Leenen's consequent definition of euthanasia as intentionally taking somebody's life upon his or her request by a physician. More importantly, by defining euthanasia on the one hand as a medical problem and on the other as a human-rights problem, he defined a medical–juridical approach for euthanasia. Ethicists were not as outspoken as Leenen regarding the role of the patient in euthanasia. The ethicist Beemer expressed his doubts about 'knowing' the will of the patient. By bringing the rather common distinction between voluntary and involuntary euthanasia up for discussion, he also put the 'will of the patient' in a very different perspective from Leenen (Beemer, 1977). Beemer opposed the idea of making euthanasia possible, within or without a medical context.

At the end of the seventies there was a variety of proposals to handle the new problem of end-of-life decisions. The old jurisdiction, a monopoly for the medical profession, was destroyed. A new jurisdiction, however, had not yet emerged. The

different approaches of ethicists and lawyers showed that there was no commonly agreed upon new approach. These differences legitimised the existence of (at least) two different kinds of expertise or more broadly, two different disciplines. Whereas there was consensus on causal responsibility (medical technology), both the scope of the problem definition (professional versus social and cultural) and the attribution of political responsibility were disputed. The role of the physician in end-of-life matters, for example, was up for discussion. Several ethicists wondered whether a physician should have control over assisting suicide or euthanasia, while lawyers in general did not question the physician's role or even gave him a central role.

Concerning political responsibility, not only the role of the physician was debated, but also the role of the patient. Ethicists and lawyers asked attention for an improved communication between patient and physician. From a legal perspective, a central role was claimed for the will of the patient in end-of-life decisions. At the same time however, philosophers and ethicists doubted the possibility of ever being able to know the will of the patient. This illustrates a broader pattern where philosophers and ethicists limited themselves to asking broad and purportedly fundamental questions, whereas lawyers attempted to come up with more concrete answers. Although the latter may have sounded just as alarming to many physicians as the ethicist's questions, the juridical definition of the problem offered at least hope for some settlement of political responsibility that attributed a central role to physicians. In short, in the seventies ethicists and lawyers were working hard to see how expertise should or could be divided over them and the physicians.

5. A definition is claimed and accepted

Under the name of 'euthanasia' or 'end-of-life-decisions', a wide category of problems was usually discussed as a whole until the end of the seventies. Euthanasia in its current Dutch meaning was still just one element in this cluster of dilemmas. Parallel to this problem, no single area of expertise was considered fit to solve this problem. In general lawyers were better represented in official committees, and their statements were closer to physicians than those of ethicists. But there was a common responsibility for the problem and in the eighties this shared ownership was continued, with an emphasis on a medical–juridical coalition. This is shown in the definition of euthanasia which stabilised in the mid eighties. It is plain that the shared problem of the seventies, 'How can we reduce medical power?', is allowed for in the definition of euthanasia. Euthanasia was defined as life-shortening at the *request of the patient*. It was hoped that the patient could function as a safety-lock against medical power. The initiative for euthanasia should not be in the hands of a physician. In the eighties a more specific question became the main topic of debate: how can euthanasia be legitimised?

In an early stage of the debate about euthanasia the lawyer Leenen insisted on an objective definition for euthanasia. In his handbook he proposed to define euthanasia as: 'intentionally shortening life (including withdrawal of treatment) by someone, at the request of the person involved' (Leenen, 1978). With this proposal Leenen dis-

tanced himself from many other definitions for euthanasia. He emphasised the objective and neutral character of his definition in contradiction with so many others. In many articles Leenen repeated this message. As a consequence of defining the problem in this way Leenen distinguished between euthanasia and what he called 'pseudo-euthanasia', for example to stop a medically futile treatment or the refusal of (life-saving) treatment by the patient (Leenen, 1978, p. 238). This distinction implied a 'true' euthanasia and a 'true' problem. The problem was reduced to the legitimisation of a very specific type of decision by the physician.

From Abbott's perspective of jurisdiction, this effort to arrive at an 'objective' definition for euthanasia can be contrasted with the approach of influential ethicists. The Catholic author Sporken mainly insisted that the term euthanasia should preserve the broad meaning it initially carried in ancient Greece: a good death. The Protestant ethicist Kuitert, on the other hand, stated that a good definition was simply a matter of agreement. In his book about euthanasia he copied Leenen's definition to a great extent. Whereas the lawyer Leenen claimed an important aspect of the problem about euthanasia by putting a lot of effort into creating a definition, the ethicists did not really struggle for ownership. Sporken continued to define euthanasia as a social and cultural issue in the broadest sense of the words. Kuitert followed Leenen's claim instead of claiming a different or more ethical aspect. Claiming a definition is claiming part of the discussion. At the same time this is a way of leaving one's business card, whereas accepting and following a definition means missing a chance to represent one's discipline.

Today the definition mostly referred to is that of the State Committee, of which Leenen himself was vice-chairman (Staatscommissie, 1985). This definition is very similar to the one Leenen had proposed and seems to have had a stabilising effect. It was the task of this Committee to give advice on the government policy concerning euthanasia, with special attention to legislation. The lawyer Roscam Abbing praised the Committee for its work, especially concerning the definition of euthanasia. According to her the Committee had 'unquestionably' created clarity with the advice, particularly with respect to the improper use of the term euthanasia in the sense of passive and active euthanasia and direct and indirect euthanasia (Roscam Abbing, 1985). Lawyers generally supported the Committee's choice in the definition of euthanasia (Gevers, 1985; Sutorius, 1985).

In the eighties Sporken and Beemer were superseded as the leading ethicists in the euthanasia debate by Dupuis and Kuitert. This second generation of medical ethicists was much more inclined to collaborate with the lawyers and physicians in solving the problem(s) of euthanasia. This did not prevent those ethicists from taking an opportunity to stress their particular expertise. For example, Dupuis questioned the State Committee's expertise. She claimed that the 'typically ethical question' whether a right to live also implicates a duty to live was central to the problem of euthanasia. According to Dupuis this pivotal ethical question was left unspoken by the Committee. She attributed this failure to the lack of ethical know-how in the committee, because there was only one ethicist involved (Terborgh-Dupuis, 1985). Her comment consisted of a double jurisdiction claim: she emphasised an 'ethical' aspect of the debate and at the same time demonstrated ethical expertise. In short,

lawyers have put more effort in marking the debate about euthanasia, for example by demanding a 'clear' definition. Ethicists claimed their ethical expertise, but were at that time less focussed on, and involved in, policy making. The overall idea was that they would offer less instant problem-solving expertise in regulating the issue of euthanasia than would jurists.

In line with Leenen's work on the definition of euthanasia and based on the jurisprudence and the reports proposing a regulative framework, a broad consensus developed concerning how to deal with the euthanasia issue. The need to secure this consensus by legislation was deemed all the more necessary because euthanasia was by now considered accepted practice. Hence, physicians and patients were in need of clear guidelines.

6. New problems in the nineties: incompetent patients

At the end of the eighties there was, amongst a large number of physicians, ethicists, lawyers and others involved, agreement about the definition of euthanasia. Euthanasia was defined as an issue of autonomy. Patient autonomy was a necessary condition for the legitimacy of euthanasia. However, this appeal to patient autonomy did not offer a solution to the problems associated with patients such as severely handicapped new-born babies, patients in a persistent vegetative state, patients with Alzheimer's disease, and psychiatric patients. This category of non-autonomous or non-competent patients is not considered able to make a (valid) request. At the end of the eighties and further on in the nineties, this problem received broad attention. But not only was the issue of non-competent persons at stake. The concept of autonomy as the central focus of normative issues in general and the debate about euthanasia in particular, became the subject of a serious debate.

The ethicists Ten Have and Kimsma criticised the emphasis on autonomy as a central concept in health care ethics (Ten Have & Kimsma, 1987). They warned of the dangers of a reliance on autonomy as the guiding principle for medicine. Concerning euthanasia, they claimed an impression had been created that there was actually not a problem if someone voluntarily and deliberately made a request for euthanasia. They feared 'autonomy-dogmatism' would cut the moral debate short by an appeal to everyone's freedom of choice (Ten Have & Kimsma, 1987, p. 82). According to Ten Have and Kimsma, autonomy could not guarantee ethically accountable medical practice. They also feared that focussing on autonomy would imply a vocabulary of rights, allowing too much jurisdiction to the health law perspective concerning medical ethics.

The ethicist Beemer, a well-known opponent of the moral acceptance of euthanasia, was even more radical in his scepticism about autonomy. He argued that the definition of euthanasia as an explicit voluntary request mutilated the ethical debate (Beemer, 1986, p. 37). He claimed that the overwhelming attention for autonomy in the debate about euthanasia overpowered the second aspect, which was mercy killing. Furthermore he was certain that this 'repressed half' would get back into the debate, whether in medical practice or in philosophical magazines. In their criticism of the

concept of autonomy, both Beemer and Ten Have and Kimsma displayed a broader character of their discipline.

This kind of criticism was further developed into a fundamental critique of the practice of euthanasia by several ethicists in the nineties (Zwart, 1995). Their claim was that the principle of respect for autonomy functioned as an alibi for a practice of regulating death. This criticism, that existential aspects of death and dying were marginalised, was resonant with Sporken's earlier cultural criticism. These ethicists willingly took position outside the dominant debate about regulation, widening the discussion and making a claim for a shift away from the use of a concept—autonomy—that was part of the language of law and lawyers.

Ethicists who were engaged in the enterprise of regulating euthanasia picked up the message that health care ethics should display a broader character. For example, the ethicist Dupuis, editor of a handbook for health care ethics, proposed to take the view of 'the supposed will' or 'best interest' in the case of 'euthanasia' for incompetent patients. The ethicist Kuitert stated that the debate about euthanasia was isolated in the early nineties. He wanted to approach the problem from a broader perspective. Treating euthanasia as 'taking life on an explicit request' did have certain advantages, Kuitert emphasised. But it did not solve every problem. As causes for the narrowing of the debate, Kuitert mentioned both the definition of euthanasia and turning euthanasia into a matter of lawsuits (Kuitert, 1993, p. 14). Kuitert endorsed the pleas for a broader perspective of context for end-of-life decisions. In their handling of these decisions physicians should be guided by a morally acceptable professional standard rather than by the judge. Thus, Kuitert made an effort to lead the problem of euthanasia away from its juridical context. Concerning end-of-life decisions in the case of non-competent persons he proposed the argument of mercy, instead of formulating alternatives for the autonomy of the patient, such as the supposed will or advance directives.

The juridical context was also 'ignored' by the Royal Dutch Society of Physicians (KNMG) in its reports about end-of-life decisions *without explicit request*. Though political consensus about end-of-life decisions with explicit request (euthanasia) was difficult—several law proposals were still debated—the KNMG considered it necessary to explore end-of-life decisions without explicit request. It argued that problems in medical practice should not be ignored and installed a Committee to advise on these issues. To pay full attention to this problem, it was the Committee's preference to bypass current legal rules (KNMG, 1993, p. 2). The KNMG obviously did not want to wait for an opinion about this complicated subject. Physicians were faced with this problem in medical practice, so whether there was a juridical frame or not, it had to be taken into consideration.

The lawyer Leenen, the most influential single spokesman in the euthanasia debate, was very clear about end-of-life decisions without explicit request. According to him, there was an essential difference between life-ending on request and without request. In his view euthanasia should not be considered 'normal medical practice', so life-ending without request was beyond the bounds of legitimate medicine. Simply because of narrowing 'euthanasia' to 'acting on request', the debate about euthanasia had so far been known for its responsible character. Leenen was therefore strongly

opposed to the government's proposal for one procedure for these two different end-of-life decisions (Leenen, 1992). Nevertheless a joint-report procedure for euthanasia, physician assisted suicide and life-ending without request has been effected since June 1994. Apparently, the jurisdiction of lawyers on this particular aspect had diminished.

In short, the consequences of defining euthanasia as life-ending on explicit request were shown in the debate about end-of-life decisions without such an explicit request. It became clear that, although this definition of euthanasia was a solution for autonomous patients, in practice physicians also had to deal with non-competent patients. Ethicists emphasised the importance of this problem. Some of them criticised the dominant character of respect for autonomy in ethics in general and in the debate about euthanasia in particular. The juridical context was kept at a distance in the debate, not only by ethicists but also by physicians. Lawyers, on the other hand, had no space to discuss this problem as they held on to the principle of respect for autonomy as the hub in the debate about euthanasia. This implied that the topic of end-of-life decisions could simply not be discussed in the way euthanasia had been. As a consequence, it was ethicists and physicians who led the debate about end-of-life decisions and non-competent patients. They were willing to put the current frame of concepts up for discussion, whereas lawyers did not want to let go of the definition of euthanasia. Although ethicists regained some jurisdiction from lawyers, one cannot speak of a stable jurisdiction of this problem. This is shown by the fact that the problem of political responsibility is still unclear and unsolved.

7. Conclusion

Our case study of the role of health care ethics and health care law in the debate over euthanasia in the Netherlands gives insight into the development of these disciplines *and* into the rise of bioethics as a new profession. Our historical–sociological perspective allows us to see that new medical technologies (and interpretations of the consequences of these technologies) gave non-physicians the opportunity for jurisdiction over questions that once were the sole property of medicine. New professions worked hard—and continue to do so—in order to negotiate jurisdiction, asserting the relevance of their expertise to claims of ownership and the consequent assignment of responsibilities.

In the fifties and sixties the medical profession was confronted with new questions and uncertainties because of developments in medical technology. Resuscitation and transplantation techniques led to the question of whether a deliberate choice not to extend life was legitimate and whether such a choice was tantamount to a deliberate choice to shorten life. At first this was regarded as a problem for the medical profession to solve on its own. But, as a result of division with the medical profession and developments in society—e.g., less tolerance of paternalism—other professions were given the opportunity to claim jurisdiction over this problem. The introduction of new technology and the perception of the need for social control of the medical profession created a niche for other professionals.

Meanwhile there had been a tacit consensus amongst physicians, lawyers and ethicists about the cause and nature of end-of-life issues. It had been defined as a problem of increasing medical power. This shared perspective did not, however, entail a common proposal for the limitation of that power. Physicians and lawyers worked together to create a clear delineation of new responsibilities for physicians. Ethicists emphasised the social and cultural aspects of medicine and called for more attention on palliative care. And lawyers and ethicists brought the patient into the limelight as a discussion partner, believing that empowerment of the patient would act as a check on medical power.

Clearly, jurisdiction over end-of-life decisions was no longer a privilege of physicians, but who controlled this important aspect of medicine? Ethicists and jurists both claimed the problem as their own. In the eighties lawyers seemed to have gained the upper hand. Consensus about the definition of euthanasia as 'intentionally taking the life of another person upon his or her request by a physician', offered a solution for the problem of increasing medical power and—because it was based in the legal concept of autonomy—reflected the dominance of health care lawyers as definers of the problem. This 'solution' to the problem of end-of-life decisions represented a medical–juridical coalition.

This legal solution was challenged when it became clear that the autonomy (or will) of the patient was a problem in the case of non-competent patients. This gave rise to new problems and offered a second chance for health care ethics in the jurisdiction process. The debate about end-of-life decisions without explicit request gave a boost to ethicists who criticised the dominant role of the (legal) notion 'respect for autonomy' in current bioethics. Indeed, the criterion of autonomy was so decisive for lawyers that they were not able to join in this debate. As a consequence, ethicists got more room to introduce and emphasise the argument of mercy killing. Ethicists regained their position in the debate about end-of-life decisions.

Our work shows that jurisdiction over medical ethical issues is not a simple power struggle, nor a matter of cognitive development, nor a direct result of 'external' economic, cultural, or political changes in society. Time-ordering mechanisms, definitions, conceptual shifts and the proposition of solutions aid in creating subtle changes in jurisdiction. We have also shown that jurisdiction is not easily gained. It takes substantial work to prove and sustain a claim to professional competence. Our analysis of the development of, and relation between, health care ethics and health law shows the relationship of the two disciplines to be constantly shifting. Thus it is not possible to speak of ethics being quasi-legal or of law being moralised. Health care ethics and health law *change* as they pursue several projects.

A complete understanding of the expanding field of bioethics requires attention to external forces that are shaping this new profession and to the internal dynamics and jurisdictional disputes that shape both the profession and the medical and social problems it purports to solve.

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