The different faces of autonomy. A study on patient autonomy in ethical theory and hospital practice

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CHAPTER 4

Method

In this chapter, I will explain and justify the method I used in order to further develop ethical theory with the use of empirical data, as well as the actual way in which I have collected my empirical material. The first section will give a general impression of the way in which I intend to use empirical research. I have used a qualitative research method and collected empirical material in the form of cases. Section 2 will explain why I have chosen to do so, and discuss why and how real cases can offer a unique contribution to theory development. Section 3 will describe and justify the way in which I have collected my material and section 4 will further explain the way in which I have used the real cases I collected in the further development of ethical theory.

4.1 Moral theory and empirical research

The goal of this study was to further develop and refine ethical theory concerning patient autonomy in a way that is relevant to medical practice by clarifying the concept of patient autonomy and by reinterpreting the principle of respect for autonomy. As indicated in the Introduction (Chapter 1) I wanted to do this not only from a theoretical perspective, but also by taking into account, in some way, the judgements, considerations and views held in practice and the factual circumstances and routines guiding that practice. To do this, I would need to learn more about the practice under consideration: that of the hospital. I wanted to know more about the specific moral problems of hospital practice (especially those related to patient autonomy); about the kinds of situations in which these problems arise; about the ways in which they are dealt with; and about the moral experiences, judgements and attitudes of doctors, nurses and patients. I chose to collect empirical material in the form of extensive case histories describing the period of hospital admission for individual patients. The case histories include information about the problems that arose during admission; about the way in which these were handled; and about the opinions, views and judgements of the physicians, nurses and patients involved in the cases. For the collection of this empirical material, I have used a method developed in the social sciences known as participant observation. The approach to theory development, however, would differ somewhat from that used in the social sciences where theory development is usually directed towards descriptive or explanatory instead of normative theories.

There are several ways in which the results of empirical research can be used in moral reasoning and theory development (Pearlman, Miles & Arnold 1993, Brody 1993). First, empirical research can provide facts that are relevant for moral reasoning. In developing Do Not Resuscitate policies, for
example, it is relevant to know the success rate of resuscitation (van Delden 1993), in justifying the use of substituted judgement in decision-making for incompetent patients, it is relevant to know how well substitutes can predict the wishes of the patient (Pearlman, Miles & Arnold 1993), and in evaluating a triage policy for ICU beds, it is relevant to know the consequences in terms of patient well-being (Brody 1993). Empirical research can also be used to ‘test’ adherence to specific moral policies (Van der Maas et al. 1991, 1996) or to offer a better understanding of the implementation of moral policies (Pearlman, Miles & Arnold 1993). Sociological or ethnographic empirical research can describe the ‘internal morality’ of a practice and the moral experiences of moral actors and explain the way in which morality works (Hoffmaster 1992). In these examples, however, empirical research is not used to explain or interpret moral principles or to develop moral theory. In the literature, two ways are suggested in which empirical research could have a more substantive role in moral reasoning itself. First, it can identify moral issues that are important in practice but have received little attention in moral theory (Pearlman, Miles & Arnold 1993, Brody 1993). Such issues could be starting points for further theory development, and the ways in which these issues are understood and dealt with in practice can offer new insights and suggest new concepts or distinctions. Secondly, the moral judgments and attitudes held in practice can be brought into moral reasoning directly and play the part of ‘considered moral judgements’ or ‘morally relevant facts’ in a process of reflective equilibrium (Daniels 1979, Gillon 1996). In this process, considered moral judgements concerning specific problems or situations are confronted with more general rules or principles, and both can be adjusted or refined (taking into account the morally relevant facts) in order to reach a more coherent and consistent network of moral principles, rules and judgements (and more general background theories). In this study, I intended to link up with the first approach, and to make use of the heuristic potential of empirical research to direct attention to new or poorly articulated issues. Moreover, I wanted to make use of empirical research in order to confront theory with the concrete situations to which it is meant to apply.

In summary, the starting point for this study was that theoretical concepts and norms can be adjusted, refined or specified through a confrontation with practice. Moral rules and principles are understood as guides to our moral actions, but ones that need to be interpreted and to be made more concrete in order to be ‘applicable’ in actual situations. Rules or principles do not dictate their own use; both the rules and the situations to which they are applied need to be interpreted before any conclusions can be reached or judgements made. When one tries to interpret practice from a theoretical point of view or to ‘apply’ theoretical norms and concepts within a practical situation, these norms and concepts have to be specified and to be made more concrete. Actual situations can force one to reconsider the meaning or content of a concept, and moral intuitions or judgements about these situations can urge one to adjust rules and norms. Moreover, practice can resist certain theoretical interpretations and suggest new or different ones. At the same time, theoretical concepts and rules guide our interpretations of and judgements about actual situations. Moral theory can be
further developed by going back and forth between principles and practical judgements, by specifying and revising norms and concepts by confronting them with actual situations, and by proposing new interpretations or concepts [cf. DeGrazia 1992]. In this way, theory can be better equipped to help solve real-life moral problems.

4.2 The use of cases
The use of - sometimes hypothetical - cases in theory development is not uncommon in ethics, but I believe that there are some advantages in using ‘real’ [empirical] cases instead of hypothetical ones, some of these advantages being closely related to the reasons for using empirical research in the first place. There are also advantages in using complete comprehensive cases instead of more isolated empirical data such as opinions, facts or separate moments of decision-making. These advantages are discussed in the first part of this section. In the second part, I will explore a number of difficulties regarding the description of real - empirical- cases.

Advantages of real cases
The first advantage of real cases over imaginary ones is that they have a different impact on theory development. Imaginary cases are usually constructed in order to illustrate a specific theoretical point and have a specific theoretical point of view already written into them. They are, as Arras calls them, “theory-driven” (Arras 1991, p. 37). This can be seen, for example, in the fact that many imaginary cases (though not all of them) are described in such a way that the moral problem is clear. Such cases are discussed in order to analyse or solve that problem. But real life, according to Arras, “does not announce the nature of problems in advance. It requires interpretation, imagination and discernment to figure out what is going on” (Arras 1991, p. 37). Missing in many imaginary cases are the questions of how the moral problem is determined in the first place and who makes this determination [cf. O’Neill 1988]. These questions, however, can have an important impact on the way a situation is analysed and judged. Prejudices can be built into the definition of a problem, and presenting a situation as an example of a specific problem or conflict can blind one to other possible problem definitions. An advantage of real cases over most hypothetical cases is that the morally problematic aspects of the case, if they exist, are not immediately clear. Real cases are more open with respect to problem definition than many imaginary cases.

Imaginary or hypothetical cases are commonly used to determine the moral relevance and weight of specific features of a situation. By varying one aspect of a case, while keeping the others constant, one can learn about the importance of that one aspect. One can also proceed the other way around, keeping one factor constant and changing the rest of the case. Imaginary cases are well suited to these kinds of ‘moral thought experiments’. But since these cases are constructed precisely to investigate or illustrate the importance of a specific feature (or some specific features), they are not
likely to reveal new and unexpected features that might be important as well. Features or properties that are not built into the case cannot easily become objects of investigation. In real cases, one does not know in advance which features are important and which are not, nor does one know in what way these features are important. Real cases offer the opportunity to discover unexpected new features and properties of moral importance as well as new issues or problems. Due, therefore, to their greater openness with regard to possibly relevant properties and problem-definitions, real cases have greater heuristic power than imaginary ones.

Another reason why real cases have a different impact on theory development is that real cases are unique cases. They are not examples of specific problems or examples of the importance of specific features. Instead, they are situations in which a unique combination of features makes up an inseparable whole. Since, according to Dancy (1985), the moral relevance of properties is always affected by other properties, one cannot take one element from a case and vary it without changing the whole case. Nor can one abstract from many features of the case without losing the characteristics of that case and without losing some of its meaning. Real cases have a holistic character; they are unique entities. In this capacity, they resist generalisation and abstraction. This does not mean that one can never generalise or abstract from real cases (if this were so, they would probably be of little use in constructing theory), but it does mean that one should be cautious and careful in doing so. Real cases draw attention to the complexities of moral life and to the interconnectedness of its various aspects and for this reason prevent one from drawing conclusions too easily. This holistic character of real cases also constitutes a reason for looking at whole cases instead of more isolated empirical data. Many aspects and features of a case receive their meaning and relevance through their connections with other aspects, and these connections would get lost if one looked only at some aspects in isolation from the whole case.

Second, real cases include the moral attitudes and judgements of the actors involved in the case. In some imaginary cases, nothing whatsoever is said about the opinions of the people involved. Moral reasoning does not appear to take place within the case itself; instead, this is done only by the author of the case who invites his readers to follow his argumentation. In other imaginary cases, we are told something about the moral opinions of some of the people involved, but only briefly. Since these cases are constructed, all of the opinions voiced by the hypothetical participants in the case are ultimately devised by the author of the case himself. As with the morally salient features, it is the author, often implicitly voicing some prejudices in the process, who decides which arguments, considerations and points of view are introduced into the case. For example, the nurse can be made to utter concerns about the quality of life of the patient, while the doctor is made to speak only in terms of medical goals. Moreover, the actors voicing these opinions are imaginary, just as the cases themselves. They have no moral views beyond the ones they are made to represent, no role apart from the one designated to them, no personal histories, experiences or idiosyncrasies. They are in no way real moral actors but only the mouthpieces of
the author constructing the case. Imaginary cases, therefore, can include only the views, considerations or arguments already known to the author of the case; they cannot offer radically different or new perspectives. In real cases, however, real persons are involved - each with her own professional or layman's role, interests, background etc. - who see the case from their own perspectives. These persons might have different ideas on 'what the case is really about', may take different features of the case to be important, or might attach different weights to the same features. Moreover, they might prefer different courses of action in handling the case or to solve the perceived problems, and they will probably use various arguments to support their points of view. Real cases, therefore, offer the opportunity to discover arguments and considerations that one has not, and would not have, thought of oneself. Real moral actors can reveal points of view that have been underexposed or even unrecognised by existing moral theories. The moral judgements of these actors can be confronted with received principles or rules and in doing so, can suggest changes in these principles or rules. Furthermore, the different perspectives of these real moral actors can suggest different problem definitions and can point out different features of the case as being morally important. In more general terms, the views, arguments and considerations expressed by participants in a real case can have a critical and innovative impact on moral theory and thus magnify the heuristic value of real cases.

Finally, real cases give a better 'feel' for everyday practice because they represent the moral problems and questions arising in that practice. Real cases are realistic and recognisable and they provide a vivid picture of the practice moral theory is supposed to apply to. They force one to take into account all kinds of practical considerations; psychological, institutional, technical and other limitations; and competing moral claims. Again, this interconnectedness of the many considerations and facts may get lost if one looks only at isolated facts or features as being separate from the context and the case as a whole. Only by being confronted with real-life situations can one discover which theories, insights or concepts are actually helpful in real-life practice and which are problematic, impracticable, or not enlightening. In other words, this helps one discover which theories and concepts 'work' and which do not. This is important if one of the goals of the research is to provide assistance in dealing with real-life moral problems. It could also be argued that if an ethical theory corresponds better with the moral conceptions and experiences of people in practice, it will probably be more easily accepted by those people, who will be more inclined to follow the rules and guidelines set by such a theory. Although this can indeed be an additional advantage, I believe it should not lead to a less critical attitude of the researcher. Acceptance of moral guidelines or prescriptions by people working in a specific practice should not become the primary goal to which the critical potential of theory is sacrificed.
Thick description

Until now, I have referred to real cases as they happen and are experienced in real life. But to discuss real cases with people who have not been involved in them, or to use them in theory development in a transparent way, these cases have to be transformed from real-life events into reproducible, communicable scenarios. Real-life events must become narratives (descriptions, plays, books, films, stories) in order to be accessible for shared discussion and reflection. In ethics, the cases discussed are most commonly recorded in writing in the form of case descriptions.

An important distinction can be made here between the ‘thin’ and ‘thick’ description of cases. The term ‘thick description’ is derived from the work of anthropologist Clifford Geertz (1973). A thick case description elaborates on the context and is rich in detail. In principle, the matter of thick versus thin description can be considered separately from the issue of real versus hypothetical cases. Real cases are not necessarily described thickly, nor do imaginary cases have to be thin. However, since the reasons for preferring thick description over thin description show considerable overlap with the reasons for preferring real over imaginary cases, the issues are easily confused. To avoid such confusion, I will first discuss the advantages of thick description and then explore the relationship between real cases and thick descriptions.

Dena Davis, in one of the rare articles on the subject, mentions two advantages of thick description. First, she says that “the importance of thick description is that without it we can only get out of a case what we put into it” (Davis 1991, p. 14). Thin descriptions can be used to communicate a specific point or to illustrate competing theories, but only thick descriptions offer the possibility of gaining new insights and of seeing perspectives that have not been deliberately inserted. In my opinion, each of the two important characteristics of thick description mentioned above (context and richness in detail) contribute in their own way to the heuristic value of thickly described cases. Details about a case can prove to be morally relevant facts in their own right and can add to the considerations deemed important. The context of a case, which consists of all kinds of facts or details that may not be important in themselves, can change the meaning of other facts or put these in a different light. Thick descriptions thus show the interconnectedness of facts and the interdependence of their meanings.

It could be argued, of course, that even if we included more detail and context in a case description it would still be us who would have put them there, and for this reason we could only get out what we put in. However, it is precisely the interconnectedness and interdependence of facts and mean-

1 An example of a non-written case used in medical ethics is the videotape of Dax Coward, which has been viewed and discussed by some ethicists; however, in order to reach a wider audience, written reports of the case and the tape have been used as well. For an interesting analysis of the various ways in which this case has been described, see Chambers 1996b.

2 Literary works, however, are also referred to as a common source of case narratives.
ings that allows for insights and interpretations that were not intended by the author of the case. All the ways in which different features of a case bear on one another cannot be known in advance; the author of a case can add some details with the intention that they will support his reasoning, but the more details are added, the greater the probability that others will not agree with the proposed interpretations of the author and instead find their own. Moreover, details and context can be added to a case description without any previously set intention, i.e. not with the purpose of inserting a specific point that one wants to convey, but to allow the case to remain open to different interpretations. Davis illustrates this point by comparing thin cases with allegories and thick cases with myths; she cites Carol Lewis who says that “into an allegory a man can put only what he already knows; in a myth he puts what he does not yet know and could not come by in any other way” (Davis 1991, p.14).

A second advantage of thick description, according to Davis, is that it allows us to focus attention not only on universalisable principles but also on how individual stories are embedded within particular communities. Thickly described cases will elicit considerations of relationships that extend over time, as well as considerations of universal ethical norms. For this reason, thick cases direct our attention not only to the general and the universal, but also to the specific and the unique; they not only show what this case has in common with other cases but also offer the details and context that distinguish this case from all the rest.

As mentioned previously, real cases are not necessarily described thickly, but it is clear that the advantages of using real instead of hypothetical cases can only be preserved in the transformation from experienced real cases to case descriptions if they are described thickly. The openness and holistic character of real cases, the insights gained into the diversity of opinions held by the people involved in the case, and the ‘feel’ of practice are properly revealed only within a thick case description.

What I have stated here might be taken to suggest that what is relevant is not the difference between real and hypothetical cases but the difference between thick and thin descriptions. I do not believe this is the case, however. A thick description serves to preserve the advantages offered by a real case, but it does not create these advantages (or at least not all of them).

The diversity of the opinions of the people involved in a case, in particular, and the ‘feel’ of daily practice are not a product of thick description but of the experience with real cases. As with myth, one might be able to insert into a hypothetical case some things one does not know and create a certain openness by doing so, but one cannot insert opinions one does not know, nor can one create a ‘feel’ of a practice one does not know. In order to construct a hypothetical case that has all the advantages of a real case, one will always have to rely on experience with real people in a real practice.

I stated above that in order to discuss real cases with others and to use these cases in theory development in an understandable way, it is necessary to transform them from real life events into thick case descriptions. However carefully this is done, it seems inevitable that some things will be lost in the process. Experiencing a case is simply not the same as reading a
case description. There is always more in a case - more details; more events; more feelings, assumptions and opinions of people involved - than one could record in a description of any reasonable length. Actually, there is always more to a case than one could ever come to know, even when experiencing it. The way in which one experiences a case; the things one sees or hears; or the observations that strike one as important or remarkable are all influenced by one's aims, theoretical knowledge, opinions and previous experiences. One could even say that 'a case' does not really exist as a separate entity; what is called a case is always a construction: a sample from an endlessly expanding mass of facts, events, thought, feelings and so forth. How this sample is taken depends on the observer's goals and theoretical background. In fact, without such a prior orientation or framework one could not even 'see' anything, since one would be unable to make any distinction or selection. In the next section, I will explain how my theoretical background has influenced the collection of my empirical material and consequently the 'construction'of real cases, but I will also explain what I have done to keep the cases as open as possible and to avoid bias.

For this study, I will use the 'raw' empirical case material (my observation notes, the transcribed interviews and my observation experiences) as a heuristic instrument, from which I will derive themes, issues and insights that will then be worked out further. To enable readers to follow the research process, to understand the origins of the issues being discussed, to understand the place these issues have in medical practice, and to understand how the theories being discussed work in that practice, I will use descriptions of the cases I collected that will be as thickly described as possible, though not as extensively as in my original notes. Section 4 provides a further explanation of and justification for how I have used the cases in developing theory and how I have created case descriptions based on the observed cases. Section 3, however, begins by describing and justifying how the empirical research that provided the material for the cases was conducted.

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3 Someone who is thoroughly familiar with a specific practice and with the opinions and feelings of the people involved in that practice could perhaps construct and thickly describe a hypothetical case which would have the advantages of a real case by drawing upon his experience. The hypothetical character of such a case would then lie in the fact that he used his imagination to connect and supplement the parts taken from real cases, or to change certain aspects of a real case, and so created a new case that did not 'really happen'. This is actually done by some authors presenting cases in health care ethics. One reason to prefer such 'almost-real' cases over real ones lies in the protection of the privacy of the participants in real cases (cf. Davis 1991).

4 I have used the term 'construction' here to indicate that real cases are always to some degree constructions. There is an important difference, however, between this kind of construction and the deliberate and purposeful construction of hypothetical cases, since it can, if carefully and conscientiously performed, preserve a much greater heuristic potential and a better feel of practice.
4.3 The empirical research

The goal of the empirical research was to collect case histories that could help answer the question about the meaning of autonomy in hospital practice. The intention was not to provide a comprehensive and representative description of hospital practice, but rather to collect real cases with enough heuristic potential to aid the further development of ethical theory. One question guiding the empirical research was whether theoretical concepts and distinctions concerning autonomy could be recognized in hospital practice, and whether theoretical notions and rules concerning respect for autonomy were used and followed in practice. A second question was whether there were actions, attitudes, or other phenomena to be found in practice which were related to autonomy but not yet sufficiently articulated in theory.

Theoretical background

According to Miles and Huberman (1990), any qualitative research, no matter how unstructured and inductive, is based on certain ideas that provide it with a focus; prior to fieldwork, one usually has at least a rudimentary conceptual framework that one employs to give some direction to the data collection. What one must consider, then, is the degree to which a qualitative research design must be structured in advance. Miles and Huberman describe how designs for qualitative research can range from loose and emergent to tight and prestructured, depending on such factors as how much is already known about the phenomenon under study and the kind of analysis to be made. According to Strauss and Corbin (1990), if one is interested in extending an existing theory or in opening up theoretical formulations and finding new meaning in them, one might begin with this theory and then attempt to uncover how it applies to new and varied situations. Since the goal of this study was to further develop and refine existing theories and concepts, I started with an exploration of the philosophical and ethical literature on autonomy (Chapters 2 and 3). However, since there is no such thing as the ethical theory on autonomy, or the concept of autonomy, and one of the goals of this study was to investigate different possible theories and meanings, the initial framework I utilised to start data collection consisted of various theoretical perspectives on autonomy. This conceptual framework is explicated in the Chapters 2 and 3, which provide an overview of the ethical theories regarding autonomy and related subjects such as informed consent, competence and paternalism.

Sampling

The observations and interviews were conducted on two wards for internal medicine in an academic hospital in Amsterdam in the Netherlands. The choice for an academic hospital was mostly pragmatic in nature: gaining entrance was easier, and the medical staff was large so that various physicians with different attitudes could be observed and interviewed. Moreover, in a teaching hospital, the staff (and patients, to some degree) on a ward are
used to having a large and ever-changing population of physicians, medical students and nursing students around, so my presence would not be very disturbing. The choice for internal medicine was made on the grounds that in this field many decisions about diagnostics and treatment are made during hospitalisation, whereas in many other specialised fields decisions are made in an out-patient setting and hospitalisation is used only to implement these previously made decisions. Since in most of the medical ethics literature autonomy is closely connected to decision-making, I wanted to study situations in which decision-making was important.

The study focused on a group of elderly patients aged 65 and older. This group constitutes a major part of the hospital population and, due to demographic changes, will constitute an even larger part in the future. The medical problems exhibited among this group are often more complex than those of younger patients, and questions about weighing the quality of life against extending life appear more frequently. For this reason, the decisions that need to be made tend to be more complicated, numerous and far-reaching in this group and would thus yield more relevant data. Moreover, it could be expected that in a group of elderly patients, problems involving competence would occur more frequently than in other groups and could thus be more easily studied. The fact that elderly people are generally more docile and have less need for participation in decision-making than younger people (Breemhaar, Visser & Kleijnen 1990, Petrisek et al. 1997), could be a disadvantage, for it could provide too little opportunity to study situations in which the patient is actively involved in decision-making. Still, not all elderly people attach limited value to autonomy and participation in decision-making, and during data collection there proved to be sufficient variation in the attitudes held by elderly patients in regard to these issues.

At the outset of this research project, the idea was to select those cases for observation and interviews in which autonomy was especially important or problematic. Soon, however, this proved to be both theoretically and practically unfeasible. Formulating criteria for selecting cases would assume certain ideas about the importance of and possible problems with autonomy, while these were exactly the issues I wanted to investigate. Erecting selection criteria would diminish the chance of discovering new and unexpected aspects of autonomy. Moreover, it proved impossible to predict beforehand the cases in which autonomy would become an important issue.

I decided, therefore, to join one ward physician in his daily work for a few (4-6) weeks at a time in order to follow all the elderly patients for whom he or she was responsible during that period. Over the whole research period, I followed a total of 30 patients. When I shifted from one physician to another, or at the end of an observation period, I kept on following the patients with whom I had started until they were discharged, transferred or had died. In total, I joined 5 physicians; of these one was an AGNIO, three were

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5 In 1997, about 29.4% of hospitalisations in the Netherlands concerned people 65 years of age and older. Moreover, the duration of the hospitalisation is longer among older patients: 53.7% lasted longer than seven nights, against 18.7% - 36.4% in the younger age groups (CBS 1997).
AGIOs, and one was an internist. All of the ward physicians worked under the supervision of an internist and I thus had the opportunity to collect some data on the opinions and actions of these supervisors as well. The third important group of research subjects, aside from patients and physicians, were nurses. Nurses were involved in the research whenever they were responsible for or were otherwise involved in the care of one of the patients I was following. I spent one week participating with the nurses in order to get more insight into their daily work.

The data collection rendered 22 cases that were useful, although they varied in extensiveness and in the amount of interesting information or events they contained. Due to practical circumstances surrounding 8 of the cases, my observations rendered too little material to count them as a real ‘cases’. The choice of the situations I observed was guided by the theoretical framework. Because of the importance of decision-making in theories of autonomy, I observed situations in which decision-making took place: staff meetings, formal and informal consultations between physicians or between nurses and physicians, and contacts between patients and physicians. At the outset, the idea was to study those decisions in which autonomy played an important or problematic role. However, just as in the case selection, this proved unfeasible. Several individual decisions were often closely connected with one another, and decision-making proved to be a continuous process rather than a series of single events. Moreover, in order to distinguish between decisions in which autonomy was important or problematic and decisions in which it was not, I would have had to rely on criteria which in turn would have presupposed a specific theoretical perspective, and thus would have diminished the heuristic value of the data. Comparing different kinds of decisions without prior selection provided a better opportunity to study the role of autonomy in decision-making. For this reason, the decisions studied varied from small, insignificant and routine to major, far-reaching and more exceptional.

I was also interested in whether autonomy played a role in situations that did not involve decision-making and if so, what this role would be. This interest increased after the first observations and analyses, since it appeared that for many patients, autonomy and decision-making were not as closely connected as had been presupposed by much of the ethical theory. Therefore, I extended my observations to problems and interactions between staff and patients in situations that did not directly involve decision-making.

Gaining entrance

After the ethics committee had approved the research design, the head of the department of internal medicine was informed about the proposed study, and gave permission for data collection on some of the wards. Next, the

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6 An AGNIO is a physician not in training for purposes of specialisation (and is comparable to a house officer), and AGIO is a physician in training for specialisation (in this case, for internal medicine, and is comparable to a resident) and an internist is a physician specialised in internal medicine (and is comparable to a consultant).
medical and nursing heads of two of these wards were approached. The actual procedures for the observation were determined in consultation with them. The staff (physicians and nurses) on the ward were informed of the study by means of a letter that explained the background, purpose and methods of the study. The purpose of the study was formulated in rather general terms as being an investigation, from an ethical perspective, into the role of patients in medical decision-making. Though I never made a secret of my objectives, I believe my presence did not really disturb the normal course of events on the ward. Most physicians and nurses were simply too busy to pay much attention to me and were also used to constantly having students around them and observing them. My presence did not seem to affect the behaviour of the physicians I joined on their rounds. This could be observed, for example, by the fact that they often forgot to introduce me to patients even when I had explicitly asked them to do so. During my presence on the ward I usually wore a lab coat similar to those worn by the physicians, with a badge identifying me as a researcher.

I was either introduced to the patients I followed by the physician or I introduced myself. I always asked the physician for permission to approach a patient and only in one or two cases did they decide that this would be too burdensome for a patient. All elderly patients were informed about the study both in writing and by me speaking to them about it and were asked to give me permission to attend rounds when they were visited and to look into their medical records. Separate permission was asked for interviews and for attending conversations between physician and patient, and patients were asked if they had objections to using their case that would be made anonymous for use in publications. None of the patients I approached refused. In cases in which I doubted the patient’s competence, I tried to obtain consent from a relative as well, or if this was not possible (because there were no relatives or because they did not visit the hospital), I asked the attending nurse to act as the patient’s representative.

Data collection

Data were collected by way of observation and open interviews. As mentioned previously, the data collection centred on cases of individual patients. The data collection took place during a pilot study lasting five weeks, and three separate rounds of nine, four and four weeks spread over a two-year period (1996-1998).

During an observation period, I spent five days a week on the ward (on average, about five hours a day) joining one physician in his daily morning rounds, his weekly grand rounds, and as much as possible his consultation with his supervisor. I attended staff meetings in which the elderly patients of that physician were discussed and whenever possible sat in on conversations between the physician and his elderly patients or their family members. In addition to these more formal occasions, I also observed discussions in the lobby or during the coffee break and sat in with the nurses when they were writing their daily reports. I recorded what information was provided to the patient by physicians and nurses and how this was done; indications of the patient’s understanding and decision-making capacities; the patient’s
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attitude towards participation; his expressed wishes and preferences; his view on his situation; and the like, as well as conversations about these subjects. Furthermore, I recorded discussions about specific decisions among the staff or between the staff and the patient (or his family); the staff member's opinions about the patient and his situation; their implicit or expressed attitude towards patient participation; and the way in which they approached and treated the patient. I also recorded and kept track of the medical information and developments concerning the patient, and I collected information about the patient's background, his life and his personal history.

I took notes on all the occasions mentioned previously, either as I observed them or as soon as possible thereafter, depending on how disturbing note-taking would be in the specific situation. On the daily rounds, for example, I could sometimes take notes unobtrusively while patient and physician were talking, but most of the time it was more convenient and least disturbing when I took notes immediately after we had left the patient's room. Most of the time, the physician himself would be writing his findings in the medical record or would have to attend to other administrative tasks, so my taking of notes did not disturb the usual course of events. There was usually time during the day in which I could elaborate my notes and enter them into computer files.

Aside from observing, I also conducted interviews with physicians, nurses, most of the patients and some family members. These were sometimes short and informal, as when I asked a physician to explain a decision he had made, or when I asked a nurse for his opinion about the degree of understanding a patient had of his situation. Sometimes, the interviews were longer and more formal. I would ask the physician, nurse or patient in question for an appointment, indicating in advance the subject I wanted to discuss with them. For these more extensive interviews I used a checklist based on my theoretical framework. This checklist included items such as information, understanding, the importance attached by the subject of the interview to the patient deciding for himself, the relationship between patient and physician and/or nurses, and more general background information on the patient and the perspective on the decision or situation held by the subject of the interview. Before each interview, I would go through that list to see what subjects were especially relevant in the case at hand. Some questions were left out and others added, depending on the situation. In general, I tried to follow a natural line of conversation, inviting the informants to give their own views on a situation and to come forth with issues they felt were important, but if important issues did not come up spontaneously, I would ask for them. The interviews were mostly about actual cases and situations; whenever more general views were discussed, I asked the informant to illustrate these with a concrete example. These interviews lasted from 15 minutes to about 1 hour. They were audiotaped with permission of the informants, and the tapes were transcribed later.

A third source of data was composed of the medical and nursing records of the patient and occasionally other written materials such as protocols or information leaflets. I regularly looked into the records of the patients I followed in order to obtain more background information or to get information on situations I had not been able or allowed to attend myself.
Avoiding bias

First of all, it is important to stress that in collecting material to document cases, strict ‘objectivity’ is in a sense impossible. Every attempt to record a case, be it in observation notes and interview transcripts or in a case description, is also an act of constructing the case. There is no such thing as the objectively true story of a case (Chambers 1996a, 1996b). It is often stated that since some selection is unavoidable and even necessary, researchers should not only try to minimise unwanted selection (bias), but should also explain what selection actually did take place and why, so that others can make an adequate assessment of the value of the research results.7

I have tried to indicate the specific viewpoint I employed during observations and interviews by explicating my theoretical framework, and I have tried to avoid making that view too narrow by including different theoretical perspectives within this framework. Furthermore, by including the views of physicians, nurses and patients, I have tried to record the cases from different perspectives, thus avoiding a one-sided picture.

A possible source of bias relevant to the method of observation and interviews is that of socially desirable behaviour and answers. This is more problematic with interviews than with observation as it is difficult for people to act in a socially desirable manner for longer periods of time, especially when they are working in their familiar routines and surroundings and are very busy. Moreover, the setting of an academic hospital made the presence of an extra person (me) less disturbing than it might have been in other settings. Wearing a white coat and being a physician myself made it even easier to fit in, at least with the doctors. For the nurses, and especially for the patients, however, this might have been a factor that influenced their behaviour or answers. Though in interviews I stressed the fact that I was working as a researcher and not as a physician, and I tried to stimulate people to tell their story, this might have influenced some of the answers. On the other hand, I found that patients often did not hesitate to relate to me their criticisms of the physicians, nurses and the hospital system and appeared to see me more as an ally than as ‘one of them’8. In general, the opportunity to express their professional and/or personal views appeared to be welcomed by many nurses and patients. The fact that the research subjects saw my research subject as rather ‘vague’ (most of them knew little if anything about ethical theories) also made it difficult for them to determine what behaviour on their part would be considered socially desirable. Because of this, the observations and interviews also offered some insight into what the subjects believed to be socially desirable, and these beliefs proved to vary considerably among them. For instance, when I asked

7 Though this is often forgotten or denied, the problem of selection is equally present in quantitative research. Knowledge of the research methods and instruments employed and the choices made in the research process is just as vital for assessing the value of the results of quantitative research.

8 The fact that I am young and female might have added to this; some patients (even after explanation) appeared to believe that I was a nurse and this apparently made it easier for them to talk to me.
whether she would want to make a decision for herself, one patient said, "No, I am not such a bothersome patient. I do as the doctor tells me." Another patient, on the other hand, said, "No, I am afraid I am not so good at that. But maybe I should, shouldn’t I?"

One physician told me that my presence had made him think more about ‘ethical issues’ and in that sense had influenced his behaviour. He once came to me and proudly announced that he had asked a recently admitted patient whether she wanted to have CPR in case of a cardiac arrest, thereby indicating to me that though this was not actually a routine thing for him to do, he believed it was morally indicated. In a meeting with his supervisor, he brought the subject up again. This resulted in a discussion about when and how patients in general should be involved in decisions concerning resuscitation policy. Though this physician was more aware of ethical issues and paid more attention to them because of my presence, the way in which he did so, the questions and problems he encountered, and the discussions this elicited provided me with some useful information.

Some physicians reacted differently, however, and explicitly placed themselves in an opposing position to what they believed to be socially correct behaviour, thereby expressing their own thoughts more forcefully. One physician, for example, remarked, "I suppose you ethicists find this [a certain action of his] paternalistic, but I don’t care. I believe that as a doctor, I should do it like this." He then started to explain his point of view.

These examples show that in research concerned with normative questions, the tension between what is perceived as socially desirable behaviour and what is actually done or believed by research subjects can itself be a useful source of information. Data triangulation - the use of different methods [observations and interviews] and different sources [physicians, nurses, patients and written material] for data collection - helped me to explore this tension between social desirability and actual practice. Data triangulation also made it possible to check factual information and to see it from different perspectives, thereby improving the reliability of the research [Mays & Pope 1995].

Another possible source of bias is the researcher’s overly close identification with the practice or subjects he or she is investigating. According to Strauss and Corbin (1990), professional experience in the field under study can block one from seeing things that have become ‘obvious’. In other words, the risk of ‘going native’ may be greater when the researcher is familiar with the field under study. On the other hand, Strauss and Corbin also note that professional experience can be a source of theoretical sensitivity. I found my experience in the medical profession useful for the data collection since it quickly enabled me to understand the organisation-

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9 Theoretical sensitivity is described by Strauss and Crobin as a personal quality of the researcher that indicates "an awareness of the subtleties of meaning of data" and that refers to "the attribute of having insight, the ability to give meaning to data, the capacity to understand, and the capability to separate the pertinent from that which isn’t" (1990, pp. 41-42).

10 During my training as a physician I have worked for more than two years on many different wards in different hospitals. After my training, I worked as a house officer for four months.
al structure and the routines of a ward; moreover, I knew where to find specific information and I could more easily understand medical information and discussions. This also made it easier to be accepted by the staff. A disadvantage was that it was sometimes difficult for me not to focus too much on medical information and follow the physician's line of thought. However, I found that alternating periods of observation with periods of theoretical elaboration and discussing the material with non-clinicians helped me to avoid over-identification and thus to reduce the problem of 'going native'.

4.4 Theory development

Initial analysis of the empirical material

Sections 1 and 2 indicated what role the empirical material was intended to have in moral reasoning. Here, I will try to describe the resulting process of data analysis and theory development in more detail.

The collected data were entered into computer files that were classified in two ways. First, there were files for each day, in which all observation notes (including brief interviews) of that day were collected and files for each informant in which all interview data from that informant were collected. Second, there was a file for each case in which all data pertaining to a specific patient (both observations and interviews) were recorded in chronological order. In this way, it was possible to read the material case by case, but also to check what a specific informant had said about other cases, to check what happened on a specific day, or to look into the ways different physicians behaved on their rounds.

The analysis of the data started as soon as the first data were collected. Between the episodes of data collection, the analytic process continued by means of rereading my notes and transcripts, thinking about them, and discussing them with my supervisors. The development of ideas went hand in hand with data collection. The data collection was guided by theoretical concepts and issues taken from the literature or derived from the analysis, while the data in turn guided the analysis and the further use of literature. This resulted in a research process with a cyclic structure in which data collection, data analysis and the use of literature were tightly interwoven processes (cf. Strauss & Corbin 1990). The important role of ethical literature and theory did not mean that the data collection was exclusively directed towards finding a confirmation of theoretical points or that the literature was used only to explain or justify the things I saw in practice. On the contrary, it was especially the situations in which there was a lack of correspondence between the theoretical framework and the data (or between 'theory' and 'practice') that yielded new insights.

In the initial analysis of the empirical material, I compared the cases I had collected with different concepts and theories taken from the literature to see which theoretical formulation(s) could adequately describe the situation at hand, provide useful insights, and do justice to the morally important aspects of the case. Whenever I found that the available theories and concepts were inadequate, I asked why this was so. What aspects of the
situation were underexposed or even left out by the theoretical formulations? What other formulations could be used to described these aspects of the situation? How could the theory be adapted to incorporate or at least do justice to these new issues? I also investigated how rules or directives for action derived from various theoretical perspectives could have been applied to the specific situations I had observed, and how they would have worked out, as compared with each other and with the ways people actually proceeded in practice. Again, wherever there were discrepancies, I would ask why this was so and, especially, whether these discrepancies revealed new interpretations or pointed to as yet unnoticed morally relevant factors. The initial analysis of the empirical material resulted in a global description of hospital practice with regard to patient autonomy and in the formulation of ideas and issues that seemed relevant to further analysis and theory development.

**Theoretical elaboration**

The final step in the research process was the elaboration of the major issues and ideas in order to further develop the theory of autonomy. This was done in much the same way as the initial analysis, although the role of theory and theorising became a more important factor. As a starting point for the further elaboration of an issue or problem, I read through my notes and transcripts again and marked all references relevant to that issue. I also made a separate file for each issue; in this file were the reflections and questions elicited by the material as well as my preliminary conclusions and analyses. I investigated what could be said as based on various theoretical perspectives about the problems and issues elicited by the analysis of the empirical material, and I investigated whether existing theories could be adapted to include these problems and issues, and I investigated how this could be done. Often, it proved necessary to find and read some more literature on the subject. Because the theory I was trying to develop and refine was normative as opposed to descriptive or explanatory in nature, I not only tried to adapt the concepts and theories to fit the empirical material but I also critically reviewed the way in which cases were interpreted and dealt with in practice. If there was a discrepancy between the theory (how people should act) and practice (how people actually acted), it was not automatically the theory that had to be changed. Such situations could also lead me to reconsider the arguments and justifications provided by both the ethical theory and the people working in practice. This could lead to the conclusion that the theory provided good reasons and arguments and needed no correction. Abstract concepts and principles were therefore tested for their explanatory potential and their practical effects, while actual situations and actions were screened against theoretical norms and arguments. This might suggest that theory development was a matter of either adapting theory to practice, or criticising practice on the basis of theoretical norms. However, while this was sometimes the case, I also tried to find new interpretations and new perspectives that would put the 'same' things in a different light, thus suggesting changes in the approaches of both theory and practice. In the
confrontation of theory and practice I looked for new distinctions; for new subjects or considerations that were suggested by practice; and for concepts that proved to be underdeveloped or issues that were poorly articulated in theory.

Presentation

The results of the initial analysis of the empirical material, including the selection of issues for further analysis, will be presented in Chapter 5, while the Chapters 6 to 10 contain the further elaboration of the selected issues and the further development of ethical theory. These chapters actually constitute the sediment of the analytical process I went through during the entire research period. The reasoning presented is more structured and polished than it was during the research process (in my own thinking, in discussions with others, in memos and first drafts), but I believe that it is not essentially different. In order to make the research process more transparent and verifiable for the reader and in order to illustrate the function of the empirical material, I have used descriptions of some of the cases I collected. I have tried to leave these case descriptions as 'open' as possible, meaning that I have tried not to write my own interpretation into them in a way that excludes other interpretations. I did this by exhibiting as much as I could of the different points of view held by the people involved in the case, and I wrote the case descriptions before having a clear picture of the issue(s) they could represent or how I would want to elaborate on that issue. Moreover, I have tried to make the case descriptions as 'thick' as possible by describing the context of the cases and by including as many details as possible, including details that may seem to be irrelevant at first sight (and maybe later as well). Finally, the case descriptions were evaluated by at least one other person to see if the data were not being used too selectively.

This method of presentation will enable readers to think about the cases, to critically consider my interpretations of them, and perhaps to come to different interpretations themselves. Furthermore, I hope that showing how I have proceeded will elucidate and explain those aspects that may have been left unclear in this discussion of the research method.