# INTRODUCTION

In the mid-1990s I had just completed my medical training and was working as a physician in a geriatric ward of a Dutch hospital. One of my patients was a 78-year-old lady who suffered from various diseases and was admitted for an evaluation of her growing memory problems. In the course of the diagnostic process I found that she was slightly anaemic and I doubted whether I should request a coloscopy to rule out the presence of colorectal cancer. For various reasons, I estimated that the chance she actually had cancer was rather low, and I was not sure whether subjecting the patient to the burdens and inconveniences of a coloscopy was really justified. I discussed my dilemma with an older colleague, who asked what the patient herself thought about it. To my own surprise I realised that I had not discussed it with her, nor had the thought of discussing it with her crossed my mind. Despite the fact that I had completed various courses in medical ethics, in which the issue of patient autonomy was an important subject, I discovered that I had adopted the idea from my medical training that *I* was the one to decide what should be done. Although I was well aware of the importance of respect for patient autonomy in theory, applying this insight to practice proved to be quite a different matter.

In this study I will explore and elaborate medical ethical theory concerning respect for patient autonomy. I will do so not only from a theoretical perspective, studying and commenting on literature on the subject, but I will also take into account the actual medical practice in which respect for autonomy is to materialise. In this introduction, I will briefly discuss the background and starting points of this study, the goals and questions guiding it, the study design, and the structure of this book. I will start by introducing the main subject of the book: autonomy.

## 1. AUTONOMY

Over the last three decades, the principle of respect for autonomy has attracted a great deal of interest in health care and in medical ethics. It is generally considered

to be one of the three or four leading principles of medical ethics (next to beneficence, non-maleficence and justice), and there do not seem to be many ethical problems in which it does not play an important part. At the same time, however, many authors have underlined the conceptual confusion and uncertainty surrounding the actual concept of autonomy. It has frequently been observed, for instance, that autonomy is not a single unequivocal concept with a clearly defined meaning. Rather, it is a term that is loosely associated with several ideas such as freedom, privacy, voluntariness, the ability to choose for oneself, and so on. Beauchamp and Childress (1989) speak of "families of ideas", and Collopy (1988) has referred to it as a "notional field". In medical ethics autonomy is most commonly understood as the individual's right to decide for himself without interference by others, but some authors have questioned this conception of autonomy and proposed more substantial or more relational conceptions of autonomy (Agich 1993, Manschot & Verkerk 1994, Keller 1997, Widdershoven 2000, Verkerk 2001).

Moreover, it is not only the concept of autonomy, or the content of the principle of respect for autonomy that are subject to dispute, the significance and normative weight of (respect for) autonomy are also controversial (Callahan 1984, Childress 1990). While more liberal health care ethicists consider autonomy to be the basis of morality (Engelhardt 1986), others argue that it is over-valued and given far too much prominence in moral theory (Tronto 1993). While some consider respect for autonomy to be the central value in the physician-patient relationship, others have argued that the principle is being over-burdened and that the emphasis on autonomy has unfavourable consequences. In the first place, placing an emphasis on autonomy is said to obscure the importance of other principles and values such as those of beneficence, non-maleficence and care. In the second place, it is said to disregard the fact that many patients are actually not very autonomous, and that, consequently, a principle of respect for autonomy has little to offer for these patients or even produces negative effects. For example, in psychiatry the emphasis on patient autonomy seems to lead to neglect and abandonment if psychotic or depressed patients who refuse treatment are left to their own, limited, resources (Verkerk 1999, den Hartogh & Kortmann 2000). In the care for the elderly, one is confronted with demented patients who are unable to make choices for themselves, and with patients who, due to their fragility and dependence, can no longer live up to the image of the autonomous, self-sufficient and independent individual (Agich 1990, van Delden, Hertogh & Manschot 1999).

In summary, respect for the autonomy of patients is a very important ethical principle in medicine and health care. There is considerable unclarity, however, concerning the meaning of this principle, both in a conceptual and a normative sense. It is the main goal of this study to elucidate the concept of autonomy and the principle of respect for autonomy, and to further develop ethical theory on this subject.

## 2. THEORY AND PRACTICE.

The aim of this study is not only to further develop ethical theory concerning (patient) autonomy, but to do this in a way that is useful to medical practice. The goal is to achieve a better understanding of the concept and principle of autonomy in order to help elucidate and manage the moral problems that exist in practice. This aim was inspired by the 'Ethics and Policies' research programme initiated by the Netherlands Organisation for Scientific Research (NWO) in 1995, of which this study is part. This research programme was intended to connect general theoretical ethics research with more applied, policy-directed ethics research. One of the goals of the programme was to integrate empirical and theoretical research in order to obtain results with greater practical relevance, especially on the level of policy. With this emphasis on the combination of theoretical and empirical research, the programme linked up with (and stimulated) a trend in ethics to do more empirical research and to use more empirical data in ethical theorising, a trend that has already been identified as the 'empirical turn' in ethics (den Hartogh 1999).

It has often been asserted that there is a 'gap' between ethical theory and (medical) practice (Hoffmaster 1992, ten Have & Lelie 1998, Widdershoven 1999). Physicians sometimes complain that ethical requirements are other-worldly, that they are the result of armchair theorising, or that they are too general and abstract to be of much use in daily practice, while ethicists and jurists sometimes complain that physicians fail to act in accordance with important rules or principles. It is clear that in practice, physicians and other health care professionals do not always follow the guidelines or action directives designed by ethicists or codified by law (Lidz et al. 1982, van der Maas, van der Wal & Haverkate 1996). This may be due to ignorance, unwillingness or lack of time and skills on the part of the health care professionals, but it may also be due to a disparity between ethical guidelines and actual practice. Ethical rules or guidelines may be unworkable in practice and their requirements may be unrealistic. They may proceed from the wrong presuppositions (for instance that patients are autonomous while in fact they often are not), or they may fail to take account of important facts and considerations (for instance that patients have limited capacities for information processing, or that not all patients actually want to decide for themselves). In fact, physicians deviating from these rules or guidelines may do so for good reasons. Furthermore, the interpretation of ethical rules or guidelines may pose problems to those working in the field. It is not always self-evident whether a specific rule applies to the situation at hand, how various considerations or duties should be weighed, or what exactly the rule or principle in question requires one to do. Since the correct interpretation and application of general rules and principles is the subject of a great deal of discussion or dispute among ethicists, it is not surprising if physicians do not always know how to interpret and use them either.

In medical ethics there is a growing awareness that in order to be relevant and useful in practice, the results of theoretical ethical or philosophical research cannot simply be applied to everyday practice or used in policy-making without taking into account the specific features, problems and customs of the practice under

consideration. Doing applied ethics requires interpretation of general and abstract principles and norms within the context of a specific practice. Principles, norms and concepts need to be concretised and specified in order to be meaningful for practice. To achieve this requires intimate and detailed knowledge of the practice under consideration, and such knowledge can be obtained through empirical research. Doing applied ethics also requires knowledge of the factual accuracy of certain presuppositions, the consequences of certain actions, and/or the workability of certain action directives, and this may require empirical research as well. One reason for using empirical research in ethics, then, is to aid the translation of more general and abstract moral rules and principles into concrete and specific action directives and guidelines that are both morally justified and workable in practice (Brody 1990, Musschenga 1999, Hope 1999).

Another important reason to use empirical research is that empirical facts and findings can be helpful to develop and improve ethical theory itself. Ethical notions and dilemmas do not exist *in abstracto*, but only in concrete manifestations, and it is through these manifestations that we can understand and develop theory on a more abstract level. Concepts and distinctions used in ethical theories and guidelines should be 'wirklichkeitsnah' (Musschenga & van der Steen 1999), that is, they should be recognisable and meaningful in practice. This does not necessarily mean that theory should adopt the terminology used in practice, but it does mean that an ethical theory should be able to articulate moral considerations and intuitions that are actually present and considered to be important in practice. Moreover, ethical theory should be sensitive to the various facts and circumstances that can have moral relevance in concrete situations. This implies that theory should learn from moral opinions, judgements and practices of people involved in a certain field. Taking these seriously as sources of moral knowledge and as grounds for further critical reflection can enrich and enhance ethical theory.

In summary, it has gradually become clear over the past decade that medical ethics should pursue a more integrated approach of theoretical and practical questions and problems, with greater input of empirical facts and data, in order to improve ethical theory and increase its practical relevance for health care. It is not yet clear, however, how such an approach should work out in practical terms, what kind of empirical research should be performed, or how such research should be integrated into research of a more theoretical nature.

## 3. AIM AND SCOPE OF THIS STUDY

The main questions in the present study address the meaning and content of the concept of (patient) autonomy, both in a descriptive and a normative sense, and the meaning, content and scope of the principle of respect for autonomy. What is autonomy, why is it important, what does the principle of respect for autonomy entail and what does it require of us? In order to answer these questions I will use both ethical literature and theories on autonomy, and empirical research into the role and meaning of autonomy and the principle of respect for autonomy in medical practice. By this attempt to further develop and interpret the principle of respect for

autonomy on the basis of both ethical literature *and* a study of the actual practice in which that principle must function, I hope to improve theory and to give it greater relevance for medical practice.

The empirical part of this study consists of observational research into decision-making for elderly patients in a hospital, in the assumption that this is an area where (respect for) autonomy is often particularly problematic. However, the conclusions of this study do not apply exclusively to the group of elderly patients but have a broader relevance, since problems and dilemmas involving autonomy are encountered in other age-groups and settings as well. Although the empirical research is carried out in a Dutch hospital the findings and conclusions will have relevance for medical practice in other countries as well. Many of the problems and dilemmas concerning patient autonomy that are encountered in a Dutch hospital will also be recognized elsewhere. The empirical research will be explorative rather than descriptive in character. It does not aim at giving a detailed description of Dutch hospital practice, but it will have a primarily *heuristic* function for the subsequent conceptual and normative analyses. Phrased differently, the empirical findings and observations will function as the engine for further theoretical reflection and reasoning. These reflections and argumentations will bear on a broader range of situations than Dutch hospital care for the elderly.

Since the discussions on the meaning and content of and the possibilities for 'empirical ethics' were just getting underway at the time I started this study, and since generally accepted methods of empirical ethics research were not available, the development of a research method was itself a part of this study.

Although I want to answer the questions concerning autonomy and respect for autonomy in a way that is relevant to medical practice, I do not intend to provide a set of detailed rules or action directives telling individual practitioners what to do in certain morally problematic situations or how to solve certain moral dilemmas. Rather, by analysing and elucidating the principle of respect for autonomy and its related problems, I hope to provide some general guidelines for dealing with patient autonomy, as well as outline a conceptual and normative background against which more detailed rules and action directives can be developed. Consequently, the results of this study are not meant primarily for individual physicians or other health care practitioners but rather for medical ethicists and policy-makers dealing with ethical issues in health care on the level of institutions, professional organisations or government.

In summary, the goal of this study is to further develop and refine ethical theory concerning patient autonomy in a way that is relevant to medical and particularly hospital practice, by clarifying the concept of patient autonomy and by (re)interpreting the principle of respect for autonomy. The development of an 'empirical ethics' research method can be seen as an additional goal.

## 4. STRUCTURE OF THIS BOOK

This book can roughly be divided into two parts. In the first part, Chapters 1 to 4 will set out the theoretical background and the methodology of the study and present

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