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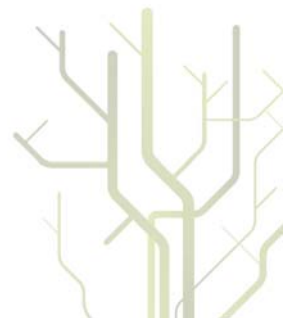
FACULTY OF HEALTH SCIENCES

Morally bound medical work

**An empirical study exploring moral conditions
of doctors' everyday practice**

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A *picture* held us captive. And we couldn't get outside it, for it lay in our language, and language seemed only to repeat it to us inexorably.

Ludwig Wittgenstein, Philosophical Investigations, § 115

Opening case

A Wednesday morning in a local hospital in Norway, and I was eagerly awaiting the weekly teaching session. Being a medical student, these sessions were always welcomed, but I was especially eager on this particular occasion because the theme was to be "Do-Not-Resuscitate orders". Since I had studied philosophical bioethics at university, I had a special interest in the topic and was looking forward to listening to the experienced doctors' moral deliberations. What is more, this might even be a time to make a thoughtful contribution myself, since I was familiar with the philosophical debate on this issue. The senior consultant explained at length what a "DNR-order" was and the kind of medical interventions it normally covered, stressing the need to assess the patient's prognosis, likelihood of successful treatment and risk of complications. He further described how to record a "DNR-order" and set out the details of the health care personnel who were authorised to do so. In fact, for a full hour, the consultant and the other doctors from this medical department talked about the "DNR-order" – a procedure describing when to not give patients life-sustaining treatment – without ever mentioning a moral issue. I was extremely perplexed by this experience, and what was even worse was that during this hour I could not think of a single moral question to pose that seemed relevant. In the time that passed after that teaching session, I could not seem to get a puzzling question out of my head: where did the ethics go?

Acknowledgements

My supervisor, Åge Wifstad, has been a vital contributor to this work. His analytical gift of grasping the two interesting statements in a page of nonsense, along with his philosophical capacity and patient support, has been invaluable. I am also grateful to Reidun Førde, who has made an effort to keep me on the practical and nuanced level needed for such an empirical project, which has profited from her enthusiasm and extensive experience in clinical ethics. Philosophically and medically, this has been a most fortunate combination. Pål Gulbrandsen renewed my appreciation of the field of clinical communication, and I have had the advantage of his competence, his curiosity and his generous housing.

The Northern Norway Regional Health Authority trustingly financed what must have seemed like an odd project, and the General Practice Research Fund supported the development of the initial idea. Finnmark Hospital Trust has provided me with financial support, goodwill and a room with a magnificent view. I would further like to thank the research group at Hammerfest Hospital, and especially Torben Wisborg for his supportive objections. Thanks to the society of Grounded Theory for their inspiration and trust, to Ingvild Agledahl for setting examples to be followed, to the Clinical Ethics Committee for allowing me to feel useful, and to the many people from the Centre of Medical Ethics in Oslo and the "Trønder group" who invited me into their fellowship when I was far away from home.

Through the ups and downs of research life, the continuous backing of my family has been important. I am indebted to Uwe; whose contributions are tacitly embedded in this work and whose presence is a *sine qua non*. I am also grateful to Sondre for asking existential questions at unexpected moments, to Emma for supporting her mum in everything she does and to Edvard for making me take a year's break in the middle of my research; forcing me to a distant reflection that probably benefited the project. Moreover, the unique combination of personal encouragement, practical relief and technical discussions offered by my parents has been indispensable.

Last, but not least, I would like to thank all of the doctors and patients who generously made this research possible.

English summary

All of clinical work also has a moral dimension since the purpose of clinical medicine is to help patients. The aim of this project is to understand how doctors deal with these moral dimensions of clinical work. The field of bioethics has largely emerged as a philosophically founded discipline, without taking into account how doctors already handle moral values as a tacit or implicit part of their clinical work. This has caused a gap between medical ethics and medical practice.

This research contains data from two qualitative studies: observations and interviews with 17 general practitioners and hospital doctors, and observations of 101 video recorded patient consultations in hospital. The doctors focused exclusively on medical issues in the encounters, even if their patient's worries could be related to more personal parts of the patient's life, such as fear of loosing one's job. Patients' personal worries were systematically ignored by the doctors. In order to help their patients by the use of their biomedical knowledge of anatomy and bodily processes, the doctors often handled their patients as objects. However, for patients it is morally offensive to be rejected and treated as medical objects, and it might feel very unpleasant. The doctors, who often kept a good tone in the consultations, did not appear to recognise their concurrent moral offence. Our research suggests that these moral infringements might be unavoidable in medical work, but that doctors, nonetheless, ought to be aware of the distress they cause and how they can reduce it.

Norsk sammendrag

Ettersom målet med klinisk medisin er å hjelpe pasientene, har alt medisinsk arbeid også en moralsk side, og hensikten med prosjektet er å synliggjøre legers håndtering av de moralske sidene av klinisk arbeid. Faget medisinsk etikk har i stor grad vokst fram som en filosofisk fundert disiplin uten å ta høyde for hvordan legene allerede håndterer moralske verdier, nettopp fordi det er en underforstått og usynlig del av klinisk arbeid. Dette har skapt et gap mellom medisinsk etikk og medisin i praksis.

Datamaterialet er hentet fra to kvalitative studier; en med observasjoner og intervju med 17 leger fra allmennpraksis og sykehus og en med observasjon av 101 videoopptak av lege-pasient konsultasjoner på sykehus. I møtet med pasientene fokuserte legene utelukkende på medisinske forhold selv om pasientens bekymring kunne være knyttet til mer personlige deler av pasientens liv, som frykt for å miste jobben. Pasientenes personlige bekymringer ble systematisk oversett av legene. For å bruke sin biomedisinske kunnskap om anatomi og organfunksjoner til å hjelpe pasientene, forholdt legene seg ofte til pasientene som objekter. For pasienter innebærer det imidlertid et moralsk overtramp å bli avvist og behandlet som objekt, og kan oppleves ubehagelig. Det virket som om legene, fordi de samtidig ofte var vennlige, ikke oppfattet overtrampet. Studien antyder at slike moralske krenkelser er uunngåelig i medisinsk arbeid, men at legene bør være klar over ubehaget det kan medføre og hvordan de kan minske det.

List of papers

The thesis is based on the following papers:

I   Agledahl KM, Førde R and Wifstad Å. Clinical essentialising: a qualitative study of doctors' medical and moral practice. *Med Health Care Philos* 2010;13(2):107-13.

II   Agledahl KM, Førde R and Wifstad Å. Choice is not the issue. The misrepresentation of healthcare in bioethical discourse. *J Med Ethics.* 2011; 37(4):212-5.

III   Agledahl KM, Gulbrandsen P, Førde R, and Wifstad Å. Courteous but not curious: how doctors' politeness masks their existential neglect. A qualitative study of video-recorded patient consultations. *J Med Ethics* [in press].

1. Preliminaries

1.1. Introduction

1.1.1. Outline of the thesis

The composition of this thesis is kept within the logic of the research project in such a way that the presentation follows the structure of the research process. This means that any significant, theoretical introduction or definitions of relevant concepts has been omitted on purpose. When conducting research based on Grounded Theory methodology, it is important to not define the theories or concepts that are central to your field of study in advance. The reason for this is that you cannot know what theories or concepts will be significant to your findings until you have actually carried out your research. In writing this thesis, there was of course a possibility to anticipate the course of events and consequently add the relevant theoretical concepts to the introduction, even though we did not investigate these until completion of the studies contained herein. However, to make the research process as transparent as possible, the work is presented in approximately the order in which it occurred. I have tried to emphasise this transparency throughout the dissertation so that readers can assess the results and conclusions on the basis of the reflections and choices made during the research process. This opportunity to scrutinise the research is an important source of this work's internal validity, and this is discussed further in the "study limitations" section.

First, I will explain the background for this project, that is, my thoughts and reflections on the field before initiating the studies and, consequently, the aim of the research. I will provide a brief introduction to the history of medical ethics and the philosophical diversity of the field, as well as give some illustrations of empirical studies conducted in the field. Next, I move on to the methodological considerations. In this latter section, my aim is to present the Grounded Theory method, our reasons for choosing it and the consequences that this decision has had on how the research was conducted. I will only cover the methodological considerations in principle in this part of the dissertation, while the more practical implementation issues are presented along with the individual studies. This seems to be the most appropriate approach, since the actual prosecution of each of the studies varied considerably. These studies are then presented in the order in which they were conducted, and some

of the theoretical reflections we undertook during the process are also dealt with. This mode of presentation has been chosen to reflect how the research developed, with all of its different steps and various considerations. According to the methodology, the researcher must be open to the results that emerge from the study and let the research be guided by what is found. Consequently, the progress of the research is an important part of the method, and it is only by revealing this progress that our research can be presented in a truthful manner.

Following the presentation of the three studies, I describe the main findings in relation to our research aim. Subsequently, in the discussion, I will try to contextualise our findings in light of our results and the related theoretical considerations. In other words, I will attempt to place the research in its proper context, which was not really known beforehand. In Grounded Theory research, the relevant context is not defined by the research field, but instead by the theoretical concepts that we explore in our findings. This is the reason why the theoretical position is not established until the final section of the thesis. In this case, I will build upon the theories of ethics, as well as using ongoing discussions in philosophy and sociology and other related empirical research to both demonstrate the contribution made by our work and also demarcate its scope. Next, I attempt to critically evaluate our findings, both according to Grounded Theory standards and more general criteria for qualitative research. In particular, I review the validity of the studies and the limitations of our work, as well as the consequences thereof. Finally, in the conclusion, I will underline some of the consequences identified from the results and discuss how they point to possible new areas of research.

1.1.2. Background

If you follow a doctor around a hospital on a working day, it is very rare to ever hear him or her mentioning an ethical dilemma or a moral value. Instead, cases are understood, analysed and discussed in medical terms, such as a patient's prognosis, the probability of a favourable outcome and possible complications. Some researchers have suggested that doctors cover their reasoning in medical terms to avoid ethical justifications (Sayers & Perera, 2002); others have proposed that doctors have poor moral perception (Casarett, 1999). In his doctoral thesis, Terje Mesel found a discrepancy between the normative ground of the medical profession

and the moral reflections of the interviewed doctors (2009). He suggests that professional codes of ethics are often considered alien to daily practical work. While the field of medical ethics is growing, it is more grounded in the tradition of moral philosophy than that of medicine. Most of the scientific articles on the topic are confined to specialist journals dedicated to issues of ethics and philosophy, and do not, therefore, come to the attention of the majority of clinical doctors. The introduction of medical school courses devoted to medical ethics may be taken as a sign of progress when it comes to appreciating ethics in medicine, but these classes are sometimes characterised as poorly integrated in the rest of the curriculum (Coulehan & Williams, 2003; Loewy, 2003).

Nevertheless, doctors are not insensitive to moral issues. On the contrary, they often set high moral standards for their work, and being "a good doctor" is a powerful ideal for most of those engaged in clinical practice (see for instance BMJ's special issue "What's a good doctor and how do you make one?", 2002). Indeed, the medical profession has long-standing moral traditions, some of which stem from the Hippocratic Oath from 500 BC. The traditional aphorism "To cure sometimes, to relieve often, to comfort always – this is our work" is also the symbol of good clinical practice today (Strauss, 1968), and is incorporated in the first article of the Norwegian Medical Association's Code of Ethics (Legeforeningen, 2011). Moreover, the aims of a good clinician are normally perceived to include practical human knowledge and empathy, while relieving suffering and helping patients is seen as central to the role of the medical profession.

This leads us, however, to a paradox which reflects my puzzling experience referred to in the opening case: the field of medicine has evident moral dimensions, and yet they are barely visible in practice. It is difficult to see the relevance of the principle of justice or the value of autonomous choice when you are examining a middle-aged woman for sub-acute abdominal pain. Somehow then, it seems as if the norms and values of medical ethics do not fit properly with medical reality. One reason for this might be that the field of medical ethics has, above all, concentrated more on the big and controversial issues in medicine, like abortion, euthanasia and genetic technology, and less on the field of everyday medical practice, which occupies most doctors' working life. As a result, the focus of medical ethics may well not be

relevant for most doctors. This lacuna could also be interpreted as a universal gap between theory and practical work, which exists in many different fields. There is a divergence between theoretical knowledge of how to do the work and a practical understanding of how to *actually* perform it, referring to an age-old distinction made by Aristotle (1980). Abstract ideas can be difficult to transfer to the nitty-gritty of everyday practice, and this could be the reason why practicing medics find ethical theory so difficult to apply. Yet doctors are certainly used to relating their practical work on individuals to theoretical models and abstract concepts, since medical practice is firmly built on scientific medical theory. While it is often difficult when dealing with a patient to determine how one's general knowledge of medical theory applies to this particular case, problems with medical ethics seem to be of a different nature altogether.

Some empirical studies have indicated that the principles of medical ethics are not wholly internalised in the medical profession, and that doctors instead feel alienated by the language of bioethics (Davies & Hudson, 1999; Karnieli-Miller & Eisikovits, 2009). Doctors rarely articulate moral judgements in their daily practice. Yet, rather than interpreting this as a lack of moral understanding, it could be that medical language and clinical practice are "morally loaded"; in other words, the moral dimension is always implicit in the medical judgements that doctors make in a way that means that it is superfluous to refer to a moral principle. Some studies have mentioned the concept of <u>responsibility</u> as being an important notion with which to understand doctors' perceptions of morality in medical practice, yet this is not a concept that is much used in the medical ethics' literature. Søren Holm, a medical doctor and philosopher, and Reet Arnman, an experienced doctor, have both interviewed health care personnel, and describe the discrepancy between bioethical concepts and the practical reasoning of doctors (Holm, 1997; Arnman, 2004). Holm came up with the notion of "protective responsibility", which he argues is a better description of what health care personnel perceive to be morally significant. Arnman also emphasises how doctors' moral experiences deviate from medical ethics discourse. "The doctors did not talk like moral agents with dilemmas (…) they spoke like moral persons with bad consciousnesses" (Arnman, 2004, p. 85). This leads Arnman to conclude that doctors' perceptions of ethics are closely related to their experiences of professional responsibility.

The discourse of medical ethics does not seem to reflect doctors' own moral experiences, making it difficult for them to relate to its moral demands. Moreover, the ethical dimensions of doctors' current medical practices remain tacit and, as such, hidden from moral enquiry.

1.1.3. Research aim

What initially led me to this project was the persistent and perplexing impression that medical ethics did not "fit" into clinical practice. My theoretical knowledge of the topic and my incipient practical knowledge of health care somehow seemed to take place in two parallel dimensions, with neither of these being concerned with the other or even compatible. Discussions in medical ethics often focus on principles and ideals that do not seem to be relevant in daily clinical work. Yet, at the same time, the field of medical ethics does not appear to address the most pressing concerns of practicing doctors, like how to decide if this patient is too old and fragile for an important surgical operation or how to cope with angry relatives who distrust any of your medical interventions. In other words, the ideals of medical ethics seem to fall short of the real challenges of clinical practice.

Certainly, this is one way of defining the problem. You could, however, begin with the same premises and conclude that doctors fall short when it comes to exercising medical ethics. Indeed, there might be nothing wrong with the concepts of medical ethics if only intractable doctors could comply with their demands. Variations of this conception of medical practice seem to flourish in the medical ethics' literature. All too often, when discussing why doctors do not seem to respect patient autonomy or provide paternalistic support, the proposed solution is to change doctors' attitudes and behaviour (Corke et al., 2005; Braddock et al., 1999). However, this sounds like an easy way out, because it does not examine <u>why</u> doctors appear to act contrary to stated ethical obligations. For this reason we have chosen to adopt another approach to the problem, instead asking why the expanding field of medical ethics does not seem to concern doctors in any significant way.

From this angle, the problem seems to be related to the premises of medical practice, which, being understood as helping patients and relieving their suffering, must be abundant with moral actions. Even if doctors do not talk of their actions and decisions

in terms of values, these values must nonetheless be present in medical practice. Doctors seem to deal with these values in quite an implicit manner, relating to them through their practical work rather than expressing them as moral acts or decisions. Indeed, doctors' approaches to moral values seem largely to be imbedded in their clinical work. If this is in fact the case, the challenge would be to gain an understanding of doctors' implicit handling of moral values, since this knowledge may throw light on practitioners' moral inducements and, perhaps, even identify the missing link to medical ethics.

We did not know in advance what these values would be or how the doctors dealt with them, and so we could not formulate the research questions in any detailed manner. Moreover, an open approach is essential when using the Grounded Theory method that we chose to employ herein, and this approach will be explained in detail later. Nonetheless, we had a clear interest in conducting the present studies: Our fundamental aim was to explore the unspoken dimension of medical practice that involves moral values. Accordingly, for each study, we have addressed different aspects of this dimension.

1.1.4. Tacit knowledge

The concept of tacit knowledge has taken root in everyday speech, yet it has a whole spectre of meanings. Since the aim of this project is to expose the values in clinical practice that are implicit or tacit, it is important to clarify what the concept means. The term "tacit knowledge" is commonly thought to originate from Polanyi, but its use has also been heavily influenced by Wittgenstein. Strictly speaking, Polanyi mainly speaks of "tacit knowing", which refers to the function or use of tacit knowledge. However, for our purposes this distinction is not central, and I will therefore stick to the term tacit knowledge, which is the concept that is most commonly used today.

A central premise of tacit knowledge is that "we know more than we can express" (Polanyi, 1967). Human language does not exhaust our experiences. The image of an iceberg is an often-used metaphor, where our explicit knowledge forms the top of the iceberg that is floating above surface, while the part that remains under water represents our tacit knowledge. Polanyi provides several arguments in favour of the

existence of tacit knowledge (Rolf, 1991): First of all, human language is not refined enough to cover all of the complexities of reality, and so it cannot capture all of our knowledge; we are often able to grasp more nuances of a particular situation than we are able to articulate. Moreover, the system of language is a common tool that each of us masters to a varying degree, meaning that it contains both more and less explicit knowledge than each individual possesses. Furthermore, he argues that the vocabulary is constantly changing, especially when it comes to the progress of new sciences, technologies and professions, which seem to develop faster than the language in each field. Finally, learning how to speak a language means that you are dependent upon knowledge that is not in itself in a linguistic form. In other words, our understanding of how vocal sounds (or written symbols) relate to the world around us cannot rely on a form of knowledge that is contained within the language.

Even though the existence of tacit knowledge seems plausible, what is not apparent is the kind of knowledge that this is. A central issue is whether tacit knowledge can ever be explicit. Wittgenstein speaks of the parts of knowledge that are inexpressible; that is, they cannot be expressed in language (Wittgenstein, 1967). He also claims that many of the existential aspects of human life cannot be made explicit, although our use of language can point towards them. It is here that Polanyi's concept of tacit knowledge differs from that of Wittgenstein in that the former asserts that all tacit knowledge could, in principle, be made explicit; while language is too rudimentary to capture the complexity of human experience and knowledge, there is no specific element of this tacit knowledge that could never be articulated.

For Polanyi, tacit knowledge functions as a kind of mental and sensorial tool that supports our intended actions, making a necessary background for all of our expressed knowledge. When you are driving a car, your focus is on the road and the traffic, but at the same time you are feeling the acceleration, listening for the rpm, using the clutch and changing gears almost automatically. Although you had to focus on these latter tasks when you were learning how to drive, the management of the car's tools has now become tacit knowledge if you are an experienced motorist. You would be aware of these tacit elements if you choose to, for instance, focus on the gears, but they are normally used tacitly. According to Polanyi, tacit knowledge is thus knowledge that is in the background and is not our prime focus. It is a

prerequisite for expressed knowledge. The kind of tacit knowledge involved in medical practice can also be related to Dreyfus and Dreyfus' notion of expert knowledge. In contrast to lower stages of competence, which depend on rules or guidelines, they maintain that practical expertise is marked by intuition and a general grasp of a situation, rather than being able to articulate the reasons for the response (Dreyfus et al., 1986).

In this research, when aiming for the implicit moral values of clinical practice, we relate the concept of implicit values to Polanyi's concept of tacit knowledge. We seek to focus on the elements of medical practice that are not articulated, but still form the basis for most doctors' actions. More specifically, our focus is on hidden <u>values</u>, which are intended to refer to the tacit dimensions of value-laden decisions and actions. There is, however, an intrinsic challenge in the effort to study a tacit phenomenon, even if we presume that tacit values do not have to remain unspoken. Many researchers question the possibility of converting tacit knowledge into explicit knowledge (Haldin-Herrgård, 2005). This does not mean that studies of tacit phenomena are futile, but that the tacit knowledge subsists as such, while the studies might create new, explicit knowledge about the phenomenon. With reference to Polanyi's concept of tacit knowledge, we will try to bring the background knowledge of doctors into focus by systematically collecting, analysing and reflecting upon empirical data from doctors' clinical work. It may not be possible to articulate the doctors' underlying values, as in completing a list of biomedical principles. Still, we aim for an explicit reflection on this moral dimension and how it influences medical practice, which will hopefully contribute to our knowledge of the values embedded in clinical work.

1.2. Medical ethics

Before entering the field of medical ethics, a comment on the distinction between the concepts of "morality" and "ethics" is perhaps due. Although they have no precise definition in philosophical discourse, "morality" and "moral" is more often used in relation to concrete actions. "Ethics" and "ethical" generally refers to a more theoretical reflection on an action; it is often used when describing the rationale and motivation behind an action or referring to a philosophical system of values. Morality is what you *do*; ethics is your *reasons* for doing so. Although this distinction is

generally reflected in my thesis, I might not always be consistent because the concepts are often used interchangeably in everyday speech.

1.2.1. Establishing a field of medical ethics

Medical ethics is a field that is marked by a moral plurality, which arises from how and why the discipline was first established in the United States in the late 1960s (Jonsen, 1998). The advance of medical ethics as a discipline was occasioned by a remarkable development in the field of medical technology, which created new problems that required new answers. In addition, the public had been shocked by the disclosure of brutal abuses in the name of medical research, with well-known cases being the Nazi experimentation during World War II (Lifton, 1986) and the Tuskegee syphilis experiments in the United States (Jones, 1981). A growing consciousness among medical professionals and the general public of the moral perils of modern medical progress required experts from different professions to address these new issues. Medical ethics thus arose from a conglomerate of professions, which was dominated by philosophers, theologians and jurists. Accordingly, the birth of medical ethics as a discipline was not driven by doctors, but instead by forces that wanted to draw attention to doctors' self-governing moral judgements. What emerged was a corrective to doctors' professional practices. As a consequence, for many of these practitioners, the field of medical ethics developed as an external and redundant instruction, which was just one more attempt to deprive the profession of power and autonomy.

The field of medical ethics cannot really be seen as a continuation of doctors' professional ethics, but rather as a new discipline that is in addition to, and often in conflict with, doctors' traditional moral discourse. The American term for this new field was "bioethics", which distinguished it from traditional medical discourse within the medical profession while also encompassing the new issues of biological and technological advances. In Europe, the term "medical ethics" is frequently used for this new discipline, which implies a primary focus on the field of health care that is often even further restricted to mean reflections on the specific moral duties of doctors. In many European languages, the term bioethics aroused certain negative connotations with biotechnology and the biological foundations of ethics, but it is now also widely accepted in Europe and used to represent the distinct discourse and

range of issues that are modern medical ethics. The terms bioethics, medical ethics and sometimes even biomedical ethics are often used rather interchangeably, especially in European discourse. However, bioethics in its strictest sense covers a wider field of biotechnology and "all living organisms", meaning that medical ethics can be seen as a branch of bioethics that concerns itself with the moral aspects of health care and doctors' professional moral duties. It is this narrow definition of medical ethics to which I refer when using the word in this dissertation. Indeed, I deliberately limit my discussion of the wider issue of biology, while also confirming that my thinking stands in a European tradition which, when it comes to expressed challenges and theoretical foundations, may well diverge to some extent from American discourse.

The fact that the discipline of medical ethics took its form from outside the medical profession has probably played a part in alienating doctors from a field that had traditionally been their own. This meant that the discipline of philosophy typically got to define bioethics, basing it on philosophical concepts and ethical theories, with the result being that health care personnel were displaced from any key position when it came to the development of the field. Yet, it would certainly be wrong to suggest that doctors disregarded ethical considerations. A traditional understanding of professional virtues and codes of ethics remained within the medical profession. Several doctors raised concerns about questionable medical and research practice, and worked for a development of doctors' professional moral conduct. The Declaration of Helsinki is an example of this work, which was driven by the World Medical Association (2011). The Declaration establishes an ethical standard for medical research, leaning heavily upon the Nuremberg Code (National Institutes of Health, 2011). An important reason for the medical profession to engage in ethical discussion has been the need to protect its autonomous status. It is generally believed to be a vital asset for any profession that it is able to execute some form of control over its members (Grimen, 2008). As the field of bioethics developed, the medical profession also saw it as important to prevent the legal system from taking over large parts of the medical domain. Indeed, in the United States, there was a growing tendency to take difficult medical cases to court instead of dealing with them within the medical context. The legal discussions would then often influence the bioethical discourse, meaning that the law and bioethics, particularly in the United States, have

developed hand in hand (Jonsen, 1998, p. 342). As a consequence, central concepts of American law now have essential positions in bioethics, with the first among these being the right to self-determination. The case-to-case analysis and procedural reasoning commonly used in bioethical discourse probably also stems from the practice of law. The intrusion of non-medical personnel into the realms of medicine has been eloquently described by Rothman in his book "Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making" (1991). Rothman also emphasises doctors' ambiguous attitudes towards bioethics; although it was often doctors who informed the public about dubious medical practices, at the same time they were concerned about a loss of professional autonomy.

Since philosophers and jurists had defined the concepts and relevant questions in medical ethics, there was a growing tendency to separate the ethical and medical aspects of clinical cases, with doctors largely withdrawing to their own uncontested field: clinical medicine. This development is important in enabling us to understand both why bioethics has continued to be a discipline that exists outside the medical profession and why there is some resistance to medical ethics discourse among doctors.

1.2.2.   Development of ethics in medicine

Other social forces have probably contributed to the development of ethics in medicine. While being a doctor used to be a mission in life, or at least a profession that defined an individual in society, it has gradually become a more ordinary occupation. Nowadays, being a doctor has to fit in with the rest of your life, including your family and leisure pursuits, and is perhaps driven less by a sense of duty towards potential patients or humanity. These changes are not unique to medicine; we are less likely to regard a job as a doctor, dentist or lawyer as a personal calling. It is likely that these sociological changes have also had an impact on professional ethics, reducing awareness of the common moral duties of a particular profession.

Other changes from within medicine itself have also seemed to play an important part in the development of medical ethics as a field outside the medical profession. Medicine has undergone significant changes ever since the Age of Enlightenment, with the more spiritual dimensions largely disappearing and the scientific ideal

becoming the central model for medical knowledge. Modern medicine is built on a thorough understanding of human anatomy and physiology, even down to the cell and atom level, and being able to analyse the human body as a finely tuned mechanical instrument has proved to be an efficient approach that has led to ever new medical discoveries. Along with, and as an effect of, this development, medicine is guided by ever more technical instruments. Meanwhile, the profession today has become highly specialised, needing not only expert medics in specialist fields, but also expert technical personnel who are capable of handling technologically advanced tests.

Does this seemingly neutral and scientific development of medicine have any moral consequences? Probably not, in the sense that it has not changed the underlying goals of medicine: doctors still try to heal or help their patients. Yet, just as the field of scientific medicine undergoes substantial changes, so do the practice of clinical medicine and the approach of doctors to patients. The discipline of ethics relates to the appreciation of what it means to be a human being. When each body part and function of an organ are analysed as detached elements of a mechanical body, the moral aspects of a patient encounter are easily shattered. How much moral value can you ascribe to a finger, a blood vessel or a kidney? Moral dimensions are thus deprived of meaning when concentrating on small, separate units, and it makes no sense to talk of ethics when you are focusing on a small and detached part of a human being. The scientific development of medicine may thus have had an impact on the moral understanding within the medical profession, since the focus of attention has shifted away from the patient as an individual who is suffering, to the functions of a mechanical body. This makes the moral dimensions of medical interventions all the more imperceptible.

1.2.3. Bioethical reasoning

Although the first accounts of the discipline of medical ethics asserted that there was no more to it than applying standard ethical theory to the problems of medicine (Reich, 1978), the field actually has no unified theoretical foundation. This means that it is often taught as a mix of different ethical considerations, where principles, consequences and virtues are all taken into account.

The prevailing textbook in bioethics today is the now 6th edition of the "Principles of Biomedical Ethics" by Beauchamp and Childress (2009). Here, the writers identify four moral aspects as the main principles of medical work: autonomy, beneficence, non-maleficence and justice. These are emphasised as "prima facie" principles, meaning that they are each morally binding unless they conflict with another morally binding principle that is more or equally important in a specific situation. These four principles are considered to be morally equal, and they have to be weighed against each other in the specific situation at hand in order to decide which principle to act upon. It is not enough for a doctor to argue that a medical intervention is in a patient's best interests on the basis of the principle of beneficence; what the patient wants is also morally relevant according to the principle of respect for autonomy. In deciding what to do, the doctor thus has to balance these two important principles against each other and assess what action will be morally preferable overall. This model of moral reasoning is widely acknowledged in the field of bioethics, and is incorporated as the standard form of moral analysis. The model is practical to the point of being pragmatic, and can incorporate a plurality of moral arguments by relating them to the four principles and weighing them against each other. Certainly, the model does not solve the problem of the combination of the different forms of ethical reasoning that constitute the field of ethics. This means that the problem continues to be one of how to balance the different ethical principles when they conflict, and this is one of the major criticisms of the model (Callahan, 2003; Lee, 2010). Another common concern is the emphasis that is often placed on the principle of autonomy, despite the explicit statement that all four principles should be given equal weight. Holm (1995) has drawn attention to the fact that the application of the "four principles approach" is often biased by the American emphasis on personal freedom.

While the four principles' approach is explicitly based on a form of common morality, it has deep roots in traditional philosophical ethics. In fact, it can be interpreted as an attempt to reconcile two traditional, opposing theories of ethics: utilitarianism and deontology. Utilitarianism emphasises the importance of anticipating the consequences of an act and assessing what action will produce the most benefits for the most people. This is similar to the principle of beneficence (and the principle of non-maleficence). The principle of autonomy, meanwhile, stresses

the morality of the action in itself, not the consequences of it, in line with deontological ethics (O'Neill, 2002). According to this kind of reasoning, some actions, such as respecting a person's autonomy or abstaining from torture, are morally good or bad independently of the results they produce.

A different and strong current in the field of medical ethics is the ethics of care. This movement regards the relationships between people as being constitutive of our moral responsibility. The presence of another person requires that I relate to him or her as a fellow human being, and the ethics of care emphasises that this mere presence has a moral meaning (Lévinas, 2003). In this view, the moral meaning is more than a calculated balancing of principles. Instead, what are central to this morality are feelings, compassion and empathy. This is seen as being particularly relevant in the field of medicine, where human suffering is often present, and the ethics of care as a discipline has been embraced by nurses in particular, who have more or less incorporated this approach into their professional identity (Tschudin, 1992). The ethics of care also has clear roots in traditional moral philosophy, in which there is an array of movements that share some of the same moral grounds, such as the ethics of proximity, relationist ethics and feminist ethics (Martinsen, 2011; Donchin, 2001). All of these movements share a common foundation in the ethics of virtue, which originate from Aristotle (1980). Virtues like courage, empathy and patience are moral dispositions that people may possess to varying degrees. In contrast to principle-based ethics, the ethics of virtue put the emphasis on the individual who acts, and not on the action or the consequences thereof. An individual's motivations for acting play a vital part in how their actions are judged morally. The ethics of virtue often relate to striving to reach moral ideals, and it is your efforts that are important, not the effects you happen to have. This approach also has a clear resonance in professional medical ideals. Indeed, professional codes of ethics for medics were originally based on the image of a virtuous doctor, like in this quote from the first article in Percival's medical codex (1985): "[Doctors] should study, also, in their department, so to unite *tenderness* with *steadiness*, and *condescension* with *authority*, as to inspire the minds of their patients with gratitude, respect and confidence." In more recent codes, a form of principled-based ethics has become more prominent, as exemplified by the first article in the American Medical

Association's Code of Ethics (2011): "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."

Casuistry constitutes a third form of reasoning in medical ethics. It is worth mentioning in this brief overview because, although the term is not generally appreciated, the method is widely used in moral reasoning, and perhaps particularly so within medicine. Casuistry is a practical way of assessing moral cases, but has no firm theoretical basis. It originates from a Catholic, moral theology tradition that is occupied with resolving cases of conscience (Jonsen & Toulmin, 1988; Ruyter, 1995). The method involves interpreting and analysing difficult moral cases by comparing them with similar examples that are already known to be morally good or bad. The point is to compare the specific circumstance before you with similar situations you have experienced or learnt from in the past. The purpose of this is to assess which morally relevant aspects of this new situation are different and which are the same. Should we assess this new circumstance in the same way, or are there morally important differences that compel us to modify our judgement? In this way, you build upon your previous moral knowledge and experiences in a very direct and concrete manner. This mode of moral reasoning by comparing circumstances with previous cases is very intuitive, and is often used by lay people. This means that this approach is attractive in medicine, since most health care workers have no training in philosophy or theology (Braunack-Mayer, 2001a). Moreover, the method concentrates on particular examples, and does not depend on theoretical agreement, which is often lacking in cases of medical ethics. While the tradition of casuistry has a rather poor reputation in moral philosophy, it has strengthened its position in medical ethics, in particular perhaps as the dominant mode of reasoning in the growing number of clinical ethics' committees (Strong, 2000). The casuistic case-to-case approach is also well known in legal circles, and in recognising the close relationship between jurisprudence and medical ethics, the development of this form of reasoning in the latter should not be surprising.

1.2.4. Empirical research

I have already postulated that doctors rarely articulate moral judgements in their daily practice. However, instead of interpreting this as a lack of moral understanding, it could be that their medical language and clinical practice are "morally loaded"; in other words, the moral dimension is always implicit in doctors' medical judgements

in a way that makes it unnecessary to refer to a moral principle. This tacit way of handling the moral values of clinical practice makes it difficult to study the moral judgements made by doctors. Almost all of medical ethics research deals with ethics and values in an open and explicit way, yet some research does address the shortcomings of the dominant positions of medical ethics. I will not, however, attempt to provide a complete overview of the field of empirical research in medical ethics; instead, I will focus on the methods that have been used in this type of work and illustrate some of the various findings that have been made.

Most studies approach the moral aspect of medical ethics in a straightforward manner, asking doctors or other health care personnel to speak about their experiences with moral problems in their work (Hurst et al., 2005). These studies are mainly based on qualitative interviews, and provide an interesting insight into the conscious moral reasoning of health care personnel when it comes to how they approach their work. Yet, one must expect this expressed moral analysis to be heavily influenced by modern bioethical principles, and it is questionable whether such an approach accurately reflects what the participants really do in a clinical setting. One concern relates to whether doctors really speak truthfully when asked about personal judgements that may have caused patients harm, while another is the natural tendency to embellish one's own decisions in retrospect. A more serious problem, however, is that the researcher asks directly for the doctors' experiences of <u>moral problems</u> or <u>ethical dilemmas</u>. This provides an insight into what doctors themselves perceive as morally important or difficult, but means that the researcher cannot penetrate the doctors' descriptions and interpretations of what constitutes a moral action. When you ask someone to describe a moral problem, it requires whoever is interviewed to have defined these experiences within the field of morality. Accordingly, by asking these particular questions, a researcher would probably identify either the more exceptional, problematic or agonising cases, or those that have involved a major degree of conflict. Studies of clinical ethics' committees reveal that these are indeed the types of cases that health care personnel label as "ethical problems" and thus present to an ethics' committee (Førde & Vandvik, 2005; Hurst et al., 2007). Consequently, normal, day-to-day moral conduct or decisions would probably not be thought to be worth mentioning, or are not even thought of in terms of ethics by the respondents and so would not arise in such an interview.

While the tacit element of doctors' moral conduct is barely touched upon by these direct questions, they do provide us with valuable knowledge of doctors' explicit moral reasoning. Indeed, several of these studies have detected a discrepancy between bioethical categories and doctors' actual reasoning, thereby discovering moral dimensions that were important to the participants, but are seldom addressed by bioethical discourse. We have already mentioned the studies by Holm (1997) and Arnman (2004), which drew attention to the notion of responsibility. Braunack-Mayer (2001b; 2005) focused on the gap between moral theory and moral reasoning in her interview studies with general practitioners. She found that doctors' moral reflections are richer than those in mainstream bioethics, with issues of relationships, personal integrity, accessibility and continuity being raised. Meanwhile, by asking internal medicine residents about improper, wrong, unethical, or unprofessional experiences, Rosenbaum et al. (2004) drew attention to issues of professional self-regulation and the limits of personal competence. The focus group is another method that is commonly used for the same purpose. In their study, Ginsburg et al. (2002) utilised focus group interviews with medical students, asking them to discuss professional dilemmas and lapses in professional behaviour. It was found that issues which do not fit easily into the category of traditional moral principles, like communicative violation, role resistance and objectification, were raised. A number of quantitative approaches, and telephone questionnaires in particular, have also been used to address ethical experiences in medical practice. DuVal et al. (2004) found that nearly 90% of doctors questioned had recently faced ethical dilemmas, with end-of-life care issues and questions of justice being those that were most commonly encountered. Although these studies have a certain validity that might persuade quantitatively inclined medical professionals, they are actually even more bound to the pre-set definitions of ethics and moral reasoning. This means that they are unfit for purpose when it comes to identifying new and unexpected aspects of the reasoning of doctors.

Some studies focus on the other moral aspects involved in caring for patients, with moral distress being one example. Kälvemark et al. (2004) used focus groups to investigate the moral distress of health care personnel, and found that the entire sample had experienced this form of stress, which was often caused by conflicts

between personal moral standards and institutional or governmental regulations. Førde and Aasland (2008), meanwhile, used a postal survey to investigate the moral distress experienced by Norwegian doctors, and found that it was widespread, particularly in relation to dilemmas concerning a lack of resources. Like research into moral experiences, these studies also rely on predefined notions of moral issues and ethical problems. Other empirical studies, however, aim to evaluate the <u>moral competence</u> of professionals, and many of these pieces of work apply approaches from moral psychology (Bebeau, 2002). The studies typically rely on interviews or questionnaires to identify the participants' moral assessments through their arguments in a hypothetical moral case. Using a questionnaire and coding answers by stages of moral development, Patenaude et al. (2003) identified a significant decline in the moral development of students between their first and third years of medical school. Similar approaches have been used to examine the <u>moral reasoning</u> of health care personnel. In particular, Self et al. (1993) used interviews to analyse this issue and found that the doctors in their sample had consistently lower scores for this skill than the clinical ethicists. This research probably reveals some elements of the cognitive ability of doctors to make moral judgements according to a set of bioethical principles. However, it again does not tell us much about how doctors actually behave in the clinical setting. In particular, using predefined answers in a questionnaire or hypothetical cases shapes participants' answers to a great degree. Moreover, such approaches do not adequately take into account the fact that the respondents may have a deeper and more complex understanding of the issues than the researcher. Accordingly, the moral understanding that comes with managing actual cases, with all of their situational nuances, is thus poorly measured by these kinds of studies.

Another common way of addressing the moral content of medical practice is by observation, using a more descriptive or ethnographic approach. Utilising participant observation, Robertson (1996) studied a psychiatric ward for geriatrics and found that while the health care professionals did not discuss issues in ethical terms, traditional ethical concepts were useful for describing their ethical approaches. However, because Robertson defined relevant events as "ethically laden decision-making", and tested the relevance of three different moral principles on the basis of these events, his observations and analysis are closely bound to traditional bioethical concepts.

Meanwhile, Braddock et al. (1999) analysed audio taped patient-doctor encounters to explore how well the latter adhere to the requirements of informed decision-making. Their conclusion was that patients were not adequately included in the decisions made about them, while ethical ideals were not implemented in the doctors' routine practices. Others have used a more open approach to observation, and have not started from explicit moral principles. Reiter-Theil (2004), for example, developed the concept of the "embedded researcher", in which researchers conducted their investigations in the relevant clinical context without participating in clinical practice. The purpose of this approach was to enable the more rigorous observation and documentation of clinical reality. In their study of an intensive care unit, they found that ethics was understood as a matter of personal sensitivity, integrity and conscience, and did not involve the interpretation of ethical guidelines. Kaufman (1998) used an ethnographic approach to observe elderly patients who died in an intensive care unit. Although she did not focus specifically on ethical issues, she concluded that the way in which we speak about end-of-life choices and our ideas of "a good death" are far from the practical reality of dying in hospital.

If we understand the practical morality of everyday medicine as a tacit dimension in doctors' language and practice, we can hardly expect to expose it by direct questioning. Furthermore, using well-known ethical categories will probably hamper any attempt to reveal the novel dimensions of doctors' moral reasoning that might reduce, or at least explain, the lacuna between medical practice and medical ethics. While the large and varied field of research into medical ethics has provided us with some important insights into what doctors perceive as moral problems, how they use ethical concepts and how they argue about values, there seems to have been little work on the tacit moral dimensions of everyday medical practice.

1.3. Method

Since the main starting point for this study was that the field of medical ethics does not seem to fit well with medical practice, it was vital to not begin the research with predetermined categories from this discipline, an issue I will soon return to. Our aim was to identify the values that are implicit in the clinical work of doctors, but do not seem to correspond with established principles of medical ethics. With its aim of

generating new theories from empirical data, the Grounded Theory approach appeared to be suitable for the purposes of undertaking such a research project.

1.3.1. Grounded Theory

In 1967, Barney G. Glaser and Anselm Strauss wrote "The discovery of Grounded Theory", and in doing so developed a new method that has greatly influenced qualitative research, initially within the field of sociology, but eventually in other areas such as the study of health care (Glaser & Strauss, 1967). The authors originally developed the method as an alternative to what they called "grand theories", namely the major sociological theories in which abstraction, logical coherence and deductive reasoning are the central elements. According to Glaser and Strauss, these grand theories have a tendency to lead to concepts and hypotheses that are difficult to use in practical work, and which often fit poorly with how participants in the research field actually experience their actions. To counter this, they believed that new theories should be grounded in empirical data from the field. They also wanted to distance themselves from research which merely seeks to provide a thorough description of the research field. Instead, they stressed the importance of processing descriptions in order to produce analytical concepts and gain a theoretical understanding of the data. The end product of Grounded Theory research is specifically meant to be a theory of the research field. In order to avoid too much hypothetical speculation and abstract construction, researchers should enter the research field without a clear-cut hypothesis. The main point of this method is to not force a predefined theory onto the research material, but to instead enable the theoretical concepts to emerge from it, thereby obtaining a theory that is grounded in the data. According to Glaser and Strauss, this grounding ensures that the theory fits the research field, that it is relevant to the participants and also has consequences for practical work.

Glaser and Strauss' reflections on sociological theories, which led to the discovery of Grounded Theory, did also seem relevant for the perceived difficulties with bioethical theory. Indeed, beginning with empirical data to improve a theoretical understanding of practice did coincide with the ways in which it seemed useful to address the clinical field. Moreover, the method's focus on the need to create new concepts and hypotheses that are: based on empirical data; illuminating; and useful to participants matched our purpose of achieving new explanatory models with which to improve

our understanding of how doctors deal with the moral aspects of clinical work. Grounded Theory is partly rooted in pragmatism and symbolic interactionism, and seeks to conceptualise the meaning of social events and interactions (Wilson & Hutchinson, 1991). The emphasis on the significance of actions also seemed to fit our purpose of illuminating the tacit values of clinical work: how are doctors' moral values expressed through their medical language and clinical practice?

Another major aspect of Grounded Theory is that the method seeks to create new theoretical explanations, thus distinguishing it from studies aimed at testing predetermined hypotheses. Grounded Theory research is not intended to verify or reject existing hypotheses or theories of the field. Instead, the aim is to develop a new theory in either an area of research that has been inadequately explored, or in areas that are dominated by deductive, abstract theories. This was fitting, because we considered it to be essential to not start from the traditional concepts and theories of modern bioethics. Instead, we wanted to identify new ways of describing the moral dimensions of clinical work which relate to doctors' own understanding of what they do. The method differs from descriptive analysis and ethnography in that it does not aim to produce a mere detailed description of the research field. Instead, the goal is to achieve a more abstract understanding of the data, thereby generating theoretical hypotheses in the field of research based on the material that is obtained. Likewise, the aim of our research was not to describe the doctors' decisions and actions, but to enhance the theoretical understanding of moral action in every day clinical work.

1.3.2. Previous knowledge

A more problematic aspect of Grounded Theory is its disapproval of previous knowledge. Indeed, the method can be interpreted as asserting that all previous hypotheses and knowledge of a research field are distracting and constricting elements that must be discarded in order to identify the "real" issues of the field. This interpretation is reinforced by the fact that the method was launched as an alternative to deductive theories and the testing of hypotheses. Glaser and Strauss explicitly deny that the researcher is supposed to approach the field as a "tabula rasa", but they do nonetheless express a strong objectivity ideal. For instance, they emphasise that researchers should ideally have no previous knowledge of the field in order to concentrate on it without bias and prejudiced hypotheses. This includes not reading

literature or studies on the subject before conducting a piece of research, and attempting to disregard known concepts and theories. According to Glaser and Strauss, researchers should also not approach the field with a prepared research question, because this would imply that you have already defined what is important or what constitutes an issue for the participants you wish to study. Taken to the extreme, this view corresponds to a positivistic belief that the truth will emerge if you just stare long and objectively enough at the data. Sometimes, Glaser and Strauss seem to trust that the theories will be embedded in the empirical data, and believe that the researcher's work should involve the discovery of this inner logic. Indeed, critics do allege that the method verges on radical empiricism (Thomas & James, 2006).

In light of modern philosophy of science, believing that you can study the data without preconceived categories appears naive. Certainly, it would be impossible even to approach a research field if you do not in advance identify what the research field is and why you want to study it by using predetermined categories. In subsequent books, Glaser has met these objections and even stressed that researchers need to expand their knowledge of theoretical codes in order to improve their theoretical sensitivity (1978). Still, the rejection of previous knowledge was especially problematic for our research because it was precisely this that led us to this project. It was a familiarity with ethical theory along with the experience in clinical work that bioethics does not "fit" the context that had been decisive in even identifying a problem. Without this kind of previous knowledge, we might have more readily accepted the participants' explicit beliefs about medical ethics even if it did not match their moral conduct. Since we wanted to study how doctors deal with the moral aspects of their clinical work, it seemed vital to be aware that they rarely discuss moral questions openly, with moral dimensions instead being imbedded in a value laden medical language and practice. Indeed, to reach these hidden aspects of medical practice, we found it advantageous to be familiar with the inner structures of the profession, the significance of medical terminology and where the medical decisions are made. Moreover, particular knowledge of the field could make it easier to direct resources to where you would get the most out of the data. At its best, previous knowledge seems to enable the researcher to probe deeper into the field than is possible for unbiased researchers who rely on approaching the data with "an open

mind". Although there is certainly a risk of being blinkered when conducting research in one's own culture, previous knowledge may also be quite valuable.

1.3.3. Trusting the researcher

Perhaps the model of Glaser and Strauss do not have to be interpreted as strictly as some critics choose to. Indeed, throughout the research process, these authors maintain confidence in the researcher's ability to recognise what is relevant and important for a particular study. When they state that a theory will emerge from data, this can be understood as trusting the researcher's personal ability to conduct a meaningful analysis of the material that has been collected. This confidence in the researcher's ability to critically analyse his or her own work without a rigid, predefined set of rules, gives the method a flexibility that makes it well suited to research in which the actions of the participants cannot be predicted in advance. It also provides an opportunity to focus on the aspects of the data that prove to be the most interesting and informative during analysis. Instead of predefined selection criteria, Grounded Theory employs what is described as theoretical sampling, meaning that the researcher must re-evaluate which groups of participants to include during the course of a study. In this way, the study can adjust to what the data gradually reveal.

Moreover, by placing trust in the researcher's management and analysis of the data, the method also allows the use of many different types of information. Casual observation, overheard conversations and different forms of literature also count as data if they are managed as separate sources thereof and critically assessed as such. All sources of data are, in principle, allowed as long as the data are analysed according to the context in which they appeared. Glaser and Strauss also explicitly state that the method is suitable for both qualitative and quantitative research, although few quantitative studies have actually used it. The multiple data sources and the autonomy of the researcher are justified on the basis that the method does not pretend to verify a hypothesis, but is aimed at generating new theories. Reading Grounded Theory with some goodwill, researchers are given freedom and autonomy as long as they constantly and critically assess for possible bias and ground their analysis in real, empirical data. The details of the method can thus be regarded as

practical steps that generate creativeness and enable the researchers to conceptualise empirical data.

1.3.4. Glaser or Strauss

It is crucial to note that Grounded Theory is not an unambiguous method; its two authors have gone on to develop it in divergent directions since their initial joint publication of "The Discovery of Grounded Theory" in 1967, creating two separate "schools" of Grounded Theory in the process. Indeed, both Glaser and Strauss have published subsequent textbooks which describe in more detail how to perform Grounded Theory studies. Yet these books differ quite considerably, and the former partnership turned into a disagreement about what the method was all about and who was entitled to describe a particular approach as Grounded Theory (Glaser, 1992). In collaboration with Juliet Corbin, Strauss wrote a textbook on qualitative research and Grounded Theory which was very popular among qualitative researchers and profoundly affected the development of how the method is conceived (Strauss & Corbin, 1990). Glaser has also written several books in which he explains the method in more detail, while simultaneously distinguishing it from Strauss and Corbin's more descriptive approach (Glaser 1978; 1992; 1998; 2005).

In their textbook, Strauss and Corbin formulated a detailed description of the analytical procedure in Grounded Theory, stressing a systematic approach to the data and leading to a standardisation of the research process that makes it easier for beginners to use the method. This description differs from Glaser's version in several ways, and I will only comment on some of the main differences here (Hartman, 2001). According to Corbin and Strauss, a researcher should begin by defining a research question. This approach clearly already departs from that of Glaser, who maintains that it is important not to define a research question before commencing a study, because this will guide the approach to the field; if a researcher wants to understand the behaviour of participants, one has to be genuinely open to what they themselves regard as being important. Corbin and Strauss divide research into three different phases: open, axial and focused. While the open phase is similar to Glaser's open coding, in the axial phase, the researcher describes the properties of and relationships between categories according to an elaborate paradigm model. In terms of cause and effect, this model is intended to force the researcher to think

systematically about his or her categories and their relationships. Glaser, meanwhile, believes that this procedure is in opposition to the notion of Grounded Theory. This is because it forces the researcher to think about the data according to a predetermined scheme, creating connections that might not be relevant to the research field. In Corbin and Strauss' focused phase, the researcher is expected to choose a core category, integrate the theory around it and attempt to verify it through a constant comparison of cases. In Glaser's version, meanwhile, the core category is chosen much earlier in the research, which makes it central to the further gathering and analysis of the data. In this way, the core category guides the emerging theory to a greater extent. Glaser also rejects any attempts to verify the theory in the same data from which it emerged. All in all, Corbin and Strauss seem to have developed their method more in line with analytical description, focusing less on the abstraction to theory and depending more on predetermined hypotheses in data processing. Glaser is generally thought to have remained more faithful to the original method as launched in "The Discovery of Grounded Theory". In our research, we have mainly followed the Glaserian account of Grounded Theory, which is also the version that is closest to our intentions for this research project.

1.3.5. What is theory?

In daily speech, the word "theory" is used to describe a range of different features, such as an analytical distance, lists of definitions, hypotheses and mathematical equations. Often, the term is used to attain an air of credibility or prestige, which is indeed some of the objections that have been raised against Grounded Theory, and this is why it might be helpful to clarify the concept.

In philosophy of science, a theory is generally understood as an aggregate of hypotheses in which the relations between the hypotheses are defined (Bojer et al., 1993). For our purpose, we can roughly differentiate between two types of theory; theory that aims to *explain* a phenomenon, and theory that aims to *understand* a phenomenon. These distinctions more or less correlate to the differences of natural science and humanistic interpretation, which Snow described as "the two cultures" (1993). Theories in physics, for instance, aim to explain and predict physical phenomena, and the hypotheses are intensively tested in an attempt to falsify the theory. Theories in social science, on the other hand, focus on interpersonal,

meaningful phenomena, which cannot be explained and predicted in any equivalent sense. They are rather interpretations and patternings that help us in thinking about a phenomenon. Furthermore, in social science, the hypotheses are often more loosely related, and theories are rarely described in strict terms of cause and effect, which is the ideal of natural science theories. While a humanistic understanding might serve its purpose very well, the problem arises if researchers claim these theories to have the same epistemological status as theories of explanation.

First of all, the very name might be confusing, because Grounded Theory does not purports to be a theory in itself, but a *method* that facilitates the generation of theories (more specifically, the generation of grounded theories). While Grounded Theory embraces both quantitative and qualitative studies, the method is firmly based in social science. It seeks to verbalise phenomena into categories with certain properties and to express the relations between them. These relations may be described in terms of causes, but also as contexts, processes, degrees, dimensions and so on (Glaser, 1978, p. 74-81). When Glaser and Strauss emphasise that the end product of a Grounded Theory study is a theory, we perceive this in the sense of social science theories that aim to *understand* a research field. With our research, we hope to generate abstract concepts and interrelations that will illuminate medical moral practice.

Glaser and Strauss tend to engage in polemics against grand deductive theories, and they have been criticised for idealising inductive reasoning and ignoring the close relation between deduction and induction in theory construction (Thomas & James, 2006). This is, however, an overly negative interpretation of the method. While they emphasise the importance of inductive reasoning when managing empirical data, Glaser and Strauss also repeatedly stress the deductive elements of the method, like theoretical sampling and testing of conceptual ideas. It is not to be ignored, however, that there are ambiguities to Grounded Theory and its theoretical end products, not least because of how its two originators have diverged in their development of the method.

1.3.6. My use of Grounded Theory

We have used much time to clarify whether or not we could use Grounded Theory for this project. I presented our plan for the first study on two consecutive Grounded Theory seminars led by Dr Glaser in London in 2006 and 2007. Our use of the method was thoroughly discussed and supported by Dr Glaser and the group of experienced Grounded Theory researchers. The crux of the matter was that we wanted to look specifically for how doctors handle the <u>moral</u> dimensions of clinical practice. To narrow down the research focus to a specific field of interest, is generally frowned upon within this method. The main objections that were raised were that one could not know beforehand that moral issues would emerge from the data, and thus we risked that the doctors would not be concerned with moral issues and that we would not get the data we needed. An often-used example is a researcher who set out to study risk-taking among steeplejacks by the use of Grounded Theory and discovered that they did not speak about risk-taking at all, and so had to give up this focus (Glaser, 1998, p. 115). Although the problem of defining an issue before undertaking a study is pertinent in principle, the starting point for our research was quite different. I would not be surprised if doctors did not speak of ethics; on the contrary, this was expected from my knowledge of the field. Still, the moral aspects of the doctors' conduct would be present even if the doctors did not mention them, and our intentions were to see how the doctors dealt with these dimensions, implicitly or explicitly. What gradually became clear was that, while in the field, the data collection should not be limited to the moral dimension. We ought to gather the data broadly, looking for the participants' main concern in line with Grounded Theory requirements. When analysing the data, we could then focus more specifically on what the data meant to the moral dimension of medical practice.

To us, the issue was not how to carry out the study within the Grounded Theory paradigm, but whether the method was suited to accomplish the kind of research that we wanted to conduct. Objections can be made to our use of the method because of our previous knowledge, our delimited focus on ethics and because we started out with a research question, however loosely defined. Although we do not find it vital to label our method "Grounded Theory", we have followed the theoretical foundations and practical procedures of the method to such an extent that it would be misleading

not to do so. My previous knowledge stemmed from first hand experiences from the field and our research question was grounded in empirical data, even if it was not collected systematically or scientifically. We were acquainted with the literature and theories of professional culture and medical ethics, but we did not follow these theories in the data collection and analysis. Indeed, in line with Grounded Theory, we attempted to remain open to the participants' own explanations and motives, and to analyse their moral conduct on the basis of how the doctors acted in their clinical work. We have tried to take the consequences of the central theme in Grounded Theory, also supported by philosophical hermeneutics, to treat all information as data, including our previous knowledge and experiences as well as the reactions to our findings, as will be revealed later on.

2. Conducting the studies

2.1. Study I

2.1.1. Practical considerations

The ideal in terms of our research would be to address clinical practice in a way that interferes as little as possible with normal clinical work. This would be an approach that allowed the doctors to carry out their normal work routine, and at the same time revealed some of their moral assessments. Since our interest was primarily in doctors' tacit knowledge, we were reluctant to use interviews as our main source of data. Accordingly, observing the clinical setting seemed to be the only way forward. It is not, however, easy to intrude into clinical practice without disturbing a normal consultation between patient and doctor. Yet, much of the work done by doctors is not as private and sensitive as one might expect. Indeed, in hospitals, a lot of work is carried out in collaboration with others, such as nurses, assistants or other doctors. Moreover, many aspects of the work are conducted when the patient is not even present.

Our intention with the first study was to follow several doctors over the course of their working day, using participant observation to obtain the most accurate impression of their normal activities, different work settings and concerns in trying to perform their day-to-day tasks. In particular, we wanted to observe how different moral situations arose during the day and how the doctors responded to these. This

would mean observing the interactions between doctor and patient and thus participating in clinical consultations. Yet for many doctors, especially those who work in a hospital setting, their daily work consists of more than patient encounters. They participate in daily internal meetings and reports, they confer with fellow doctors and superiors, they prepare examinations and treatment for patients, they follow up on test results, they assist at operations and so on. Since the purpose of our research was not to study patients, but to examine doctors' actions and decisions, we concluded that it was necessary to follow the doctors throughout the day, rather than just observing their contact with patients. In addition, following each doctor over the course of a full day's work would provide an important source of continuity when it came to understanding his or her actions and choices.

This did, however, pose some practical problems. Being a doctor, I could readily get access to hospital wards. What is more, doctors are used to having third-party observers present, especially medical students or house officers, and they often enjoy having a colleague to talk to or lecture. The problem was instead related to the fact that I would now be observing, not as a fellow doctor or medical student, but as a researcher. Medical research regulations meant that I was regarded as an outsider, and thus had no involvement with the treatment of patients and no access to patient information. Research should, of course, ideally be based on the informed consent of those who participate in it. All of the doctors in our study thus received written information about the project and gave their written and informed consent to our involvement, but what about the patients? In medical consultations, it seems reasonable to include the patients as participants and obtain their informed consent, since they would be central to the circumstances and actions being observed. Yet, it would be odd to define all of the other patients in a ward as participants just because they had been admitted to it. In any event, the majority of the patients in a ward would not be observed, only those who happened to come into contact with the doctor we were watching, and even then they would not be the focus of the observation. Indeed, in studying the doctors' working day, it was other health care personnel, patients and visitors who would make up the environment in which the doctors were working and acting. Should we ask all of these "potential participants" for their informed consent? In other observational studies, such as in ethnography, it is normally just the main informant or informants who give their consent to being

observed, and not everyone that they happen to interact with. The nature of observation is considered to be much more intimidating for the prime subject thereof. Indeed, it is clear that patients should be better protected than the general population, but would it be ethical to ask every patient in a hospital ward to consider the study information, take a stand about whether or not to participate and sign an informed consent form when just a few of them would actually meet the researcher? In the end, we decided to apply for an exemption from the duty of confidentiality so that we could be present in hospital departments, observing the doctors' work and their interactions with patients, without having to ask all of those who had been admitted to a ward for informed consent. This process took a year of applications and re-applications before our request was finally granted.

In the meantime, we began by observing general practitioners. The reason for this was partly methodological and partly practical. On a practical note, general practice is a setting in which we could ask all patients for their informed consent and observe doctors throughout their working day. Moreover, methodologically, we expected there to be much diversity in terms of patient groups and clinical questions in general practice. General practitioners are relatively autonomous in their work, which we thought could lead to substantial personal variations in how they handled their patients. In addition, we did not want to select a particular branch of medicine in which we knew that the need to make clear moral choices would be abundant, such as in oncology, the provision of abortions or when issues relating to the termination of life-prolonging treatment arise; these are all cases that have been thoroughly discussed in the medical ethics' literature. Because such cases are already known to be "morally loaded", it is to be expected that the decisions made and discussions taking place in these settings would be significantly influenced by medical ethics theory, and, therefore, perhaps not reflective of the more common moral considerations made by doctors. Since we wanted to study normal, day-to-day clinical practice, we believed that general practice would be a good starting point.

2.1.2. Interviews

While observing doctors at work seemed to be the best way of addressing tacit issues, our research aim still posed us some challenges because we had opted to deal with matters of morality. Is it even possible to observe the morality of behaviour? I do not

believe that there is a simple answer to this question. Certainly, there are aspects of morality that are visible to outsiders. Aggressive behaviour and violence, as well as ridiculing and ignoring an individual, can often be noticeable to someone from a similar community. Likewise, expressions of pain, sorrow and anger may be observable. Yet more subtle feelings are not so easily spotted, and nor are other important moral dimensions like motives and ideals. We decided to compensate for some of this loss by also conducting interviews with the participating doctors to learn something about their motives and reflections. Nevertheless, because of our interest in the tacit dimension, it continued to be important to us to attach most weight to our observations of what the doctors did and let this guide the interviews. We, therefore, decided to always conduct the interviews after the observations and ensure that the questions related to the medical work we had observed. This would enable us to remain as close to ordinary practice as possible and avoid more hypothetical speculation. We chose not to interview patients because our initial focus was on the doctors, and we found this to be a necessary limitation of the research labour. As the research proceeded, this drawback became more evident and it remains an important limitation to our study, which is further discussed in the study limitations section.

We did at some point consider the possibility of conducting focus group interviews. Indeed, this may well have been time effective, since we would get the views of several doctors at once. It might also highlight certain discussions which were internal to the group and would not otherwise arise. Moreover, it would probably also be difficult for the participants to embellish reality, since there were others present who would know the same reality. So, before finishing the design of the study, I conducted a focus group test, inviting a few doctors from one medical department to an informal lunch meeting and discussion. The doctors were of both sexes, different ages and from all stages of specialisation. The tone was informal and positive and most of the doctors did participate in the discussion. However, when I asked a question about uncertainty, in particular how doctors make many of their decisions day to day, often on the basis of limited data, the talking stopped. One of the senior consultants present stated that insecurity was the preserve of house officers or students, and while discussing this topic might be an issue for inexperienced doctors, it was no longer a problem for their senior colleagues. After this statement had been made, a couple of the doctors who had seemed to be about to comment remained

silent. This incident made me realise that some kinds of confessions might be difficult for doctors to make in the presence of their colleagues, even if my question had actually been about the innate uncertainty of decisions. It also demonstrated how the hierarchical structure of the profession could silence subordinates when a senior colleague had already made his or her views known. Some of these problems could probably have been dealt with by a different focus group design, but, as we still expected the data to be very dependent on specific group composition, we decided that individual interviews would be more advantageous.

2.1.3. In the field

Forming the sample of general practitioners was initially convenience based. A GP who had a particular interest in clinical communication was asked and agreed to participate, and he contacted three colleagues who also agreed to take part in the study. The doctors were first told about the study verbally and then received an information letter about it along with the informed consent form. The doctors were told that I was working on a PhD-project in medical ethics and that I was interested in what issues doctors deal with in their clinical work, with a particular focus on the value-laden aspects of medicine. I normally went to the office in question a day before the study was to commence to notify the office secretaries about it and give them the patient consent forms. On the day of the study itself, there would be a placard on the wall in the waiting room with information about the research and which doctor was involved. Meanwhile, the secretaries would give the informed consent forms to the patients who had appointments with the doctor I was observing and then collect them when they had been completed. If a patient did not want me to be present in the consultation, the secretary would report this to the doctor and I would wait in a nearby room. Very few patients declined to participate.

In accordance with Grounded Theory, I tried to approach the field with an open mind, although being a doctor I did indeed know the clinical work and circumstances that might arise. However, I attempted to put my medical interest in the background and concentrate on the human interactions. At first, this proved to be quite difficult to achieve. I found myself wondering what illness a patient was suffering from and trying to work out what examinations the doctor would undertake next. However, I frequently forced myself to focus on other aspects of the scenario: how did the

doctors pose or move their bodies? How did the patients sit? What were the surroundings like? How did the patients phrase their concerns? How did the doctors react? When did the doctors interrupt the patients, and when did they follow up on a patient's worries? When did the doctors record in the patient journal? These were the kinds of questions that I tried to concentrate on when observing the doctors, along with the general questions that were always at the back of my mind: what is happening here? What are the doctors' main concerns?

We did not tape record the encounters because we did not want to disturb the consultations any more than I already had done with my presence. In addition, my attention was primarily on observing the encounter overall, not just the spoken dialogue, and so tape recordings would place too much focus on the audible dimension of the situation. Another option was to conduct video recordings, but we considered this to be too great an intrusion into the consultation. Moreover, since I intended to follow the doctors over the course of their entire working day, in both patient and non-patient settings, I would have been required to walk around with a video camera on my shoulder, which was not realistic. Instead, I tried to be a more anonymous part of the setting. I normally sat in a corner of the office, sometimes dressed in a white coat and sometimes in my normal clothes, depending on the doctor under observation. I took notes throughout the day, but not while a patient was present. The doctors and patients only rarely spoke to me during the consultations, but after the latter had left the former would often address me as a fellow colleague or student, inviting me to comment. I also took notes on these events, as well as on the work the doctors did in between patients. Finally, I was able to observe other non-patient situations which were part of the doctors' working day, like joint lunches, internal staff meetings, telephone consultations and dealing with paperwork.

In order to exemplify this part of the process, I give a brief illustration of my notes. The first one is taken during a patient consultation; the second one is from an internal morning session:

Young, female patient; seems new to the doctor. Immediately pulls out her mobile phone; says she has several issues and that she has brought a list. The doctor sits back in his chair, appears calm; does not speak, but awaits the patient. The patient wonders if he could check up on her blood

count, because it has previously been low. "...and I have celiac disease, just so that you know". "Yes", the doctor replies "certainly". He turns to the computer and prints out a form, the patient continues to speak.

All of the doctors are gathered around a table, the senior consultants on one end, younger doctors, house officers and students on the other end. There are not enough seats; some younger colleagues sit on chairs and sofas nearby. The house officer (who has been on duty the previous night) presents the new patients without interruptions, sometimes supplied by a senior colleague. The other doctors look down at their patient lists; hardly any comments or emotional expressions.

Grounded Theory recommends that the researcher does not record observations and interviews, but instead takes notes during the fieldwork. It is argued that recording situations produces too much data, which often overwhelms researchers. Researchers should instead trust in their own abilities to discover what is of interest in the scenario being observed. Since the method is aimed at producing a theory that illuminate what happens in the observed field rather than accurate descriptions, meticulous recordings of the precise dialogue used or body language exhibited are beyond the scope of the research. Grounded Theory stresses that researchers should be realistic about what they can do and should also take care to utilise their time and efforts where they are needed most. Consequently, researchers must use their skills actively in the fieldwork, focusing closely on what is actually happening.

After the doctor had finished his or her final consultation, we built in time for an interview, which normally lasted between 30 and 60 minutes. I began these sessions by asking the participants about how they thought the day had gone and how they had felt about being observed. Most stated that they believed that things had gone well, and while they had initially been very aware of my presence, they had soon forgotten about the observation and carried on as normal. I went on to ask about the day's work and whether the doctor regarded this to have been a normal working day. I asked if there had been patients or situations that they had found particularly difficult to handle and if there had been circumstances in which they had felt positive about their efforts and thought that they had been good doctors. Normally, this would lead to follow-up questions which attempted to probe what the doctors had experienced as difficult or satisfactory and what they were striving to achieve. I would also ask

questions about particular patients or situations that I had taken note of as being especially interesting, surprising or difficult to comprehend.

This is a small example of such a questioning from an interview:

Interviewer: Were there any patients today who you found particularly difficult or demanding?

Doctor: (stops to think) Perhaps the elderly lady, I always think that she is a lot older than she really is, I have problems in understanding what it is she really wants. I wish she could be a bit clearer and say: "I am here for a blood pressure check-up". Instead, I have to ask her: "Are you here for a blood pressure check-up?" I get so insecure...

Interviewer: She brought up a lot of complaints: aches, ringing in the ears, anxieties...

Doctor: Yes, she speaks of it every time!

Interviewer: Is that why you did not follow up on any of that?

Doctor: (laughs a little embarrassed) Yes. We have gone through these issues earlier and she presented them in exactly the same manner that time. So I did not feel like there was anything new.

After the interview, the doctors would often ask me for my opinions and feedback on what I had witnessed, but this turned out to be surprisingly difficult to respond to. My notes mainly consisted of pieces of events and analysis and associations, and I was thus rarely able to provide any clear summary or make suggestions about what all of this information might mean. After I had left the doctor's office, I then sat down to complete my notes, going over the events again and again in my mind and writing down fragments of what might be of interest. This process actually took a lot of time, even taking me up to a week after the initial observation before I was then ready to observe the next doctor.

2.1.4. Theoretical sampling

Starting with general practitioners was, as noted earlier, both convenient and methodologically favourable. Thereafter, the further inclusion of the other doctors who we wanted to participate was achieved by making reference to what we judged would provide us with the most interesting and important data; in other words, we conducted what is known in Grounded Theory as theoretical sampling. We also took some more practical considerations into account relating to who not to include. On this basis, we ruled out psychiatric departments, paediatric departments and intensive

care units because of the vulnerability of their patients and the challenges of obtaining valid, informed consent. It seemed natural, however, to try to include doctors from different specialities in order to cover a wide range of patient cases, but also because it is common knowledge among the profession that different areas of work foster (or attract) different personality types. After recruiting the initial four general practitioners, we then decided to include a department of internal medicine with a specialised field and dealing with seriously ill patients. Indeed, since the avoidance of existential issues was already apparent at this stage, we thought that it would be illuminating to include a department wherein existential issues were imminent. Accordingly, three doctors from this department were also recruited. Thereafter, we wanted to involve a surgical department because the doctors therein deal with a quite different patient group and encounter other types of challenges. What is more, surgeons are not generally known for emphasising empathic communication or expressing their interest in medical ethics. We thus involved three doctors from a general surgical department. After this, we decided to also include another department of internal medicine, in which we expected to find complex medical issues as well as a need to make difficult moral judgements. Again, we wanted to test the role of patients' existential worries, which would almost certainly be an issue for this patient group. Accordingly, three doctors were included from this department. Having spent a lot of time inside hospitals, we then decided to recruit two more general practitioners in order to test our emerging theory. Finally, over a year later, and after writing the draft of the first manuscript, we included two more doctors from a general department of internal medicine, both to investigate some of the sceptical feedback we had received on our theory and to probe where to go next with our research.

When attempting to recruit doctors from hospital departments, I first contacted the senior consultant in the department in question to explain the project and ask if I could come in for a meeting. All of the senior consultants I approached agreed to the participation of their department. When I arrived on the day of the study, usually for the first joint meeting in the morning, the senior consultant would typically point out the doctors I could possibly follow, and I then asked these medics for permission to do so and obtained their written, informed consent. None of these doctors refused to participate, although it was certainly possible that they were unlikely to do so once

the senior consultant had assigned this task to them. Overall, 17 doctors were included in the first study, five female and 12 male, varying considerably in age and medical experience. Each doctor was normally observed for one workday, lasting between six and nine hours. The study was conducted in hospital departments and the offices of general practitioners in six different locations in Northern Norway.

2.1.5. Coding and analysis

I began my analysis as soon as I had written out my notes from the first observation session and interview. Even though this initial data contained my observations of only a single doctor, there were still many different consultations and situations to examine. I started by going through the data sentence by sentence, comparing incidents and coding openly without restrictions in terms of any theme. In line with the Grounded Theory approach, I constantly asked of the data "what is happening here?" and "what category does this incident indicate?" In this way, I tried to not only interpret concrete actions or words, but to also conceptualise the meaning thereof. Where I had written in my notes that the doctor addressed me before the patient entered the room, saying, "The next patient has some psychological issues, she is a bit peculiar", I could, for instance, code this as "doctor classifying patient". Going through the text, I coded and conceptualised incidents and compared incidents with other incidents, looking for similarities and differences between them. Later on in the text, where I had written that the doctor smiled after the patient had left, saying "That was a consultation, like, 'Could I have a sick note if I ever need it, just in case'!" this was also coded as "classifying", but now as "doctor classifying situation". Thus, both similarities and differences between incidents were noted when constantly comparing them. The properties of each category also gradually accumulated during this analysis. For instance, when it came to the concept of "categorising", I would note how some patients were labelled negatively and others positively. It is of course possible that I sometimes interpreted a gesture, action or phrase in a way other than what was intended by the participants, even if I strived not to. However, since the analysis rested on numerous situations with different doctors and different patients, an occasional misinterpretation was unlikely to affect the end result.

After spending some time on open coding, I found that the data generated fewer and fewer new codes. Most of the text was now being coded using my established

categories, which each had various properties attached to it and thus extended to cover a large number of incidents. This development took place gradually, and after having observed ten of the participating doctors, I switched to a more selective coding process. This process focused on what I perceived to be the most important codes in the analysis. On the basis of the identified categories and the relationship between them, we then established the core category, which is the one that appeared to be central to the emerging theory and could best explain what actually happened in the field. In this first study, we initially chose "medical reconstruction" as the core category, which was intended to describe how the doctors first deconstructed the patients' problems, redefined the pieces and reconstructed them into a specific medical complaint. However, on conferring with Barney Glaser at an advanced Grounded Theory seminar, he suggested changing the core category to "essentialising", which reflects how the doctors focused on what seemed to be essential to their specific objective while neglecting other dimensions. This concept was not only potentially more illuminating as the core of the emerging theory, but was also more general and applicable to similar processes outside the field of medicine. Accordingly, after choosing the core category, I delimited my coding to the other categories that seemed to be related to it and were the most important in the data. This left me with 20-30 conceptual codes. I went through the data again, this time focusing only on these particular categories, conducting selective coding to enable me to add cumulative properties thereto and discover the theoretical relationship between them. Later, these sub-categories were reduced to five main categories in order to delimit the theory. These were: "breaking down"; "concretising"; "categorising"; "existential filtering"; and "functional focus", and were in addition to the core category of essentialising. This theoretical structure was defining for the configuration of the first manuscript, in which each of these categories was explained and clarified with empirical examples.

While this analysis slowly advanced, I continued to observe and interview new doctors. This move between data collection and analysis was very valuable when it came to conceptualising the data. In particular, it enabled me to check my formulated categories and interpretations and develop the concepts that seemed to be the most valuable. It prevented excessive speculation or theorising and ensured that the analysis and emerging theory remained close to the data. The alternation between

gathering empirical data and theoretically analysing it also generated a lot of ideas and thoughts about: the data; why the doctors and patients acted like they did; how the different concepts and parts of the analysis were related; the different aspects of theory that I had studied earlier; and similar findings elsewhere, or even links to phenomena in completely different sections of society. I tried to capture these ideas in the form of the brief, explanatory notes that Grounded Theory describes as "memos". Writing memos is an important part of the method, and it is emphasised that when the researcher gets an idea about the data, he or she must always interrupt other work to write a memo about it. Memo writing stimulates researchers' creativity, encourages theoretical analysis and exposes personal conceptualisations and interpretations of the material. These memos were thus added to the data and analysed and interpreted in relation to the rest of the information we had collected.

I used the NVivo 7 analysis tool, which is computer software for qualitative data analysis, to assist with the coding and systemising of categories and memos (Gibbs, 2002). The kind of software is designed to organise and analyse unstructured data, although there is some reluctance to use it in Grounded Theory circles due to fears that it takes the focus off the collected data and the scenarios observed by occupying the researcher's mind with computer tasks. Furthermore, the manner in which the software is structured, the opportunities it provides to make notes and links, and its preset categories force researchers to organise data in a predetermined manner that is contrary to the aim of the Grounded Theory method. While I believe that these are fair reasons to be cautious about the use of data analysis software, it is my view that the advantages outweigh the risks. Some of the concerns are related to a lack of experience in using the software. Normally, however, the more you use a computer program, the more you will be able to master it as a tool for your own purposes instead of being led by its innate possibilities. For example, while writing on the computer in Microsoft Word might have obstructed my text when I was inexperienced in using the program, now it is just as easy (or even easier) to work in this way as opposed to writing by hand. In addition, there was a large advantage in using the software to keep track of my coding. When there are hundreds of codes, categories and memos, the need to ensure that they are maintained in an accessible system is considerable. So, my primary use of the program was as a way of keeping

track of my analysis and displaying the links between related situations and connected categories.

2.1.6. Summary of the first manuscript

In our first study, what was most striking was how alike the doctors' approaches to their patients were, despite major differences between individual medics and medical settings. I followed general practitioners of both sexes, different ages and with varying experience, and their style of doing medicine obviously differed. Some were efficient, worked fast, concentrated on test results and notes and did not chat a great deal to their patients. Others were more laid-back, kept on friendly terms with the patients and referred to their personal experiences. Yet, when it came to what the doctors focused on, what held their attention and what they disregarded, their clinical approaches were surprisingly similar, and we have thus tried to describe five of the most important elements thereof. When the patients told their medical story, the doctors were not particularly interested in the narrative element, but in the medical facts and clues that it contained. This often caused them to either interrupt with specific questions or ask the patients to repeat parts of the story. We described this step as *break down* to describe how the doctors concentrated on getting a grasp of the elements of medical information contained in a story by breaking down the patient's presentation of events. The doctors also often interrupted to get the patients to specify their complaints or describe what had actually happened, a step we called *concretising*. The doctors made a lot of effort to ensure that the complaints, findings or events were objective and measurable. This could be as simple as asking when the patient took a last dose of medicine, but might also involve quantifying the distances that patients were able to walk or levels of pain they were experiencing. The doctors likewise strove to interpret the meaning of the diverse information they received from both the patient and any examinations, assessing this from a medical point of view. We called this step *categorising*, in which events and findings are classified according to medical knowledge and clinical language. So, a patient's description of a feeling in her chest is categorised as "chest pain" or even "angina"; a cold foot is described as "poorly circulated"; and a patient is noted as being "depressive". These three steps can be seen as normal aspects of the medical processing that doctors conduct to utilise their specific medical knowledge to help patients with their diverse and often diffuse problems, and would probably not be very surprising to clinicians.

Yet, this medical processing also contained other elements that are normally less explicit, but are nonetheless related to the steps already described. An example was when the doctors strove to convert patients' afflictions into a medically relevant question by breaking up the narrative and concretising and categorising the information. This meant that their connection to their patients' personal lives got rather lost; the personal meaning of an illness and the patient's private feelings were not incorporated in the medical question, and were even actively excluded. We called this step *existential filtering*. For instance, a patient might be disconsolate because her painful shoulder makes it impossible for her to help her elderly mother with the housework. The doctor, however, would probably take no notice of this, perhaps even ignoring the patient's personal distress in order to focus on the delimited medical affliction. The doctors' medical decisions were not focused on the patients' expressed worries, but rather on a medically relevant question that could be answered by the use of medical knowledge that is based on anatomy, physiology and the functions of the body's systems. We named this step *functional focus*, because the doctors seemed to concentrate their efforts on improving the functional health of the patients physically and, sometimes, mentally. While we divided the doctors' clinical approaches into five discernable steps in order to better understand their actions, in reality these are all mixed up and some even occur simultaneously. However, together they constitute the elements of a systematic medical process that we called *essentialising*, which is intended to describe doctors' practical ways of handling complex and often ambiguous clinical situations in a medical manner, thereby establishing what they perceive to be the purpose of clinical intervention.

2.1.7. Reactions to the first study

Not all of our conclusions from the first study were very popular with the doctors. When we presented the results in various fora, they would generally recognise the process of essentialising in the way they handled their patients, but many objected to the concept of existential filtering, and particularly so the general practitioners. They claimed that they dealt with their patients as complete individuals, and related to their personal lives as well as treating their medical afflictions. This should not perhaps come as a surprise. Stating that doctors do not genuinely care for their patients as human beings is bound to upset those who strive to do so because they believe it is a

necessary part of being a good doctor. This reaction could, in fact, reflect our research findings. Since we found that most doctors were driven by a moral obligation (to benefit their patients' health), it is no wonder that criticising doctors' work is met with moral indignation. On the other hand, we were somewhat surprised by the reactions because we did not intend to criticise them, but to instead illuminate why it is so hard to meet the moral ideals of a good doctor.

Indeed, we do not disapprove of the doctors' essentialising processes, but describe how they occur and highlight the rationale behind them, namely a moral obligation to improve patient health. Essentialising might be an indispensable element of the clinical encounter if doctors are to practice medicine in the way we understand this profession to be. Modern medical practice is so profoundly bound up with medical science and knowledge of anatomy, physiology and biology that it is hard to see how doctors could ever avoid analysing patients as medical objects if they are to apply this medical knowledge to their patients' bodies. Accordingly, our theory says something about how the premises for clinical work restrict what doctors are able to do. The process of essentialising explains why it is so difficult for doctors to care for patients holistically, and why this is perhaps not even desirable given the primary responsibilities of the profession. Moreover, the process may shed light on why some patients feel that they are not adequately met or cared for as human beings. In summary, the theory illustrates how the medical profession is constantly torn between the responsibility to improve patient health and care for them as human beings. What is more, it may even alleviate some of the worries for not being a good enough doctor. However, as it turned out, many of the doctors included in the study would not accept our conclusions and instead maintained that they attended to their patients as individuals and cared for them in a holistic manner.

This reaction puzzled us. Our theory felt certain and grounded in the meticulously acquired data, and most of the doctors also seemed to recognise the patterns of essentialising that existed in their own work. So, why was there this opposition to the notion of "existential filtering"? There were several potential answers, the first of which was the possibility that our theory was wrong in relation to this aspect of the doctors' performances and we had misjudged the observational and interview data. Researchers must always be open to this possibility, but even though we conducted

two more days of observations and interviews, we could not interpret the data in any other way: the existential filtering conducted by the doctors seemed to be systematic and evident. Another explanation was that the doctors were wrong in claiming that they cared for their patients as human beings. In other words, it might be the case that they were denying our theory because it threatened their image of the medical profession, since they could not regard themselves as good doctors if they did not care for patients existentially; compassion and empathy are widely held to be important elements of a patient-doctor relationship, and our study questioned this notion. Indeed, in Norway, general practitioners often express their ideological foundation by the words Continuous, Extensive, Personal and Binding [Kontinuerlig, Omfattende, Personlig og Forpliktende] (Alment praktiserende lægers forening, 1978). Alternatively, perhaps the doctors had not fully understood that the description of essentialising was not a criticism of their work, but an explanation of the premises of clinical practice. Nonetheless, it would have been rather arrogant to explain away the complaints by stating that the doctors had misunderstood our arguments or did not want to face the truth. So, why do doctors believe that they take existential care of their patients as well as medical? This question continued to bother us after we had concluded the first study.

2.2. Study II

2.2.1. Remains of the data

After writing the first manuscript, the original plan was to go into the field again to collect more material and conduct further analysis. As mentioned earlier, I collected data from two more general practitioners after saturation of the first study. This was done in part to test our theory of essentialising against the critics who maintained that doctors do care for their patients as human beings. However, the settings and circumstances were now so familiar that I could only see further confirmation of our already established theory; our theory of the subject was so saturated that more observations did not seem to bring anything new to the table. On the other hand, the material we had collected was so rich and complex that we had barely scratched the surface, and there were many interesting and remarkable aspects of it that could be analysed independently of the theory of essentialising.

One such aspect was the practicality of clinical work. Often, medical practice and the patient-doctor relationship are discussed in slightly ethereal terms, which focus on the sanctity of professional secrecy in a relationship that is based on empathy or the mystery of the human body. Even when not explicitly mentioned, these dimensions are often implied in the argument (Thomasma & Kissell, 2000). Yet, when you observe doctors at work, everything is very practical and concrete to the extent that it is hard to see where the more existential dimensions of life even enter medicine in practice. It is also difficult to identify the moral aspects of doctors' work or define their moral choices. This often makes it a challenge to relate discussions in medical ethics to common clinical settings, and can sometimes even obscure the issue. The tendency to speak about clinical practice using a particular form of jargon may be ascribed to the medical field being relatively difficult to access for non-medical outsiders. However, over the course of the last decade, an increasing number of empirical studies have been undertaken in the field of bioethics, and a vital contribution thereof is to correct misapprehensions about the medical profession and the field of medicine.

2.2.2. Preface to the second study

One of our discoveries from the data that had already been collected was the suggestion that doctors were chiefly driven by a responsibility to improve their patients' health. This strong moral motivation behind their clinical work was surprising, and it also seemed to override other moral values, such as justice or patient autonomy. Nevertheless, in medical ethics, beneficence is not appraised as being the most important value. In "Principles of Biomedical Ethics" (Beauchamp & Childress, 2009), beneficence is one of the four prima facie principles, although in practice it is often assigned a lesser status because the greatest weight is usually attached to the principle of respect for autonomy. Indeed, this latter principle often seems to trump other values in bioethical discourse, referring to human rights or the rationale of informed consent. Beneficence, on the other hand, is sometimes portrayed as being morally ambiguous, thus emphasising the short step from it to paternalism, a concept which has clearly negative connotations (Gillon, 2003). So, how can the value of beneficence be such a vital part of medical practice when its importance is not reflected in the medical ethics discourse and the principle is even, to some extent, discredited in line with paternalism?

In medical ethics, the discussion is often polarised between the value of autonomy and the value of beneficence. While the doctor may know what treatment will probably benefit his patient the most, it is up to the autonomous patient to decide whether or not to comply with it. In line with the development of the rest of society and the influence of human rights, respecting the autonomy of the patient has become morally important. However, in medical ethics' discourse, the notion of patient autonomy has been given a more specific meaning, namely that of autonomous choice (Beauchamp & Childress, 2009, p. 100). Accentuating the importance of this has led medical ethics discourse to formulate distinct moral problems, such as how to attend to the autonomy of non-autonomous individuals through living wills, proxy decision-makers and substituted judgements (Maclean,

2006; Sulmasy & Snyder, 2010). It has also created an ideal of "shared decision-making", where doctors and patients discuss treatment on equal terms, sometimes reducing the former to a medical counsellor who informs the latter about his or her condition and leaves it up to the individual to decide the approach to be taken (Falkum & Førde, 2001; Sandman & Munthe, 2010). However, there has also been widespread criticism of the notion of respecting a patient's right to autonomous choice. This criticism has particularly addressed the American cultural interpretation of autonomy and patients' lack of capacity and knowledge to make truly autonomous decisions (Holm, 1995; Pellegrino, 2006). Yet, in the light of our empirical data, we struggled with an even more basic issue: what is an autonomous choice in clinical practice? What does this concept mean? We had previously found it difficult to identify doctors' moral choices, and it was now equally challenging to define patients' autonomous choices. Again, it seemed as if the language of medical ethics had created an image of clinical work that was, perhaps, as obtuse as it was revealing. Indeed, when we observed doctors' clinical work, there were very few situations that could be labelled as "respecting a patient's autonomous choice", even when the patient was more or less directing the course of action. Overall, the very notion of "choice" is not easily interpreted in clinical practice. This is because the decisions to be made are often complex (what examinations to undertake, what treatments to commence), and the actions of both patient and doctor, as well as other health care personnel, are deeply intertwined in a way that can obscure who really decided what. The medical ethics literature is strong on the issue of respecting patients' autonomous

choice, but if it was so simple and so obviously a matter of morals, why would doctors defy it? These questions led us to the second manuscript, in which we wanted to shed light on the concept of choice in a health care setting by drawing upon our empirical data.

2.2.3. Summary of the second manuscript

Our intention with this manuscript was to use the empirical data collected for the first study as a basis for the closer investigation of the concept of autonomous choice as it is described in the medical ethics literature. It is an empirical investigation in the sense that observation and interview data constitute the main sources of reflection. Despite this, it is not traditional empirical research because we did not collect any new data. Instead, using data from the first study along with our own practical knowledge of the field, this study is a systematic, theoretical reflection upon concrete medical practice as it is exercised in everyday life. In the course of our empirical examination of how moral values are tacitly handled in medical practice, we found it to be important to illustrate a key lacuna between medical practice and bioethical discourse. Accordingly, in the second study, we aimed to demonstrate how the bioethical focus on autonomous choice misrepresents the moral aspects at play in this setting.

The first problem with the notion of autonomous choice is in identifying what really constitutes a choice. Although patients are predominantly free to refuse medical interventions, the cases where a patient gets to choose openly between two or more clear options are, in fact, rare. Indeed, health care is difficult to describe in terms of the separate elements of a decision; it is a much more dynamic process which develops over time. What we normally think of as a single action often actually consists of a series of actions, like taking an X-ray, operating, or following up on high blood pressure. Furthermore, it is often inaccurate to speak of a single person or a single intention behind a course of action, since providing health care for one particular patient generally involves many different people who act in accordance with each other and lay the premises for the actions of others. Accordingly, to investigate or treat a patient is a collaborative act wherein many people are involved in the planning.

On the other hand, if we look at cases in which patients really are given a clear choice between two options, it is still rather misleading to portray this as the signpost of respecting patient autonomy. This is because we do not have knowledge of all of the decisions that the doctors have made in order to present these options to the patient. Since health care is a continuous process involving many people over time, any attempt to break it down into aspects of decisions is bound to be somewhat arbitrary or artificial. The mere presence of a choice does not ensure the empowerment of patients.

Another factor that reduces the availability and perhaps even the desirability of choice in health care is the very purpose of medical practice, which is aimed at improving patient health. Accordingly, within the health care system, patients are not free to choose a course of action that is unlikely to improve their health, whether mentally or physically. Indeed, if a procedure is either clearly beneficial or harmful to a patient, it cannot be put forward as a matter of choice. This means that only the procedures that have a limited or uncertain effect are on offer.

In addition, it is important to bear in mind that clinical decisions do not occur in a vacuum. Although the form of organisation may vary between countries, professional medical treatment occurs within the organisation of a health care system, which entails many practical factors and limitations that also affect medical decisions. These factors are not only financial considerations, but also available staff, access to equipment, administrative policy, infrastructure, distance to specialists and so on, all of which can have a profound impact on the choices that are open to both patients and doctors.

Our point is not to demonstrate that patient choice is a superfluous concept in health care or patient autonomy is not important. Instead, we want to shed light on the concept of autonomous choice that has gained so much attention in the medical ethics discourse yet is somehow poorly grounded in medical practice. While it seems easy to argue in favour of the importance of autonomous choice in principle, it is difficult to understand the moral implications in practice. The concept, originally taken from medical research and its requirement for informed consent, does not properly fit with clinical reality. This leads to a misrepresentation of health care practice, which makes

it easy to misjudge the moral aspects that are actually involved therein. "The illusion of choice" is an expression meant to illustrate how the very concept tricks us into thinking in a misleading way about practice. The problem is not only that the concept of autonomous choice is overrated as a moral concept in health care practice, but that it also masks what is really at stake in caring for patients.

As with our first manuscript, our intention with the second manuscript was to bring normal medical practice into the light by analysing what clinical behaviour and activities could mean in a moral language, thus reflecting another part of my original question: how do doctors handle the tacit moral dimensions of clinical practice? In doing this, we hoped to uncover ways in which our language and theories obstruct rather than enable reflection. How we classify our perception of the world and our actions within it not only reflects how things really are, but also constitutes a specific way of looking at the world and guiding what we do in it. Words are not only words; they provide us with certain ways of thinking about a subject.

If our classifications or descriptions of the world are inaccurate or imprecise, they can cause difficulties and obscurity rather than enlightenment. This is why we have scrutinised the gap between medical ethics and medical practice. If ethical awareness is to be more than acting according to a set of predefined rules or moral demands, an important undertaking is discerning the essential moral elements of practice. What is morally important and what is not? In order to answer this, we have to dissect the very meaning of the phenomena. To respect a patient's autonomous choice in health care is sometimes morally important, but sometimes it is not, and it is perhaps even often immoral. Theoretical ethics applied incautiously in the field of medicine may create discussions that are conceptually detailed and argumentatively sound, but at the same time miss the point completely.

2.3. Study III

2.3.1. Professional responsibility

Working with the issue of respecting patient choice initiated reflection on the other moral demands that are commonly upheld in bioethical discourse. A growing humanistic movement in medicine apparently stipulates that doctors engage their patients more holistically, rather than just taking care of detached body parts, with empathy and understanding being upheld as vital ideals (Epstein, 1999; Sucman et

al., 1997). Yet, the results from our first study, which revealed how doctors systematically neglect patients' existential issues, were so far from the empathy ideal that we began to wonder what was going wrong. Indeed, in light of what we had learned in our research, it was unclear whether doctors could possibly care for patients as human beings given the confines of their professional role. By human beings, we here refer to the individual humaneness of patients in an existential manner, encompassing their intrinsic human value, as opposed to treating patients as objects.

When analysing the duties and responsibilities of doctors, one cannot only regard them as any other random individual, because their specific role as professionals also has to be considered. Patients go to the doctor because they need help with physical or mental suffering, and this is what constitutes the fundamental basis for the patient-doctor relationship. Doctors are taught to help patients on the basis of scientific knowledge of the construction and function of the human body, and are supposed to use this to help to restore their patients' health.

The theory we developed in the first study indicated that doctors have to essentialise a situation in order to use their medical knowledge and act as doctors. Indeed, according to our analysis of the data, the doctors did not consider their patients' more existential values in their reasoning, and so these had no consequences for how the medics dealt with the circumstances in front of them. Yet, it is also possible to believe that doctors care for the whole patient in addition to essentialising the situation. Perhaps they care for the patient as a person at the same time as they conduct their clinical analysis? Or perhaps they restore the patient as an individual after the essentialising process and the medical decisions have been made?

However, my experiences from the fieldwork suggest that many doctors believe that they do care for their patients existentially, even though our studies show that they do not. Most of the communication in clinical encounters appears to be clinically targeted, and the ways in which doctors approach patients seem to be guided by the information they would like to obtain from them or their ability to influence patient compliance. There were many cases in which doctors expressed the view that their empathic (or sometimes threatening) modus operandi was a conscious way of getting

the necessary examinations done. Moreover, good communication and a holistic approach were frequently described as being important because of their positive effect on patient health.

2.3.2. Non-instrumental values

When communication and empathy are utilised by doctors to ensure a favourable clinical outcome and, consequently, function as means to improve patient health, they lose their own, independent moral values. Empathy in these circumstances would not then be an expression of a human relationship, but an aspect of the clinical rationality that focuses on improving patients' mental and physical functions. It is worth noting, however, that such an instrumental use of empathy or techniques of clinical communication are by no means immoral just because they are instrumental. On the contrary, it is important to bear in mind that we found the doctors to be primarily motivated by a moral aim to help their patients. Some doctors manage to individualise their patient communication and sensibly explore how their patients' social context relate to their illness. Such sensitivity might generate more detailed information about medical issues, suggesting possible solutions, mapping out patients' resources and improving patient satisfaction and compliance. In her doctoral thesis about female patients' encounters with general practitioners, Malterud established a clinical method including what she called "key questions", which were meant to influence the patient-doctor interaction in such a manner that the position of the female patient was strengthened (1990). Her stated reasons for doing so were not primarily to strengthen patients' autonomy, but to improve the doctors' capability to get hold of these patients' medical concerns and opinions. Malterud compares the method to a tool in a medical toolbox that can be used strategically on specific indications (Ibid., p. 192). Indeed, the method she here proposes is a very refined clinical tool that probably enhances communication and patient cooperation, but it is still a method with a clear medical aim: benefiting patients' health.

For our moral enquiry then, the remaining questions are: are there any non-instrumental aspects of the patient-doctor relationship, and, if so, what are they? Can doctors essentialise a situation and, at the same time, care for other non-instrumental values or the more existential aspects of the patient?

Certainly, doctors do relate to patients as human beings, not as inanimate objects. Most greet the patients, shake their hands and generally behave politely. Sometimes they also chat about the weather and other issues unrelated to the clinical problem. It is, however, worth noting that this form of conversation is often used by doctors as a way of evaluating their patients' general condition, in which case it is actually a part of clinical reasoning. Patients rarely enter a consultation as a mere object (although it does happen!); they are objectified when doctors go about determining the clinical problem. At other times, it is difficult to discern that the doctor has any human relationship with the patient at all. This is especially true when the patient is not present, such as during ward sitting rounds or when doctors confer with each other. Indeed, if existential values play any part in doctors' clinical reasoning, you would expect to find them in evidence when they discuss their patients with others, but in our study, we did not. When doctors talk about non-medical aspects of a patient, these comments are left out of the clinical discussion.

2.3.3. Professional empathy?

Professional medicine appears to be linked to the process of essentialising, in which patients' existential values have no independent significance. The concept of essentialising includes communication and empathetic approaches to patients when they are intended to improve the clinical utility of the encounter; indeed, individualising medical care is seen as an important asset of a good doctor. However, existential values are left out of the clinical question. Moreover, attending to a patient as a fellow human being seems to vary a great deal between doctors, and is perhaps more related to each medic's set of personal moral values. Perhaps, when doctors meet and acknowledge their patients as fellow human beings, they do not act primarily as professionals, but by virtue of being human. If so, the two systems of personal and professional values may collide. The personal set of values that leads doctors to treat others, including patients, as human beings, may vary between different people. In addition, doctors have another responsibility imposed upon them by their profession, namely the duty to benefit patients' health. The relationship with a patient is based on a doctor's professional role, and it seems that this professional element takes precedence when the two systems of values clash. Consequently, doctors' moral practices will always remain in a delicate balance between human and professional considerations. The more doctors attend to patients' personal values, the

further they move away from their professional role. Indeed, in order to be able to handle a situation medically, doctors need to let professional considerations overshadow the immediate human aspects of the circumstances they are dealing with. According to this, it is vital to differentiate between empathy as a part of clinical reasoning and empathy as an independent recognition of the patient's existential value. This is because, as an independent value, empathy is actually in opposition to essentialising and clinical reasoning. This issue is of central importance, because it indicates to what extent and in what ways it is possible to teach doctors and medical students to be more empathic as professionals. It is also vital when it comes to evaluating the extent to which we actually want doctors to care for patients existentially, because if they do it might be at the expense of professional conduct.

2.3.4. Planning the third study

In our third study, we wanted to focus on doctors' care for their patients. Do doctors care in any way other than medically? Do doctors care for patients as fellow human beings? We originally planned to conduct another round of data gathering with observations and interviews in line with the first study. However, before we started the fieldwork, we received an offer to make use of a large amount of video-recorded patient consultations which had already been collected for another study on patient communication.

Following the RCT "Better clinical communication in hospitals" research, which was financed as a PhD project by the South-Eastern Norway Regional Health Authority, Bård Fossli Jensen and Pål Gulbrandsen collected 500 videotapes from encounters between 71 doctors and their patients in Akershus University Hospital in the period April 2007-June 2008 (Fossli et al., 2010). The study group was randomly drawn from the population of doctors working in clinical non-psychiatric departments as of February 2007, and very few declined to participate. The material represents a convenience-based sample of outpatient consultations, encounters at admittance and discharge, bedside encounters on rounds, and times when doctors were performing diagnostic procedures (EKG, EMG, echocardiography etc). The data were collected as part of an intervention study wherein doctors were given a 20-hour course in clinical communication. Informed consent was provided by the patients involved, who were able to choose between imposing a limitation on the intervention study and

agreeing to "studies on dialogues between doctors and patients" up to 2020. Very few patients limited their consent. The intention of the study was to use the collected data in different research settings to describe and understand the processes that are ongoing in medical encounters in hospital, including ethical, sociological, medical, ethnic, quality and safety issues. The sample is probably the largest hospital-based, cross-specialty, representative material of its kind in the world.

It soon became clear that access to these data would complement our own material in a constructive way. One of the objections that we had faced after the first study was related to the method of data collection, since we had relied on observations and interviews carried out by a single individual, without employing any form of direct recording other than written notes. Some complained that this made the data highly subjective in that we could not be certain that others would have interpreted the circumstances in the same way and we were also unable to reproduce the findings, and using video-recorded encounters would indeed answer this criticism. This material would enable us to reproduce the findings, have different people watch and analyse the same encounters and, consequently, permit there to be a comparison of our interpretations of what was going on. It would also make it possible to review the consultations repeatedly if the dialogue was unclear or if anything particularly important or surprising happened.

2.3.5.   Selection of data

We decided to go through a random sample from all of the video consultations that lasted less than 20 minutes. The reason for this was that many of the encounters that lasted longer than 20 minutes contained long periods of examination that were not visible on the tape. This was because the video recorder was placed in one location in the examination room, usually before the patient entered, with the intended focus being on the communication between doctor and patient. Accordingly, if the patients were examined on an examination table, they often moved out of the frame of the video recorder and were not visible on screen. This was done partly for practical purposes and partly as a way of protecting patient privacy as much as possible in the setting. Another problem with the longer recordings was the poor sound quality during the examinations that took place out of sight of the video equipment. Since most of the taped consultations lasted less than 20 minutes we decided to eliminate

the longest encounters to avoid spending a lot of time on those that were difficult to study. We were aware that this choice might introduce a selection bias, because it is possible that patients were better cared for in the consultations that took the longest time. However, we have reason to believe that this did not in fact have any major impact on our analysis. Firstly, as already explained, the extra time was often spent on examinations rather than on communicating with patients. Secondly, we observed that even when the doctors had plenty of time (and explicitly stated this to be the case) they did not use this on the patients' personal issues. Finally, since we had already conducted an observation study in which consultations of all lengths were included, we did also have experience with longer encounters and the impact of time on patient care. What we did, however, notice was a difference in the very shortest consultations, where there were generally poorer levels of communication and the patients were more objectified. We also restricted ourselves to the encounters that were taped before the participating doctors had undertaken the course in clinical communication, since this intervention might have affected how they cared for their patients.

We applied for and were granted ethical approval for the study on the basis of the patients' broad consent. The recordings were stored as an enciphered file in an external database at the Akershus University Hospital Research Centre and we had to be physically present there to watch them.

2.3.6. Method

Since we planned to elaborate on the findings from the first study, and because we had had positive experiences with the method we used therein, we wanted to use Grounded Theory on this new material. Moreover, changing the mode of data collection would not pose any difficulties to the Grounded Theory approach, since one of its main doctrines is "all is data". What might, however, have been problematic was the fact that we were now approaching the field with a more concrete research question relating to how doctors cared for their patients, instead of having an open approach as the method explicitly requires. Yet, this new work was really an extension of the initial study and an attempt to develop and tease out the nuances of concepts that were already established. Accordingly, we decided that it was legitimate to proceed with the Grounded Theory approach. Moreover, the new

research question was not a preconceived, theoretical query, but had emerged after thorough work with data from the field. Although renowned philosophers have written about caring and empathy in medical ethics, we did not use these theories to explore the material, but instead we made an effort to stay grounded in the empirical data and open to new possibilities and unexpected answers to our questions.

We conducted the study in much the same way as we had with the first. I travelled to Akershus University Hospital Research Centre and looked through the taped consultations while taking notes. I watched most consultations only once, trying not to get caught up in the possibility of reproducing every incident, but to remain focused on the core question: what is happening in this setting? More specifically, I had listed some elements that might get us closer to providing an answer to our research question:

- Do the doctors care for or touch upon existential values in their conversations with their patients? Are the patients' personal experiences and values taken into account?
- Are existential values given any value beyond their medical significance, for instance as symptoms of depression?
- Do the patients' personal values affect his or her treatment, especially in consultations with those who are chronically ill, seriously ill or dying?
- How do the doctors display signs that they are treating the patients as individual human beings?
- To what extent are the patients treated only as objects? How does this transformation from person to medical object take place?
- After objectifying a patient, thus in a sense ruining the human relationship, do the doctors do anything to restore this relationship with the patient?
- How do the patients react to being objectified, especially in vulnerable situations?

The plan was to watch a large number of consultations instead of discussing only a few of them in detail. Initially, I watched each encounter once, repeating parts only if the setting was unclear. I took notes of situations which were particularly interesting, illustrative or incomprehensible in light of the research questions, and I also noted

seemingly deviating events or incidents that suggested a novel explanation. I likewise recorded the specific points in the consultations where existential dimensions or caring for patients as human beings were apparent.

Even though we intended to collect data in much the same way as for the first study, the setting was now quite different; I did not have to sit in the corner of a doctor's office, trying to be invisible and not disturb the consultation in any way. Instead, I sat in an ordinary office, drinking coffee, taking notes openly, reacting to extraordinary events and stopping the tape whenever I needed to. This had both a positive and a negative influence on the data collection. The advantages are obvious: I could relax, take breaks and write openly. I could also rewind and watch interesting parts over and over again, and could even get the precise wording correct and return later to re-watch a consultation after having reflected upon it. I could not, however, see beyond the frame of the video recorder, which meant that I could not see the entire room and I could not follow the action when the patient or doctor moved, for instance, to the examination table. The doctors' work between encounters was also missing, and so I was unable to put the consultations in their proper context. Each scenario began with a doctor meeting a patient in a set location, and this setting had the capacity to accentuate the feeling of repetition and routine work. Watching consultations on a screen also meant that I felt more distanced from the encounters. This may have contributed to a more objective analysis, but it also meant missing out on the atmosphere and feelings that these meetings evoked in me personally, which is also a source of data to be analysed.

I arranged three visits to the research centre, watching 30-40 video encounters each time. In between visits I worked with my field notes, analysing them in relation to the first study and in line with the Grounded Theory approach. In this way, I was able to switch between data collection and theoretical analysis in a favourable manner, although we did not use theoretical sampling in this study due to the fixed nature of the material. After I had sat through 101 video encounters, I felt that the emerging theory was quite saturated, and new consultations were not suggesting any novel, significant aspects. After my initial examination of the tapes, I paid four more visits to the research centre to review certain consultations and write down precise passages of conversation for illustration purposes. Two of the other authors of this work, Pål

Gulbrandsen and Reidun Førde, watched a sample of the data independently, and the former also watched some of the tapes with me while we discussed our analysis of the encounters. The emerging theory was developed with my supervisor, Åge Wifstad. During the analysis, I singled out specific consultations that were good illustrations of the emerging concepts of the developing theory. All of the four authors of this work watched these consultations together and discussed their interpretation. Despite differences in background and clinical experience, we were united in our analysis, a sign of high inter-rater agreement.

2.3.7. Summary of the third manuscript

Our empirical exploration of the tacit values of medical practice had caused us to describe the process of essentialising, during which the personal and human dimensions of patient suffering were systematically overlooked. In order to scrutinise this rather controversial finding, our aim in the third study was to focus on the tacit dimensions of how doctors care for their patients by analysing how this care was reflected in their actual medical practice.

It was also obvious in this study that the doctors were primarily concerned with improving their patients' health. This is perhaps not very surprising, since this is a key and formal responsibility of the medical profession, but the extent to which this medical focus formed the consultation was still remarkable. Most doctors were very dominant in the consultations, despite an often friendly tone. With their presentation style, attitude, gestures, wording and forthright instructions, the doctors directed the consultations firmly. They often indicated when the patients could sit, when they could talk and on what subject, when they should be quiet and when they should leave. Even if the doctors started out with an open question, they would quickly answer or dismiss their patients' questions and continue with what they regarded as the medical issue. Again, it was not the patients' problems that seemed to be in focus of the consultations, but the doctors' problem, i.e. the medical problem, as initiated by the patients.

Once more, we observed that the patients' more existential needs or feelings were generally neglected. Patients often tried to raise their concerns or reflect upon how their illness was related to their personal life, but these attempts were usually brushed

aside with a smile or a shrug or were simply ignored. The doctors in this study also seemed to be primarily interested in their patients as medical objects. However, in the third study, we noticed how the doctors made small talk during these encounters, which seemed to reveal another aspect of the patient-doctor relationship. We found that conversing lightly, acting politely and maintaining a friendly tone were prominent features of the doctors' behaviour. These are general signs of respect for another individual, and so the doctors could indeed be said to be attending to the humaneness of their patients. Accordingly, in this study, how the doctors maintained a relationship with their patients by acting courteously became clearer. This courteousness, while not reflecting any deeper concern for the life of the particular patient, displayed a general respect for the patient as a fellow human being. Patients were not treated <u>only</u> as medical objects or mechanical bodies; the doctors' social interactions affirmed their human relationship with their patients. Yet, at the same time, and as noted above, the doctors neglected their patients' more private sides. So, despite smiling, chatting and maintaining a good tone, they ignored patients' expressed personal concerns and did not go into any existential dimension or meaning of their illnesses. This duality in the doctors' approach was quite evident once we had discerned it. It would thus both be wrong to claim that doctors care for patients as human beings and that they do not; to clarify the issue, we need to be more specific about what we mean by "care for" and "as human beings".

Maintaining some sort of superficial human relationship with a client is a familiar issue within many different professions. Yet clinical medicine differs in vital respects from other professional-client relationships, since it is the patient himself, or more specifically the patient's body, that is the problem. The patient thus has to present himself for scrutiny by the doctor in order to get help. Moreover, because attending to the patient's body as a medical object is likely to be an unavoidable part of the clinical encounter, it is perhaps of even greater importance that the doctor also emphasises the human connections with the patient. In these circumstances, doctors' courteousness might restore the relationship with their patients, which is constantly under pressure because of the objectivation that goes on. On the other hand, it is also possible that the ways in which doctors both chat in a friendly manner to patients, at the same time as inspecting their bodily functions, confuses patients because of the mixed signals that are given out. Doctors' courteousness may in some cases mask

their purposeful interventions and the essentialising process. When doctors appear to be friendly, fellow human beings, it might be perceived as even more surprising and offensive when they do not want to hear about patients' personal suffering.

In our data we observed how doctors spoke in a friendly and medically correct manner to patients who were dying of cancer without ever addressing the fears that were expressed. We also saw patients who spoke of the relationship between their illness and their deceased spouses and were ignored by the doctors. We likewise observed doctors who were very friendly and forthcoming, but never got to the bottom of the patients' enquiries because the medics paid no attention to the related existential issues.

The doctors' care for their patients as individuals thus seems to have at least three dimensions. Firstly, there is the medical concern, which is constitutive of the patient-doctor relationship and based upon a humane and moral duty to relieve patients of their suffering and restore their health. Secondly, there is the demonstration of general courteousness, maintaining social contact with their patients and showing respect for their integrity as human beings. Thirdly, there is the existential care for patients as individuals which includes their feelings and private values. In our study, we found that all of the doctors displayed medical concern for their patients; almost all exhibited courteousness (although the amount varied); and hardly any displayed existential care. This demonstrates that the question of whether doctors care for patients as human beings is too complex for a yes or no answer. If we demand that doctors care more for their patients as individuals, we must specify in what way we want them to care. Likewise, when patients feel that they are not being cared for by the doctor, what aspect of caring is being referred to?

I suspect that many doctors often intuitively think that good communication is the same as caring for patients. Being polite, looking at patients while talking to them, and letting them formulate their own questions are indeed ways of showing respect for them as fellow human beings and is certainly positive. However, this does not nullify the existential neglect that is a part of the process of essentialising. By ignoring patients' expressed existential concerns, doctors disregard their humanity in a way that can be morally offensive even if it may be unavoidable. While most

patients probably allow for this, those with conditions that fundamentally affect their personal lives may be particularly vulnerable.

3. Main findings

In order to shed light on the gap between medical ethics' discourse and medical practice, our aim with this research was to explore the unspoken moral dimension of medical practice. We found the following:

In our first study, we found that doctors deal with patients in a distinct, systematic manner, despite individual differences between doctors. We established this as the process of essentialising, in which doctors transformed patients' expressed problems into discrete medical questions. This process involved breaking the patient's story down, concretising his or her complaints and categorising the symptoms according to a medical interpretation. Patients' existential meanings were removed, and the focus placed on their functioning.

In our second study, we illustrated how a distinct element of bioethical discourse, namely that of respecting autonomous choice, is based on a poor conception of medical practice. We highlighted that the image of a doctor and his or her patient in confidence confronting a medical challenge together is a misrepresentation of actual health care practice. Medical decisions are mainly made over a period of time, involve several different doctors and other professions, and the options that patients are given are rather arbitrarily constructed within the constraints of the organisation of the health care system.

In our third study, we further explored doctors' concern for their patients. We found that while patients' existential meanings were overlooked and the doctors' main focus was on their medical function, the medics did demonstrate considerable courteousness. In order to identify how doctors care for patients, our study highlighted the importance of discerning between courteousness and existential care. Furthermore, doctors' friendly and jovial attitudes may mask the moral offence of disregarding patients' existential concerns.

Taken together, I believe that these three studies have revealed some aspects of the tacit moral dimension in medical practice. In particular, we have managed to expose some of the premises of doctors' work and how this affects the values involved. The process of essentialising shows how patients' existential concerns are systematically neglected in order to deal with them medically, which might be morally offensive. Doctors' explicit courteousness may alleviate, but also masks, this recurring repudiation for both them and their patients. We have also shown how the specific social and practical contexts of clinical practice constitute a tacit dimension that restricts and shapes clinical work, and that is fundamental to assess the moral values that are involved in this work.

4. Discussion

In this section, I will try to place our research in its proper context. In other words, I will present other fields of research that touch upon concepts and theories that are similar or relevant to ours. Although a large amount of work has been conducted on medical ethics, much of this literature is not pertinent to our discussion of the values imbedded in medical care. Instead, I have attempted to contextualise the theoretical concepts that have emerged from our studies.

4.1. An internal morality of medicine?

The concept of essentialising suggests that doctors deal with the moral values present in medical practice in a more or less automatic manner, and as an integrated part of medical reasoning. In the observed clinical encounters, the doctors hardly ever seemed to express their own personal values. Although the level of communication with the patients did indeed vary somewhat, what concerned the doctors' *medical work* was largely guided by a common morality, a form of inner logic within the medical field. This moral conduct is not schematised or expressed by the doctors, but closely integrated in their medical decisions. In disregarding their patients' personal interpretations, the doctors maintained a strict focus on anatomy and physiological function, creating a question with a medical answer in order to improve patient health. It should not, of course, be surprising that doctors are focused on improving the health of their patients. However, the strength of this moral duty was still unexpected, and it directed the entire medical consultation. Indeed, the doctors often

seemed to let this moral duty overrule other relevant moral values without any form of reflection. This is actually in stark contrast to how the field of medical ethics is usually portrayed, in which different moral principles, such as autonomy, beneficence, non-maleficence and justice, in the four principles approach, are weighed against each other.

4.1.1. Medical ethics' discourse

Whether or not there is a specific morality that is internal to medicine has long been the subject of theoretical discussion in medical ethics. Theorists have tried to specify what the proper aims and benefits of medical practice could be, discerning between internal and external goods. In 1975, Kass conducted an analysis of "the end of medicine" (1975), which was based upon Aristotelian ethics. Yet MacIntyre (1981) is thought to have started much of this discussion by claiming that some advanced forms of practice have aims and goods that are constitutive or internal to the practice thereof, and he also noted that medicine could be an example of such a practice. MacIntyre's notion of internal morality also partially builds on an Aristotelian conception of ends, but he sees these as being constituted by society. The medical profession is a distinct activity that is constructed by society, and this construction incorporates internal moral standards that are not established by each member of the profession.

Pellegrino is one of the most prominent advocates of the claim that medicine has an internal morality, and he too draws heavily on Aristotle's teleological ethics. He rejects the idea of the internal morality of medicine as a social construct, and claims that the ends of medicine are ontologically internal (Pellegrino, 1988). He also defines the goal of clinical medicine as the healing of the patient, which is a moral aim he regards as being essential to the very idea of medicine. Pellegrino sees the clinical encounter as the fundamental phenomenon that defines the morality of medicine, and he argues that "Medicine exists because being ill and being healed are universal human experiences" (Pellegrino, 2001). These universal experiences are the reasons why the medical profession and clinical medicine exist at all. Understood in this sense, internal morality does not rely on some external authority, like doctors' personal convictions, societal demands or a professional code of ethics; it is instead inherent in the concept of clinical medicine. For Pellegrino, the healing of the patient

is taken in its broadest sense. What is medically good for the patient is only one aspect of healing and, thus, only one aspect of the aim of medicine. Healing also involves the patient's own perception of what is good, the good that is specific to human nature in general, and the spiritual good. The internal morality of medicine encompasses all of these dimensions, according to Pellegrino, including what are regarded as common bioethical principles, such as beneficence and autonomy. However, for Pellegrino, these principles are eternal and grounded in the logic of nature, not in common morality or a social construction.

In contrast to Pellegrino, a non-essentialist notion of the internal morality of medicine suggests that medical morality is not static, but evolves in correlation with society (Brody & Miller, 1998). The aim of medical ethics is thus to integrate the internal morality of medicine with the rest of the external morality of society. The internal norms are those that are seen as being appropriate to medicine, like relieving suffering or the promotion of health. Precisely what these norms are can be the subject of debate, but they continue to be specific to the medical profession. The existence of internal norms conforms to the tradition of professional practice and the ongoing need to regulate doctors' behaviour. External morality, meanwhile, constitutes the norms of the society in which the practice of medicine is embedded. Moreover, the development of society and the external norms exert pressure on the internal morality of medicine, which develops in congruence with the traditional values thereof.

4.1.2.   Internal morality in our research

The findings from our research make a relevant empirical contribution to the discussion of medicine's internal morality. Moreover, our concept seems promising as a way of better understanding our observations of doctors' value-laden decisions in patient-encounters. If a basic morality is incorporated in medical knowledge and clinical practice, it might explain why doctors do not speak explicitly of moral values. Proper moral conduct is thus embedded in the medical profession and learned simultaneously while performing clinical medicine. This might also explain certain doctors' resistance to modern bioethics; because it does not take internal morality as a basis for clinical decisions into account, it is perceived to be of little relevance. The existence of an internal morality that does not stem from each individual doctor, but

belongs to the specific field of clinical medicine, might explain the similar moral behaviour in the patient encounters of the doctors studied herein. Our results suggest that doctors, in their work, act more on behalf of their profession and less as independent moral actors.

The idea of values that are internal to medical practice is appealing. It seems almost to be a linguistic definition, and the meaning of the very concept of clinical medicine, that its purpose is to help patients. In contrast to, for instance, medical science, clinical medicine is not about the acquisition of knowledge, but a means of helping patients. In view of this, morality can be labelled as being internal to medical practice because it is a part of its definition. Furthermore, since medical knowledge is directed at bodily functions, both physical and mental, and not at patients' existential needs or spiritual suffering, this too forms what could constitute the aim of medicine. The knowledge base of all Western medicine is founded on natural science, in which the body is interpreted according to its functions. An internal morality of Western medicine must, accordingly, relate to improving bodily functions.

Indeed, we have then distanced ourselves from Pellegrino's conception of an inner morality. While the concept seems to be illuminating, defining inner morality as an absolute and unchanging entity actually appears to be an attempt to stem the social constructionists, rather than it being a probable and useful account. Moreover, by including natural human and spiritual goods, the concept seems to encompass the entire domain of ethics, and transpires to be of little use when it comes to explaining the phenomena that are specific to clinical medicine. Although the non-essentialist view of internal and external norms might be closer to the notion of internal values that are consistent with our theory of essentialising, it actually turns out to not be particularly useful either. According to this view, external values, such as autonomy, can be adopted as internal values if doctors come to understand them as such. Yet this makes it difficult to understand how internal norms are legitimised. It would follow that any conflict between internal and external values would not survive, because they develop in accordance with each other. Yet in these circumstances it would hardly be necessary to separate internal and external values. Many philosophers do indeed reject the notion of an inner morality of medicine on these grounds (Veatch, 2001; Beauchamp, 2001). Medicine is just one part of society, and the norms of

society must also apply to it. As Veatch points out, the values of medicine are not independent of the general values of society, because medical values have their content and meaning in relation to a specific society and moral conception. Furthermore, the goods of medical practice are so closely related to the goods of our entire being that we cannot possibly separate them or define the aims of medicine without knowing the purpose of our very existence.

4.1.3. Internal morality and social construction

Medicine is certainly situated in society and must derive its meaning and aims from it. It is, however, appropriate to emphasise the special conditions of the medical profession. Our organisation of medical care implies that the professionals are given specific resources and specific duties. This means that doctors are permitted to behave differently towards patients in that they are allowed to ask intimate questions and undertake invasive procedures. The medical profession is thus organised as an exemption within society, and, as our studies have suggested, this also affects the morality involved. The medical profession is based upon a moral understanding that assesses human beings as intrinsically valuable and in which helping people is considered to be morally important. The practice of medicine has developed within this moral understanding as a means of alleviating human suffering, but still has a more specific aim within this structure. Medical science does not engage with all kinds of suffering, but with the elements thereof that originate in the human body and its functions. The field of medicine can thus be understood as a kind of institution within which to engage in the suffering that befalls human beings as bodily entities. In line with this, it would be reasonable to assert that the aim of clinical medicine is benefiting patients' health. Health is not to be taken as an absolute good, but as a goal within medical operating conditions. Consequently, there may be some other good that is more valuable overall. Other values that stem from outside the medical field, and from other parts of our culture, might limit these medical values. Indeed, respecting patient autonomy may be such an external value, and as a society we may want this value to curb the medical aim of improving patient health. Yet, there is a conceptual difference between regarding respect for patient autonomy as something internal and in congruence with medical aims, or considering it to be a medical constraint. Perhaps the latter interpretation is closer to doctors' own perceptions of

their medical duties, and it is tempting to interpret our empirical data along these lines.

The philosophical basis for an internal morality of medicine has yet to be established, but this is beyond the scope of this thesis. Nevertheless, our empirical findings seem to provide some support for the legitimacy of the concept.

4.2. Medical sociology

An important aspect of our findings was how doctors' behaviour and decisions did not seem to be individually fashioned, but the result of acting as professionals. Furthermore, their actions were restricted by professional and practical arrangements. Within the field of medical sociology important work has been done in describing factors affecting how doctors behave. Such factors are conditions for doctors' medical practice and the institutionalisation of medicine.

4.2.1. The social role of the doctor

Talcott Parsons' analysis of the medical profession is a central work (1951). He describes how the role of the medical profession is construed in order to overcome "obstacles to the effective practice of scientific medicine" (ibid., p.454). Among other things, Parsons demonstrates that doctors' medical competence is based on universal scientific knowledge, and he describes how the universalism of the medical role serves to protect doctors against personal relationships with their patients. This professional distance is, he asserts, necessary, both to protect doctors from the emotional pressure of entering into an affective relationship with the patient, but also in order to be able to penetrate patients' personal affairs by remaining as an objective outsider. Parsons describes this as "an 'Archimedean place to stand' outside the reciprocities of ordinary social intercourse" (ibid., p.461). He points out that the restriction of doctors' concern for their patients serves to regulate and justify their interventions. Doctors are allowed to behave in certain ways because they have a legitimate purpose for their actions in alleviating their patients' health problems, and their exceptions from normal behaviour are restricted to this purpose. Parsons is particularly occupied with the social role of the doctor, how this role deviates from other roles, and how this affects the relationship with the patient. His discussion supports many of our findings, particularly the description of how the conditions of

the medical profession guide doctors' actions and interactions with patients. Doctors have a purpose with their interventions which affects what they can legitimately do and what they can care about. We can regard this as a sociological explanation of our observations of the essentialising process, the functional focus and existential filtering.

The field of medical sociology is vast, and I will not attempt to provide any systematic introduction to the discipline, but it is of interest to our findings how medical sociologists and ethnographers approach the field of medicine in general. Most commonly by the use of observational methods, these sociological empirical studies aim to uncover structural elements in the behaviour of their participants. This has provided important insight into how medical students are socialised into becoming professionals (Becker, 1961; Hafferty, 1991) how students learn to manage uncertainty (Merton et al., 1957), and how doctors cope with medical errors (Bosk, 1979). Some sociological findings are strikingly similar to our results, with Renée Fox's concept of "detached concern" being one example (Lief & Fox, 1963). Lief and Fox describe the stages of a medical education in which students are actively trained to care for their patients in a detached and objectified manner in order to act professionally as doctors. The concept is very similar to our findings that doctors act courteously, but show very little existential care. Other recent examples are Orfali's ethnographic study that compares decision-making in neonatal intensive care units in France and US and Risør's anthropological analysis of the professional development of doctors (Orfali, 2004; Risør, 2010). Orfali found that despite social an legal differences in the two countries, doctors articulate ethical dilemmas in medical terms in order to maintain control. Risør establishes that "The interns learn to perform according to a basic scheme for decision-making [...]. A problem must be expressible in a clinical language where pathology and epidemiology are the ideal and which is in line with established truths about cause-and effect and logic." (Ibid., p. 237).

In general, medical sociology reveals, in very concrete ways, how the behaviour of doctors is formed within the profession to enable them to perform their professional tasks, thus raising our awareness of the collective dimensions of behaviour. In terms of ethics, the understanding that our conduct is not only the result of individual decisions, but also formed by strong social forces which restrict our options, is vital.

4.2.2. Sociology and ethics

Medical sociologists like Parsons are primarily concerned with the sociological aspect of the medical profession, and do not therefore pay attention to how these arrangements affect the ethics involved. Parsons describes how the circumstances relating to the medical profession make it possible for doctors to perform certain tasks. While these arrangements might appear to be a purely practical way of easing into clinical work, they do actually change the morality involved in the setting, for instance because they impose additional responsibilities on the doctors. In our study, focusing specifically on the moral dimension of clinical work ensured that we were able to say something about how the process of essentialising altered the doctors' moral assessments of situations. In medical ethics, however, the contribution of medical sociology has rarely been taken into account. Indeed, in the branches of bioethics that focus particularly on the patient-doctor relationship and patient communication, the circumstances are frequently compared to an ordinary meeting between individuals in which the need for empathy, personal involvement and mutual respect is emphasised (Janssen et al., 2008). Regarding the patient encounter in this manner often leads to a portrayal of doctors as reserved or even disinterested, and much of the literature on bioethics concludes with the claim that greater empathy and involvement on the part of the doctors is required (Larson & Yao, 2005). If we take Parsons' sociological description to heart, however, and pay more attention to the social function of the medical profession, we might have to reconsider these ethical claims.

Barry Hoffmaster is an ethnographer who has criticised medical ethics for ignoring the contributions of medical sociology (Hoffmaster, 2001). Medical ethics has been too concerned with normative issues and ethical arguments, he claims, and so has failed to see the normative consequences of descriptive studies. In the first edition of the influential textbook on medical ethics, Principles of Biomedical Ethics, the authors stated that descriptive ethics was only secondary to bioethics (Beauchamp & Childress, 1979, p.9). While this statement was omitted in subsequent editions, it illustrates the traditionally inferior position of descriptive studies in medical ethics. Hoffmaster emphasises that in medical practice, moral and medical decisions are so entangled that it does not make sense to separate them in order to study one or the

other. How bioethical problems are shaped, and how patients and illnesses are defined are philosophical questions that can only be answered within the proper context of medical practice. As a consequence, Hoffmaster sees descriptive research, such as ethnography and medical sociology studies, as important sources of ethical reflection (Hoffmaster, 1992). While it is remarkable that important insights from medical sociology have not been taken up in the discourse of medical ethics, the recent development of empirical ethics might hopefully be a sign that the contribution of descriptive studies on ethics is finally about to be recognised.

4.3. The empirical turn in bioethics

4.3.1. Medical practicalities

Bioethics has traditionally been quite theoretically loaded, drawing upon more general theories from philosophy and ethics. It is commonly described as a branch of applied ethics, which implies the use of general philosophical ethics in the practical field of medicine. Applying the general moral rule that you should not lie, would, in medicine, mean that doctors must tell the truth to their patients. With the development of new technologies and cumulative biomedical knowledge, medicine continued to produce new moral questions which had not really been answered or tested before. In this way, it provided the field of ethics with ever more dilemmas to resolve, as Toulmin pointed out in his much cited article "How medicine saved the life of ethics" (1982).

The field of medicine, in becoming ever more complex, has also made bioethical discourse more complicated, meaning that moral questions were often firmly embedded in the clinical setting. In addition, the juridical aspects of medical decisions have been constantly scrutinised, particularly in the United States, and the development of law and bioethics has gone hand in hand. This required more specialist knowledge in difficult medical areas, such as knowledge of medicine, law and bioethics, and has paved the way for a new group of experts: clinical ethicists. Clinical ethics is the branch of ethics that is occupied with the moral questions that are embedded in actual clinical practice: could we terminate nutrition support to this unconscious, vegetative patient? Should the parents be allowed to decide that their daughter should not undergo surgical intervention which could prolong her life? The term clinical ethics is now mainly used within the context of clinical ethics'

consultations. In other words, it is concerned with the provision of consultation services on ethics by the growing profession of ethics' consultants. Such consultation services involve not only moral issues, but also questions of group psychology, conflict resolution, power inequality and so forth.

Recently, another branch of bioethics has also emerged, due to the growing number of empirical studies undertaken in the field. As we described in the introduction, these studies cover matters like interviews with health care personnel, observations of medical departments, and questionnaires relating to the moral grounds for medical decisions. Recently, these endeavours have been gathered under the new term, empirical ethics, and there has been much discussion about what this entails and what purpose it actually serves (Molewijk et al, 2004; Musschenga, 2005). Many of the empirical studies in question are descriptive, recounting matters like the arguments of doctors or nurses or describing a particular medical practice. Traditionally, moral philosophy has had a rather constrained attitude towards descriptive research, referring to the fundamental gap between is and ought, which originates from David Hume (Hume, 1978). The thesis says that describing how the world is cannot tell us how we ought to behave. Even if 90% of all of the doctors in a study consider it to be morally right to not reveal the full truth about their prognosis to dying patients, in order to protect them from severe depression, they may still all be wrong. Our accepted moral practices, like slavery once was, can always turn out to be morally wrong. There is no logical way to infer what ought to be done from what is actually the case. The "ought" and "is" statements belong to two fundamentally different classes: normative and descriptive statements.

4.3.2. Empirical ethics

Why do we need empirical research into ethics then? We ought to distinguish here between (at least) two different types of research on ethics. A common way of empirically exploring the field of medical ethics is to study the moral attitudes of health care personnel. Even if you cannot infer what is morally right from what the participants in a study believe, their comments can inform medical ethics about the kinds of arguments that are prevailing and how health care personnel assess the moral values involved in different settings. This knowledge could enable the field of medical ethics to target its moral arguments in such a way that they have an impact

on how medical decisions are made. Exploring these attitudes is also often used to reveal cases of malpractice and to target areas in which the moral standards of health care personnel need to be improved.

Another way to conduct empirical ethics is to describe actual medical practice. This approach can inform medical ethics about the organisation and practice of health care by illustrating how and what kinds of situations arise. This is perhaps the most important contribution made by the discipline. If ought-statements from moral philosophy should have any implications for actual medical practice, then they must relate to what medical practice is really like. A crucial role of empirical ethics is to display the particularities of medical practice in order to understand what the practice implies in ethical terms. If most doctors believe that it is morally right to deceive a dying patient, the interesting question is <u>why</u> they think that this is morally defensible. We might discover that the answer is not moral negligence or a lack of moral sensitivity that needs to be corrected; there may be other, overriding moral considerations that we have not yet discerned. Indeed, the peculiarities of the situation may have moral implications that are not as easily detectable by outsiders, but are nevertheless sensed by the participants. When people behave immorally, seemingly for no good reason, or seem to be immune to moral correction, it might be appropriate to ask if there are aspects of the situation that we have not properly understood. This seems to be relevant to medicine, given doctors' fairly modest interest in bioethics.

In particular, empirical ethics has the potential to contribute to a fuller understanding of the premises of health care and the medical profession. All too often, bioethical discussions seem to be so stuck on the theoretical arguments that they remain blind to obvious practical circumstances that limit their relevance. This is not chiefly a problem of how to apply moral demands in medical practice; it is instead a question of how the practical arrangements of the medical profession form the ethical decisions that are involved therein. Many practical conditions limit the freedom of action of the participants. Some are obvious in health care, like resources and time, while others are perhaps more hidden, but they all curb the possibilities of moral choice. It might not be philosophically legitimate to infer what *ought* to be done from what *is* the case, but what ought to be done nevertheless rests upon what it is possible

to do. This normative aspect of empirical ethics has been addressed by several ethicists, exploring how empirical ethics bridges the gap between facts and values (de Wries & Gordijn, 2009; Kon, 2009).

4.4. The patients' lot

We did not specifically investigate the patients' perspective, and I have gone through the reasons why, as well as some of the drawbacks, in earlier sections. In this section I will discuss some of the aspects of the patient's position that we could, nonetheless, identify in our findings.

4.4.1. Medical depersonalisation

In our first study, we found that the doctors took special care to filter their patients' existential issues in order to address medical matters more specifically, and this was further supported and elaborated on in our third study. At the same time, the patients' complaints were made to be as concrete and measurable as possible. This way of addressing patients as objects requires some form of medical depersonalisation, which is an ability to look beyond the specific personhood of the individual. In many cases, being objectified is probably not an issue. When the patient sees the doctor with a well-defined concern, such as a broken finger or an ear infection, it is of little consequence that the medic treats your finger or ear as an object, and neither patient nor doctor would want it any other way. Yet maybe more often than we are normally aware of, this depersonalisation does affect patients.

As we have only observed patients' reactions and not interviewed them about their experiences, I have borrowed an illustrative example from the authors Gulbrandsen and Schei (2000):

The patient, Mona, is 35, a waitress and mother of a 5-year-old girl. After a difficult childbirth she developed a weakness in the rectal musculature. When the general practitioner asks about her consultation at the specialist, she starts to cry.
"The doctor examined me down there, and asked me how I was doing. But when I tried to answer him, when I started to tell how horrible it is to carry heavy trays at work, that I hardly can walk on trails where others are present, and that my sexual life is ruined, then he turned away and started to read my journal!"

Compared with our own empirical data, the example appears to be credible. We observed many similar situations in which the doctors turned away or changed the subject when the patients tried to express something which was personally important. Many patients seemed to react in a negative way to personal issues being ignored, and although we could not confirm these interpretations, watching the situations unfold, and by putting ourselves in the position of the patients, we could recognise the feeling of being rejected. To be reduced to a medical object can be an unpleasant and morally offensive experience, which threatens to aggravate a patient's distress instead of alleviating it. This has led to a demand for a more humane form of medicine, where doctors are not only body technicians, but also attend to the entirety of human nature.

But what does it mean to care for patients as complete human beings? It seems to imply that doctors should address patients' personal values as well as their medical issues, and should also be cognizant of their existential dimensions when treating them. Doctors could ask: "What does this suffering mean to you?" or "How does your illness affect you in your life?" Yet, what right do doctors have to ask questions that go beyond medical issues, and what would be the purpose? As doctors, the professionals have the opportunity to ask patients about private and intimate details, their sex life, abuse, or psychiatric symptoms, but only providing that they have medical reasons for doing so, and on the basis that medical remedies might exist. Doctors possess no special knowledge of life's existential dimension; they do not know better than anyone else what gives meaning to life. Moreover, by probing into patients' private matters, doctors distance themselves from their professional role and risk invading the privacy of their patients' lives. If the medical sphere does not limit doctors' concerns, just how far should these commitments extend? Should doctors not only concern themselves with the possible depression of their lonely patients, but also their loneliness? Should they attempt to find some friends for their patients? Should doctors make friends with their lonely patients? Somehow it seems that it would be impossible and even harmful to compel doctors to engage with their patients as people. The professional distance, as described by medical sociologists, is important, not only to avoid that doctors are exhausted with personal requests from

patients, but also to protect patients from having their lives invaded by well-intentioned doctors.

4.4.2. Unavoidable clinical harm

Our findings suggest that reducing patients to medical objects is unavoidable in the work of a doctor. In order to use their medical expertise, both theoretical and practical, they have to be able to approach patients as objects. How else could doctors, put bluntly, cut open the stomach of a pregnant woman during a Caesarean section? This ability to deal with patients as medical objects is meticulously learned during medical school and practice, and is also described in several renowned studies in medical sociology (Parsons, 1951; Becker, 1961). This reductionism is a central premise of modern medicine; a premise that most patients readily accept. A patient with an ear infection expects the doctor to focus his attention on his ear, not on the rest of him. Yet, the patient might feel uncomfortable if the doctor did not greet him, if he just stared at the computer when he spoke, or if he did not take the time to explain the treatment he was recommending. Even if the patient accepts the doctor's medical approach to his ear, it is crucial that the rest of him is treated as a person. In many ways, this corresponds to the distinction we discovered in the third study between existential care and courteousness. While doctors have to overlook existential matters when dealing with medical issues, they can still express human courtesy. As we have emphasised in the third study, this may actually disguise the ongoing objectivation of patients. It could also cause confusion if doctors believe that they are caring for patients as people while patients feel that they are existentially neglected. Yet, we do not mean to devalue doctors' courteousness. At its best courteous behaviour might alleviate patients' experiences of being objectified, even if it cannot prevent medical reduction of the patient. However, in order to achieve this, the real significance of this form of human interaction must be appreciated.

Respectful human interaction is always a positive thing to encounter. In normal social contact in the workplace, and during commercial interactions, we appreciate being treated in a friendly and respectful manner. When you take your car to the garage, you expect the mechanic to say hello, listen to your explanations and repair the car. However, if he fails to greet you, you are unlikely to be seriously, morally offended by this. Presenting yourself to the doctor is not, however, quite the same as taking

your car for inspection. In a medical consultation, the patient offers himself up for scrutiny, without the option to deliver his body to the doctor, leave and collect it later when it has been repaired. The patient not only has a body, he also is the body, referring to a phenomenological insight by Merleau-Ponty (2002). When the doctor goes to work and approaches the patient's body as an object, the patient is also treated as an object. This is why doctors' expressions of mutual respect have even greater significance in the doctor – patient relationship. Acts of recognising the human value of patients are a way of restoring this relationship, despite the fact that doctors systematically damage it.

4.4.3.   Moral residue

Realising how doctors' displays of respect can be vital to restoring a patient as a human being, and being aware that doctors' courteousness can play a more important role than ordinary, friendly social interaction, leads us to a moral concept that has traditionally been paid relatively little attention. In Principles of Biomedical Ethics, Beauchamp and Childress introduce the notion of moral residue, a concept that adds complexity to the principle-based theory, but is not elaborated on in the book (2009, p. 16). If you have to decide between two conflicting principles, the one that is overridden does not just disappear. Instead, you have to try to repair the moral damage caused by overriding this principle, thus minimising the negative effects thereof. If, for instance, you have made a promise to a family member and a friend that happens to clash in time, you will have to break one of the promises. You will, however, have an obligation to minimise the effects of the broken promise. You may try to reschedule in advance, provide compensation in some other way or at least excuse and explain your behaviour to the person you let down. Failure to deal with the consequences of your broken promise will add to your moral devaluation.

Some authors have used the concept of moral residue as an indication of the existence of real moral dilemmas. This is because even if we choose what we consider to be morally right in a difficult situation, we may still feel remorse and guilt as indicators that we also did something morally wrong (McConnell, 1996). Without taking a stand on the existence of moral dilemmas, the concept of moral residue still identifies a significant aspect of morality that is often omitted from bioethical discussions. When two moral principles or values conflict, and you have to override one of them in order

to fulfil the other, more important principle, it is still not right to override the value in question. It is simply more wrong to override the other. Doing the right thing still involves the commission of a wrongdoing, creating a moral residue in the form of a continuing moral duty to compensate the wrongdoing. This takes us away from thinking of morality in terms of punctuate choices. The moral content of a choice goes beyond the mere decision that is made. The morality of a distinct choice adheres to what you have done in the lead up to making the decision (was it preventable?), how you carry out the decision you have made and how you respond to the moral residue and new moral duties that are the result of the initial choice. We can relate this insight to the findings of our second study: describing morality in terms of the presence of a choice does not do justice to what morality is all about.

4.4.4.   Moral residues in clinical practice

The notion of moral residue is particularly interesting in light of our analysis of the existential filtering of clinical practice, and might point to possible resolutions to the conflicting duties of the doctor. Doctors have a moral duty to respect their patients as individuals, in the same way we all have a duty to respect the people we interact with. In addition, doctors have a professional moral duty to help patients medically. To assist them in doing this, we have suggested that they are required to treat their patients partly as an object, and must also leave the patients' existential issues out of their medical reasoning. This disregard of the patient as a person is a moral offence, which the patient can experience as being more or less offensive depending on the circumstances. It may, however, be unavoidable when it comes to acting professionally. Many doctors might excuse inauspicious encounters by the use of this rationale. When patients complain that the doctor did not take the time to speak properly to them, or only focused on an injured body part and took no notice of them personally, their doctors would probably respond with an explanation of why this was necessary to fix the affected elbow or shoulder. For doctors, the handling of patients partly involves opposing duties. Nevertheless, when it comes to the concept of moral residue, even if doctors' professional duties require them to sometimes disregard the patient as a person, it does not simply eliminate the principle of respecting the patient as an individual. When doctors disregard the personal aspects of patients in order to treat them, it leaves a moral residue that requires them to minimise the effects of this depersonalisation. This could be achieved by shortening the period of objectification,

objectifying patients as little as possible, affirming the human contact with the patient when possible and perhaps apologising for neglecting personal issues.

In our study of videotaped patient encounters, we looked for any signs of the doctors trying to repair the moral offence of depersonalisation. We observed some attempts to do so, for instance, by apologising when turning to the computer screen during a conversation. However, these observations were few and far between. In general, it looked as if the doctors were unaware of the offending nature of the depersonalisation. Possibly because they were so used to it and regarded it as a necessary element of their clinical work, they shifted readily between social talk and, for instance, objectifying examinations, seemingly without even noticing when they were treating the patient as a person and when they were treating him as an object. Patients do indeed anticipate some of these transitions and expect the doctor to focus on the injured body part. Accordingly, the degree to which the depersonalisation is experienced as a moral offence probably varies. However, it is possible that many of the negative experiences that patients report from their medical consultations are linked to this depersonalisation.

The concept of moral residue points towards a possible way of dealing with the negative effects of an objectifying medical approach. Doctors should be aware that their methods perhaps inevitably inflict some harm on patients, even if the moral intention is to help them. Doctors should, however, learn to take responsibility for these infringements, rather than dismissing them as inevitable incidents or, worse still, denying that any moral offence occurs as part of the medical process.

4.5. Relation to other empirical work

4.5.1. Empathy and moral development

Much attention has been paid to the development of students' attitudes during their time at medical school. Several studies have shown that students' moral perceptions, empathy and communication skills decline during these years of training, which is a quite alarming fact (Coulehan & Williams, 2001; Patenaude et al., 2003). This negative development is commonly explained by the lack of formal training on these issues and the significant influence of the informal curriculum (Wear & Zarconi, 2008). The term informal curriculum describes the tacit elements of medical practice

that students and young doctors learn from their more experienced colleagues. It is considered to be important elements of learning how medicine is actually practiced and what it means to behave as a professional, but is not a formal part of the medical education. This tacit curriculum is part of the socialisation in the norms of the profession. Doctors learn clinical work by observing their superiors, who act as role models for newcomers, and it is this way of learning that is believed to have greater impact on students. For instance, students are educated in patient autonomy and the importance of informed consent in the classroom, but if they afterwards join a surgical department where informed consent is treated by senior surgeons as a mere formality, students learn to pay no heed to this aspect of the formal curriculum. Interpreting medical education in this way normally leads to questions about how to change the informal curricula, how to produce better role models and how to accentuate the formal curriculum on ethics and communication (White et al., 2009).

There is, however, another way to look at the alleged decline in medical students' empathy that will produce different questions and perhaps suggest other solutions. I believe that the concept of essentialising is useful when it comes to understanding this phenomenon. Medical school teaches students basic anatomy, physiology and pathology and how different diseases affect the human body. Students are taught techniques to approach and examine the human body and mind as entities that may malfunction. This modus operandi takes years for students to learn because they have to find out how to approach people as physical objects and how to transgress the ordinary rules of human behaviour and bodily contact. We could see the results of this process in our first study, where the doctors focused on objective measurements and bodily functions, while disregarding the more personal dimensions of an individual. However, the process of essentialising, which is so meticulously inculcated, is never the object of scrutiny in medical education. Hence, the contents and consequences of essentialising are not made explicit or discussed. When students then enter medical practice, they start acting in the ways that they have learned – not only via the informal curriculum, but no less so via the formal curriculum. Formal medical education also prepares students for the process of essentialising.

I suspect that there is no major gap between the formal and informal curriculum when it comes to the application of medical knowledge, diagnoses and treatment. However,

what students (and outsiders) might be surprised by when they enter the clinical field is what this application means in practice when it comes to dealing with patients. Attending to the functions of the abdominal organs of a patient means ignoring his personal explanations of abdominal pain (unless they provide a clue to the diagnosis), demanding his partial nakedness, palpating his stomach like just another object, and paying little attention to his possible discomfort. The concreteness of these actions lets the inexperienced doctor discover how the formal curriculum is put into practice and what clinical work is all about.

According to this interpretation, the problem with the formal education in ethics and communication is not that it is counteracted by the more powerful informal curricula. Instead, the problem is that it is separated from, and partially opposes, the rest of the medical education available, both formal and informal. In medical ethics' classes, students are taught to respect patients as autonomous beings, but the courses rarely explain how they are supposed to do this while, at the same time, retrieve the medical information they need from the patient and his body. It is thus not surprising that a recent doctoral thesis reveals that conceptualisations of empathy in medicine tend to accommodate to objectivistic ideals instead of challenging them (Pedersen, 2010, p. 171).

4.5.2. The patient-doctor relationship

Much weight has been attached to the issue of patient autonomy during the modern development of medical ethics. In line with the rise of human rights in the rest of society and the weakening of the medical authorities, the focus on the patient's position in the health care system has been emphasised. Medical paternalism has become reviled and a symbol of doctors' unjustified control over their patients (Holm, 1993; Coulter, 1999). Emanuel and Emanuel's much cited article describes the role of the doctor in terms of four different dimensions: paternalistic, informative, interpretive and deliberative (1992). While they admit that these dimensions might vary according to circumstances, their explicit ideal of the doctor is one of deliberation, wherein these professionals use their medical knowledge and, based on a patient's personal life and aspirations, offer advice about the best possible solutions: "...the physician acts as a teacher or friend, engaging the patient in dialogue on what course of action would be best, the physician indicates what the patient should do,

what decision regarding medical therapy would be admirable." (Ibid.) Similar models have been put forward by many authors of work on medical ethics, and have given rise to movements like Shared Decision-Making and Patient Centred Medicine (Sandman & Munthe, 2010; Epstein & Peters, 2009). The purpose of these movements is to neutralise the power inequality between doctors and patients, putting the latter more in charge of their health and illness. According to this view, doctors should serve patients with their expert knowledge, while patients should contribute with their personal preferences and life goals. Then, together, the doctor and the patient should try to reach a common decision about what examinations or treatments are optimal for this unique individual.

Several empirical studies have, however, shown that doctors do not adhere to these principles of shared decision-making. Instead, they inadequately discuss treatment and options, meaning that patients are unable to evaluate their full range of choices (Karnieli-Miller & Eisikovits, 2009). Doctors also fail to elicit patients' personal perspectives and preferences (Corke et al., 2005). Furthermore, the decision-making process is often described as being dominated by doctors, with little real involvement from the patients (Braddock et al., 1999). Referring to the decision-making ideals, these studies commonly result in a concern for the doctors' negligence. Our findings are consistent with the above-mentioned research, yet we conclude differently. These prescriptive ideals often do not take into account the specific conditions of clinical medicine. If doctors are, indeed, bound by a common demand of benefiting their patients' health, this profoundly restricts their possibility to engage in other, more personal aims of their patients.

Closely related to issues of Patient Centred Medicine is the field of patient communication. Although observations of patient encounters constitute a major part of our empirical data, we are interested these interactions as one of several observable parts of doctors' work. We do not concentrate particularly on communication, and only a brief reference to this vast field is due here. The literature on patient-doctor communication focuses on how to enhance patient communication for various purposes, one of which is improving the quality of medical care. In many of the consultations we observed, we could sense that the doctor's communication with the patient was counterproductive to the aim of improving the latter's health, an example

being not paying attention to a patient who was trying to explain his real problem. Our observations suggest that improving how doctors' abilities to communicate could benefit the medical care they provide when it comes to understanding what a patient's problem is, how to facilitate good examination conditions, and how to maximise patient compliance. Indeed, the numerous videotaped patient encounters we utilised in the third study were collected in order to evaluate the effects of a course on clinical communication. Yet the reason for improving patient communication is often explained with reference to its impact on patient health; it is a conditional good that gains its value from what it produces in favourable outcomes (Baile et al., 2000; Matthews et al., 1993). From this point of view, improving patient communication remains within the medical paradigm, and does not really relate to the existential issues that our theory describes.

A different and also much-stated reason for improving patient communication is the desire to develop doctors' empathic abilities and strengthen the human relationship between doctor and patient (Epstein & Peters, 2009). Indeed, this motive often coincides with that of improving patient health. Eliciting the patient's perspective is both a means to important medical information and an opportunity to develop the human relationship between patient and doctor. From a moral point of view, however, these two arguments differ in terms of what they regard as the purpose of the communication. Strengthening the patients' perspectives and improving the communication in order to reach a mutual understanding of the patient's suffering would underscore the clinical encounter as a reciprocal meeting between two human beings. This view on communication does indeed have existential undertones, but also draws upon certain humanistic ideals that I find problematic, as I will attempt to explain in the next section.

4.5.3. Humanistic ideals

Many empirical studies are consistent with our findings; both renowned work in the field of medical sociology, as well as more recent empirical research in medical ethics and communication. As discussed in the previous section, much of this work describes challenges in the patient-doctor relationship, such as doctors distancing themselves from patients, doctors' lack of empathic responses, failures to elicit patients' perspectives and poor communication. While the empirical findings

coincide with ours and thus support our theory of the essentialising process, most researchers draw different conclusions. The challenges in the patient-doctor relationship often lead the researcher to conclude that doctors must resolve these shortcomings (Fine et al., 2010; Pollak et al., 2007). Although a few have questioned the premises of the patient encounter (Greenhalgh et al., 2006; Schaufel et al, 2009), the general presumption is that these failings are deficiencies of doctors, and it is likely that many of these researchers are influenced by the prominent demands of a humanistic movement in bioethics and medicine.

This humanistic movement is not well-defined. It is a collection of trends that are concerned with the maintenance of humaneness within medical practice and with doctors' development of humanity in the medical profession (Boudreau et al., 2007). The movement might be regarded as a reaction to the technological development and specialisation of modern medicine (Cassell, 1991). It focuses on the suffering of the patient, not just the illness or the functional impairment. It also emphasises the need to address patients as complete human beings, which includes their existential and spiritual dimensions (Barry et al., 2001; Hudak et al., 2007). The post-Cartesian division between mind and body is often treated with scorn. The field of medical humanities constitutes part of the humanistic movement, and advocates the stimulation of imaginative insight into the lives and experiences of others, through literature and other art forms, in order to cultivate humane doctors who are more attentive to their patients' suffering (Skelton et al., 2000; Hunter et al., 1995). A considerable part of the humanistic movement is concerned with the development of empathy, and often recommends including more "soft" subjects in the medical curriculum, like communication and ethics as well as the non-scientific literature and art. The human relationship between patients and doctors is emphasised, accentuating the latter's obligation to put themselves in the position of the former and respond with compassion and empathy (Halpern, 2007; Charon, 2001).

I believe that the descriptions of medical practice that are highlighted by the humanistic movement are important in a particular way. They reveal and emphasise the patient's perspective, including the vulnerability and powerlessness that many feel when facing their doctor and the health care system. What I find problematical is the lack of attention that is paid to the specific prerequisites of the medical

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profession; the insights from medical sociology about the premises of medical work seem to be brushed aside. An understanding of how the patient-doctor relationship differs from ordinary human relationships and how this difference has a specific objective in medical work is largely neglected. It is easy to state that doctors should be more empathetic and personally involved in their patients' lives, but it is pointless to make this demand without relating it to the distance that is required in order to act professionally. Likewise, it is questionable whether doctors should really have to ask about or try to elicit patients' existential suffering if they do not have the means to be of any assistance in these matters. The doctors' privilege to ask their patients questions otherwise unheard of is related to their professional medical remedies, for which no equivalent exist when it comes to existential issues.

A paradox is that the humanistic movement may in fact prevent some of the changes in medicine that it seeks to bring about. This is because it tends to suggest answers that are too simple and unbalanced when it comes to complex issues. While it does shed light on some of the major challenges within medicine and medical practice, some of its straightforward solutions might actually shroud the deeper issues that are connected to health care as a social practice. Moreover, some of the movement's more imbalanced resolutions seem to repel doctors instead of drawing their attention to underlying, problematic issues. This thesis stands in the humanistic tradition in the sense that we recognise how doctors overlook existential issues and acknowledge that this might have a detrimental effect on patients. However, our work also opposes the humanistic tradition in that we are searching for explanations, and hence resolutions, elsewhere. In keeping to our empirical objective, we are not trying to look for answers in the traditional discourse of medical ethics, but are instead aiming to understand the internal logic of the participants in medical practice in order to understand why these problematic situations arise.

5. Study limitations

The measures for evaluating qualitative research are generally not as straightforward as for quantitative studies, and the criteria and terms used may vary between authors. Important aspects to evaluate in qualitative work often include an assessment of internal and external validity, relevance and reflexivity (Malterud, 2001; Giacomini

& Cook, 2000), while Glaserian Grounded Theory uses its own evaluation criteria. I will address each of these matters separately, although some of them do overlap.

5.1. Evaluating Grounded Theory

Glaserian Grounded Theory is aimed at generating plausible theories, and the focus is on the process of generation. It is not a proper method for testing hypotheses and this has consequences for how results should be evaluated. The product of Grounded Theory is a theoretical conception of the research field, which contains theoretical categories and explanation models that are not natural entities, but constructions with which to explain the phenomena in question. Accordingly, the quality of the hypotheses is assessed in terms of their explanatory power. In Grounded Theory, the theoretical end product gains its credibility from judging its fit, relevance, workability and modifiability (Glaser, 1998; 1978).

5.1.1. Fit and relevance

A theory's fit corresponds roughly to what is otherwise known as internal validity, which characterises the relationship between theoretical concepts and data. A theory that fits succeeds in representing the patterns of data it intends to signify. This implies that researchers have approached the field with an open mind and allowed the theory to emerge without forcing predetermined theoretical constructions upon the data. Closely connected to the issue of fit is the relevance of a study. A theory is relevant if it relates to the main concerns of the participants in the field. Accordingly, the relevance of the theory reflects whether the empirical data is taken seriously and the hypothesis really deals with what is happening in the field of study. In our research, we have strived to be open to the patterns that emerged through observations and interviews. The fact that we ended up with an analysis that we did not expect and that gave us new insight into the field supports our belief that the theory is based on the empirical data and not on preconceived concepts. The theory of essentialising can be judged to be relevant because it is constantly repeated in the data. Essentialising is something that all doctors do in their encounters with patients or their medical history. Likewise, we found that displaying medical concern and courteousness while neglecting existential care was a common way of handling patients. The responses to our theories from doctors and other medical personnel have shown that they immediately recognised the patterns of behaviour that we describe, and this is a

further sign of the theory's fit and relevance. One could question this relevance due to the objections of several doctors to the notion of existential filtering, which might be an indication that the concept did not, in fact, fit. However, we took this criticism seriously and explored it directly in our third study, treating it as a negative case which needed to be reworked and integrated into the theory.

5.1.2. Workability

The workability of a theory reflects how easily it is translated into practice. Its construction also has to be clear, so that it is possible to understand both how the researchers have arrived at their theory and how it is to be used on new data. A workable theory can account for most of the variations in data, and so should be able to explain what has happened as well as anticipate what will happen in a similar field. I have tried to portray as much of the research process as possible in this thesis in order to demonstrate how the theory was constructed. Whether or not I have succeeded is for others to judge. I believe that the theory of essentialising is highly workable, as it is able to explain a great deal of what happens in the data. We can understand much of the rationale behind doctors' actions in light of the process of essentialising, and we can also largely predict what they will ask and how they will behave in a variety of situations. Moreover, the theory accounts for many of the phenomena that patients experience in consultations, like being interrupted, not being properly listened to and experiencing the doctors' focus being on objective medical signs (Levinson et al., 2000; Corke et al., 2005). Furthermore, the division between courteousness and existential care explains why doctors feel that they have been kind and respectful, even though they have actually dismissed patients' worries.

5.1.3. Modifiability

A Grounded Theory is never complete, and it should be possible to modify it when confronted with new and relevant data. Indeed, use of the constant-comparative method means that the theory should always adapt to what is happening in the field. Even if, for practical reasons, researchers have to utilise a cut-off point in order to commit a theory to writing, it must nevertheless be possible to adjust it in the light of new data that affects it. Because the theory is a theoretical construct based on behaviour in a field of society, it must be possible to modify it in correlation with the development of that society. We have modified our theory several times since we

first formulated the concept of essentialising. Indeed, feedback we received about our initial findings revealed new scenarios and arguments that we incorporated into the study. We also developed parts of the theory further by performing the third study and including a different set of data. Our theory is, of course, still open to refinements or changes in light of new and confronting material.

5.2. Internal validity

Internal validity refers to whether a study has actually explored what the researcher intended to examine. We set out to investigate the implicit values of medical practice using observations and interviews. How it is possible to express tacit dimensions and access moral behaviour are obvious issues which affect the internal validity of the research, which were addressed both in the section about of tacit knowledge and in the interview section of the first study. The selection of the doctors and patients who were included in the study may have had a profound impact on its internal validity. We used theoretical sampling as our methodological strategy, and this is explained in more detail in relation to the first study. The criteria for selecting the video encounters that we utilised and the effects thereof have also been discussed earlier in relation to the third study. In a Grounded Theory approach, the emphasis on the workability of a theory, as discussed above, is also related to its internal validity and the credibility of the findings that are made.

5.2.1. Transparency

It is not possible to directly expose the kind of tacit and moral behaviour we wanted to examine in this research, and this makes us vulnerable to allegations of subjectivity and speculative analysis. Yet these are not problems that are specific to our work. Sociological and ethnographic research often depends heavily on trust in the researchers' personal ability to collect and analyse data, as well as their willingness to expose their methods to scrutiny. After all, it is often not possible to access this kind of data in any other more impartial or objective manner. Throughout this dissertation I have tried to highlight my approach to sampling, collecting and analysing the material in order to expose my line of reasoning to outsiders. It is indeed possible to question every step we have taken in this research, and I do not claim to have discussed all of the decisions that were made, since any attempt to do so would always underestimate the abundance of choices that were open to me. Yet, revealing

my reflections and methodological decisions is an attempt to make my research as transparent to readers as possible, so that they can follow the research process, evaluate the decisions we made independently and judge how these choices affected our results. Indeed, detailing our methods and analysis is actually an important step in ensuring that our research is comprehensive and also strengthens its internal validity. A discussion of my own preconceptions in the section on reflexivity is a further disclosure of these methodological choices.

5.2.2. Triangulation

Triangulation involves combining different types of data collection, methodologies, theories as well as different researchers to study the same phenomenon. The triangulation of methods was a key decision when it came to validating our results in response to the challenges of exposing tacit knowledge (Patton, 1999). In the first study, we decided to combine observations and interviews in order to address the doctors' actual work as well as their motivations and expressed reasons for their behaviour. As discussed earlier (in the interview section of the first study), the decision to combine observations and interviews in the first study was made to meet some of the shortcomings of each of these methods. The findings were explored in detail theoretically, which was one of the factors that led to the second manuscript, and this theoretical probing can be seen as a further expansion of the method by the exploration of different angles of the same field. In the third study, by watching videotaped encounters, we supplemented the theory with a whole new set of data and a different observation technique. Moreover, several researchers observed and analysed the same videotaped cases, supplying the emerging theory with different viewpoints and specialist knowledge from a variety of fields. In summary, we have tried to access the field with a range of different approaches in order to overcome some of the challenges that are related to our aim of exposing what is tacit and invisible. What we did, however, omit was the step of speaking to patients, which might have leant additional rigour to our results. This issue is dealt with more extensively below.

5.2.3. Negative cases

Searching for negative cases was also an attempt to enhance the internal validity of the research. Firstly, when deciding on the settings in which to observe medical

practice, we did not single out situations in which we expected there to be many moral issues raised. Instead, we included patients and doctors from very different specialities, and we particularly sought to include settings like general practice, which would be likely to cover some trivial medical issues, together with other settings wherein we expected a moral discourse to be absent, such as in a surgical department. Grounded Theory has a distinct way of dealing with deviant cases in the process of analysis, since the method is attuned to the possible modification of the theory in light of relevant new data. Indeed, the presence of many unusual cases signifies that there are important aspects of the research field that the researcher has not accounted for, meaning that it is necessary to continue with data collection and analysis until these atypical cases have been integrated into the theory. What might at first appear to be a deviant case, such as when a doctor expressed genuine concern about how an elderly patient was passed between departments, became after more extensive analysis an important part of the theory. This is because it enabled us to realise that the doctor objected to this patient's treatment, not because it was unworthy, but because it had a negative impact on her health. His concern was indeed moral, but of a medical nature, aiming to benefit the patient's health.

Furthermore, when exposed to our concept of existential filtering, and with the aim of debunking our theory, several doctors supplied us with case histories which demonstrated that they really cared for their patients as individuals and fellow human beings after all. If we are to take Grounded Theory's mantra that "all is data" seriously, other people's objections to our findings could be seen as an indication of the presence of atypical cases. Trying to understand the reasons for the doctors' objections, and integrating their stories into our analysis of the data, led us to discover in the third study the distinction between human and existential concern. Nevertheless, the danger remains that the researcher tries to overlook or explain away deviant cases instead of taking them as an indication of flaws or omissions in the theory. Indeed, in the third study, we did observe some patient encounters in which the doctors did not seem to cut the patients off when they expressed existential concerns, while some even encouraged such narrative. What these consultations had in common, however, was that the medical problem had already been resolved or set aside. This meant that these doctors did not have any overarching medical concern guiding the encounter, and so we could still understand what was happening on the

basis of the theory of essentialising. Yet, it is important to note that others might have interpreted these examples as atypical cases.

5.2.4. The patient's perspective

When we first initiated this research, we wanted to focus on doctors' tacit handling of moral issues. This led us to observe how doctors work and behave in a normal clinical setting, with or without patients. Our main interest was in the doctors. However, the communication between doctor and patient was of course central to understanding the former's work and to realise the consequences of it. When the results of our first study made us aware of the process of essentialising, and existential filtering in particular, it became clear that the doctors' tacit moral behaviour had considerable consequences for their patients. This was further established in the third study, wherein we became aware of the difference between the doctors' human and existential concern. What is, however, missing from our research is the perspective of patients. When we observed medical encounters for this work, we sensed that in many cases the patients were reacting negatively to being overlooked, interrupted and objectified, and it was easy to understand these reactions from the situations. Yet we did not ask the patients how they felt. What is more, we have not spoken to the patients in order to confirm our suspicions that they really felt misunderstood and were disappointed in or angry with their doctors after their consultation. Although our research has illuminated some negative effects of clinical practice, studies show that patients are, in general, content with their medical encounters (Hjörleifsdóttir et al., 2010; Isaksen et al., 2003). It is clear that it would have been interesting to explore the patients' expectations in their doctors and the health care system in order to interpret the course of the encounters we observed and the patients' reactions. This shortcoming restricts the interpretation of our results and, in retrospect, would certainly be the lacuna that we would like to fill.

Yet, there are methodological reasons why we did not pursue the patients' perspectives. Initially, our focus was on the professionals. My research question dealt with the doctors' tacit moral practice, and so we had to construct the study in order to investigate this. We could not know beforehand what part the patients would play in this investigation, and it was consistent with the approach of Grounded Theory to leave them out of the picture until they had earned their place in the emerging theory.

When we were offered the use of video-recorded data from patient consultations, we thought that this would deal with this issue to some extent. Indeed, in these recordings, we were able to observe the patients as much as the doctors and this gave us a better foundation for understanding the former's participation. Nevertheless, omitting the patient from direct study continues to be an important limitation of our research, and analysing their perspectives would be a natural continuation of our work.

5.3. Reflexivity

It is vital to acknowledge the effect of the researcher's position and point of view on the results of a study. This is often referred to as reflexivity (Malterud, 2001). I have already revealed the interests and questions that initially led me into this research, and I am aware that this has affected my way of both collecting and interpreting the data. However, our preconceptions were a central gateway for our methodological decisions, which we have discussed in detail in the method section, and they need not be taken as a form of bias as long as they are disclosed.

5.3.1. Conducting research in one's own culture

Another important issue in this work is that being a doctor myself, I am conducting research on a culture that I am already a part of. This is a topic that is thoroughly discussed in methodological literature (Wadel, 1991). In particular, there is a danger that a researcher is blind to certain aspects of a familiar situation, and there is also a risk that he or she feels a sense of companionship with the culture under study, which prevents a critical approach from being taken. As I have previously mentioned, I did at first have some problems when observing clinical situations in that I was "thinking as a doctor" and wondering about diagnoses and treatments. However, after some time in the field, and working explicitly on distancing myself from the role of the doctor, I felt I was more able to observe the ongoing processes independently of the medical content. I did feel sympathy for the doctors I observed, because I could recognise their problems and struggles, and I often admired how they handled difficult clinical situations. This may be seen as a defect in my observations, but it could also be taken as a deeper understanding of the working conditions of the professionals. Such signs of sympathy or comprehension is what I miss in many of the classic sociological studies of medical culture, where doctors are sometimes

portrayed in a very negative way which, in my view, exposes the fact that the observer has not understood what is at stake for the doctor. However, while I have sympathy and admiration for the doctors in our studies, I do not believe that this has hampered my ability to criticise them. Indeed, our descriptions of the doctors' systematic existential neglect may appear harsh to many people, as illustrated by the critical response I received from several doctors. When it comes to discussing my identity as a doctor, I also believe that it is relevant that I am a junior doctor with modest clinical experience, and so my professional identity is perhaps not too firmly set in stone. Moreover, having a background in philosophy might also add to the reflexive detachment that is required for me to step out of my role as a doctor. All in all, I believe that my medical background has been necessary in order to conduct this research, and that it does not detract from our findings.

The studies were a collaborative work with professionals from different fields, ensuring a more balanced assessment of the data. As my main supervisor was a philosopher, and my second supervisor an experienced doctor, we could approach the material from different perspectives, which complemented each other. This was particularly accentuated in the third study, where four different authors had access to the same data and yet achieved a common understanding of the interpretations thereof. Indeed, some could object that the group of observers was composed only of people with a certain interest in patient-doctor communication, and that this has biased our results. However, these potential biases are openly revealed and, as discussed in the methods section, it is often valuable with a certain previous knowledge in order to understand and penetrate into medical encounters.

5.3.2. My presence at the scene

My presence in the research setting must also be scrutinised. The fact that I was attending clinical consultations, which are normally strictly confined to patient and doctor, did certainly change the conditions of these encounters. This is an aspect of observational research that is hard to avoid. As I have explained earlier, I did try to intrude as little as possible by not recording the consultations, not taking notes when the patient was present and sitting quietly in a corner of the examination room. I was certainly not invisible or unnoticeable to the patients, but generally medical students and observing colleagues are a rather common intrusion in a medical encounter.

Since I followed each doctor over the course of a full day's work, it did seem as if the professionals gradually became more familiar with my presence, and the reality was that I probably disturbed the patients more than their doctors. This was a benefit, as it was primarily the doctors' behaviour that we were aiming to examine. The doctors were informed that I was conducting research in the field of medical ethics, and although many did not seem to have a clear grasp of what I was looking for, and very few asked for further details, I suspect that I did not observe the worst of their medical behaviour. Firstly, the doctors were probably more conscious of their actions, particularly their communication with patients, since they knew they were being observed, both in the first study and in the video-recorded data utilised for the third. Certainly, several times during the participant observation, the doctors would spend a lot of time on their first couple of patients and then become short of time and had to speed things up to a more normal pace. Secondly, I believe that the doctors in the first study who volunteered, or were volunteered by their superiors, were those who were known to have a good relationship with their patients. Indeed, in one particular department, some of the doctors kept hinting that I should have followed a certain colleague of theirs if I wanted to see some really interesting ethics, referring to this individual's controversial style of patient communication. It was not, however, our intention to seek out the worst moral decisions or incidents of poor medical behaviour. Instead, we were aiming for the normal, everyday, unspectacular events and, if anything, we probably saw situations that were a cut above the ordinary, or we at least missed out on the worst cases. Despite this selection bias, it is interesting that the existential filtering was still so prominent, a fact that actually strengthens our conclusion.

5.4. External validity

So, to what other settings can our emerged theory reasonably be applied? This question relates to the external validity of the research, or what is sometimes referred to as the generalisability of the theory.

5.4.1. Range of cases

There were 17 doctor participants in our first study. Although this would be a small number in a quantitative piece of work, it is within the normal range for qualitative research. This is because the validity of the research relies partly on the depth of the

analysis, and using too many informants could easily lead to a superficial assessment (Malterud, 2001). It is also worth noting that it is not really the number of doctors that is interesting, since they are not the unit of analysis. Instead, in Grounded Theory, each incident is compared with similar incidents and with emerging concepts, meaning that the incident is the unit of analysis. There are several incidents per patient-doctor encounter, and the first study covered over a hundred consultations. In addition, we also conducted interviews and observations when patients were not present, such as during internal meetings and collaborations with colleagues, and these generated even more incidents. The total number of incidents was also considerable in the third study, which consisted of 101 patient encounters, each of which included several analysable incidents. The large number of cases does not, of course, in itself guarantee the external validity of our results, but they do at least indicate the magnitude of the collected material.

5.4.2. Study population

The doctors who were included in the first study came from three different general practitioners' offices and five different hospital departments in three different hospitals. This was done to ensure the inclusion of a large range of doctors, patients and working environments. All of these settings were situated in Northern Norway, which may have caused a selection bias if these doctors differed from those in the rest of the country, but we have no reason to believe that this is the case. This possible selection issue might also have been mediated by the fact that several of the doctors came from other parts of the country, and had worked and graduated from universities from outside the area. Of course, the patients in Northern Norway may also not be representative of the whole country, because of regional cultural differences. Nevertheless, it is highly unlikely that these differences would affect our theory in any major way, especially since our focus is primarily on doctors' behaviour. We would, therefore, expect our theory to be valid for how doctors work all over Norway, and possibly also across other Nordic countries because of their similar systems of health care. We cannot, however, transfer our theoretical analysis from the first and second studies directly to medical practice in other countries. This is because the conditions for medical work may differ in places which, for instance, have a more commercially based health care system, and further studies would be necessary to see how the theory fits into other environments and circumstances.

Another exception to our results would be in the realm of psychiatric health care, since we did not include this group in our data. In any event, I believe that the practice of psychiatric health care is sufficiently different from somatic medicine to require studies addressing this particular clinical field in order to assess how the theory applies to these encounters.

The third study only included hospital doctors, and so these results should not be directly transferred to general practice. Many expect general practitioners to be more concerned with providing holistic care for their patients (Alment praktiserende lægers forening, 1978), and so further research would be needed to assess our division between courteousness and existential care in these settings. Nevertheless, our first study, which included general practitioners, did reveal the same process of essentialising for both this group and hospital doctors, indicating that the results of the third study might also be valid in general practice.

5.4.3. Transferability of concepts

What is vital for the external validity of a Grounded Theory is that the end product is not an empirical description, but an empirically based theory which can be transferred to settings other than the one being studied, provided the concepts fit the new environment. Our theory does not concern general practitioners' consultations or patient communication in hospital departments. The theory of essentialising actually relates to general medical practice, and so is intended to apply to all medical work, in or out of hospitals and with or without patients. The concepts should be transferable to other areas wherein similar medical work is carried out. The theory may also be valid in other settings, for example in psychiatric care, but this must first be tested empirically. What is more, the theory is always open to modification in the light of new data, as previously described. Indeed, including new fields, like psychiatric health care or privatised medical practices, may introduce new and relevant data, which would alter the properties of some of the concepts, or restrict their range, while also widening the scope of the theory.

6. Concluding remarks

My entry into this research project was a weekly teaching session at a local hospital and the nagging question: where did the ethics go? Through this persistent research process, I believe that the outlines of an answer are beginning to take shape.

The practice of medicine seems to entail a certain way of handling patients which frees it from ordinary moral considerations. Accordingly, by easing the work of doctors and enabling them to handle patients in ways that one does not ordinarily deal with fellow human beings, the existential dimensions of humaneness are omitted from the picture or, are in some way, suspended. Doctors extract the medical facts and findings they need from a fellow human being and his or her ordinary accounts of illness, and turn them into a medical issue. When doctors speak in a manner that is difficult for the laity to understand, it is probably not only an issue of sporadic Latin wording, but also due to the fact that doctors' interpretations are constructed around a strict medical understanding of human functions that is bereft of its ordinary, commonplace meaning. Having observed doctors' systematic efforts to essentialise clinical situations, I am inclined to believe that this is an inevitable part of modern clinical practice, although we cannot infer this directly from our results. In view of what medical practice entails, with bodily examinations, surgical interventions and the probing of patients' intimate and taboo issues, it seems evident that ordinary human interaction must be put aside for medical purposes. Learning how to deal with patients as objects seems to be an indispensable part of becoming a doctor. This is not only to protect the doctor from getting involved, and nor is it to protect patients from being invaded; the reality is that this approach is necessary for the application of basic medical knowledge. Depersonalising patients is a necessary part of succeeding as a doctor.

Some readers might find this unduly provoking. Yet, I believe that it can only be regarded as such if you unconditionally accept large parts of particular, prescriptive medical ethics. Unfortunately, much of the literature on medical ethics has been written without proper attention being paid to the specific circumstances that constitute clinical practice and form the behaviour of doctors. Demanding that doctors engage personally and compassionately in the life of every suffering patient

is at best unwarranted. Such unattainable demands mask the preconditions of medical practice, and possibly contribute to doctors' work-related discontent. To suspend the human dimension of the patient in order to contribute medically can be emotionally demanding. Being denounced for being inhumane makes the work exceedingly stressful. Studies on living conditions have shown that doctors are prone to work-related frustration, which might be related to this inherent distress (Førde & Aasland, 2008; Kälvemark et al., 2004). One of the important findings in our research is that the depersonalisation I speak of here is a systematic part of medical practice; it is not related to some personal quality or inadequacy of the doctors as individuals.

Nonetheless, the problem of medical practice remains. Even if the depersonalising aspect of the medical encounter is inevitable, it still affects patients. Every patient will probably be exposed to the process of essentialising and hence reduced to an object or a mechanical body. At the core of the conception of morality and human dignity is the idea that individuals are not reducible to objects, but intrinsically valuable, and so reducing people to objects in this way is indeed a moral offence (Kant, 1998). While patients themselves might very well be prepared to acknowledge this reduction as a necessary part of medical treatment, it still affects them in ways that are inescapable. Even if it is an inevitable part of medical practice, doctors are morally responsible for this offence and its possible negative consequences, as the concept of moral residue has shed light on. "Non-maleficence" or "Primum non nocere" may thus be some of the least fitting principles in medicine. This is not only because medical treatment often entails potentially harmful interventions, but also because by merely entering the medical sphere, one is morally offended by being reduced to an object. In this respect, doctors' courteousness could have an important function, as discerned in our third study. Our research revealed that doctors seemed to demonstrate human courtesy without noticing that they also objectified patients and overlooked their existential concerns, thus giving out mixed messages. Perhaps, if doctors were more aware of the process of essentialising, they could use their courteousness to repair their relationship with their patients. Acting respectfully is an important part of human interaction, and attending to the patient as a human being is even more important for doctors because of the inherent moral offence of medical practice. Doctors' purposeful courteousness may be a way of restoring the ever-challenged patient-doctor relationship.

A natural empirical continuation of this research would be to include the patient perspective, as previously discussed. The nature and magnitude of the moral offence caused by depersonalisation can only be assessed by asking patients. Furthermore, the contribution of patients can inform doctors of what improvements would lessen the potentially distressful experience. The concept of moral residue appears to be a useful theoretical approach to the problem, and an investigation of this concept could provide us with a better understanding of the moral offence and consequently of the doctors' duties. Exploring the concept could lead to proliferation of ideas on how doctors could attend to the responsibilities of a moral residue. Moreover, I believe that the notion of inner morality is worth a further analysis, seeing that the notion is closely connected to how we understand medical practice as a profession. I would advocate to explore the consequences of how the premises of medical work, such as described by sociologists and anthropologists, have implications for medical ethics. I believe the field of medical ethics could profit from looking past the more mythical images of the patient and his doctor, in order to appreciate how clinical medicine is practiced in all its concreteness.

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Paper I

Agledahl KM, Førde R and Wifstad Å.

Clinical essentialising: a qualitative study of doctors' medical and moral practice.

Med Health Care Philos 2010;13(2):107-13.

Paper II

Agledahl KM, Førde R and Wifstad Å.

Agledahl KM, Gulbrandsen P, Førde R, and Wifstad Å.

Courteous but not curious: how doctors' politeness masks their existential neglect.

A qualitative study of video-recorded patient consultations.

J Med Ethics [in press].

Appendix I

Study I: Documentation of approval

Kari Milch Agledahl
Rehabiliteringssenteret Nord Norges Kurbad
Conrad Holmboesgt. 95
9011 Tromsø

Deres ref:
Saksbehandler: imp
Vår ref: 05/4512
Arkivkode:
Dato: 04.05.2006

Vedr. klage over avslag på søknad om dispensasjon fra taushetsplikten i forbindelse med forskningsprosjektet "Klinikkens skjulte verdier"

Sosial- og helsedirektoratet viser til Deres brev av 22.01.06, vedrørende klage på avslag om dispensasjon fra taushetsplikten i forbindelse med overnevnte studie.

Sosial- og helsedirektoratet avslo i vedtak av 22.12.05 søknad om dispensasjon fra taushetsplikten for det aktuelle forskningsprosjekt, hvor De gjennom deltakende observasjon, ønsket å kunne studere legers omgang med verdispørsmål og hvordan de handler og beslutter i moralske problemstillinger. Gjennom observasjon vil du få tilgang til medisinsk informasjon om pasientene, som diagnose, prognose, behandling, symptomer osv.

Formålet med prosjektet er å heve kompetansen om kliniske legers resonneringer og valg, og øke forståelsen av de verdimessige implikasjonene av klinisk praksis.

I klage av 22.01.06 er gjennomføringen av prosjektet fremstilt på nytt, da De mener Deres tidligere fremstilling har vært noe uklar. Det fremkommer av klagen at observasjon av personlige konsultasjoner skal baseres på samtykke fra den aktuelle pasient, slik at denne delen av prosjektet ikke lenger omfattes av dispensasjonssøknaden. Klagen gjelder dermed avslaget på søknaden om å kunne observere/delta i interne møter og på visittrunder. Deltakelse i de interne møtene vil ikke innebære kontakt med, eller observasjon av pasienter. Det er legene og deres resonneringer som skal observeres. En slik tilstedeværelse vil imidlertid medføre at De får kjennskap til taushetsbelagte helseopplysninger om de pasienter som diskuteres. Videre omfatter klagen avslaget om å kunne delta på helsepersonellets visittrunder. Det vil heller ikke her være snakk om noen aktiv innhenting av helseopplysninger, men en observasjon av helsepersonellets interaksjon med pasientene. Det er planlagt å observere ca 30 leger, èn dag hver. Antall pasienter som omfattes vil dermed avhenge av hvor mange pasienter legene møter i løpet av arbeidsdagen. Også deltakelse på visittrunder vil medføre at De får tilgang til taushetsbelagte helseopplysninger om pasientene.

Det foreligger klagerett etter forvaltningsloven (fvl.) § 28. Klagen er fremstilt innen fristen, jf. fvl. § 29, og vurderes dermed etter fvl. § 33 annet ledd.

Sosial- og helsedirektoratets vurdering:

<u>Vedrørende dispensasjon for deltakelse på visittrunder</u>
Sosial- og helsedirektoratet har på grunnlag av klagebrevet vurdert saken på nytt. Vi har kommet til at vi ikke kan omgjøre vedtaket vedrørende dispensasjon fra taushetsplikten for deltakelse på visittrunder.

Det rettslige utgangspunkt etter helsepersonelloven (hlspl.) § 21 og forvaltningslovens (fvl.) § 13 er at helsepersonell og enhver som utfører tjeneste eller arbeid for forvaltningen, skal hindre at uvedkommende får adgang til taushetsbelagte personopplysninger de får kjennskap til i forbindelse med sitt arbeid. Tilgang til taushetsbelagte opplysninger vil derfor bare kunne gis dersom de pasienter som er beskyttet at taushetsplikten, jfr. hlspl. § 22 og fvl. § 13 a, har samtykket til dette, eller det blir innvilget dispensasjon fra taushetsplikten etter hlspl. § 29 og fvl. § 13 d. Etter hlspl. § 29 og fvl. § 13 d kan departementet bestemme at opplysninger kan eller skal gis til bruk i forskning og at en slik utlevering kan skje uten hinder av taushetsplikten. Dispensasjonsadgangen er delegert til Sosial- og helsedirektoratet som foretar en konkret helhetsvurdering av saken.

En person har selvbestemmelsesrett vedrørende opplysninger om seg selv og eventuelt deltakelse i forskningsprosjekt. Helseopplysninger hører til de mest sensitive opplysninger vi har om oss selv. I tilfeller hvor andre får tilgang til slike opplysninger, vil dette kunne oppfattes som inngrep i den enkeltes privatliv. Ved å delta på visittrunder vil De få kjennskap til sensitive opplysninger om et stort antall pasienter. De anfører at Deres dispensasjonssøknad, i forhold til pasientens selvbestemmelsesrett, må vurderes på en annen måte, da det til forskjell fra tradisjonell forskning ikke søkes om tilgang til pasientopplysningene i seg selv, men om tilgang til sitasjoner som til tider kan inneholde slik informasjon. Direktoratet vil i forhold til dette presisere at der kjennskap til opplysningene bare er en konsekvens av en tilstedeværelse og ikke et resultat av en aktiv innhenting, har ikke noen betydning for taushetspliktens gyldighet. Pasientene er beskyttet av regelverket i sammen grad som om det var de som primært var gjenstand for observasjonen.

De anfører videre at Deres tilstedeværelse ikke kan anses integritetskrenkende, da man som inneliggende pasient uansett er gjenstand for en "indirekte" observasjon. Dette være seg observasjon av medpasienter, pårørende og helsepersonell. Hvorvidt for eksempel pårørende eller medpasienter "observerer" andre innlagte, kan etter direktoratets oppfatning ikke sammenlignes med en aktiv observatør som i forskningsøyemed er tilstede i en behandlingssituasjon. Taushetsplikten er ikke bare en plikt til å tie, men også en plikt til en viss aktivitet for å hindre uvedkommende i å få tilgang til taushetsbelagt informasjon. Informasjon som fremkommer under helsepersonells samtaler med pasient på sengepost, må derfor i størst mulig grad skjermes for medpasienter. At disse i noen tilfeller likevel vil kunne overhøre deler av konsultasjoner, vil ikke gjøre Deres tilstedeværelse som observerende forsker mindre inngripende. De mener videre at Deres tilstedeværelse vil oppleves som mindre inngripende, da De selv er lege. Direktoratet kan heller ikke se at dette er av betydning for om De skal få tilgang til de taushetsbelagte opplysningene. Taushetspliktens hovedregel er at helsepersonell skal hindre at uvedkommende får adgang til taushetsbelagte personopplysninger de får vite om i egenskap av å være helsepersonell. Hvorvidt personen som mottar taushetsbelagte opplysninger er lege

eller ikke, er uten betydning for hvem som regnes som uvedkommende i denne sammenheng. Utveksling av taushetsbelagt informasjon mellom helsepersonell skal kun skje dersom det er nødvendig for å kunne gi forsvarlig helsehjelp.

De vil i forkant av observasjonsrundene ikke vite hvem som "indirekte" vil bli observert. I forhold til dette hevder De at samtykke praktisk sett ikke vil være mulig å innhente. De opplyser imidlertid at pasientene på de ulike avdelingene, skal få muntlig og skriftlig informasjon om forskningsprosjektet og din rolle som forsker. Direktoratet kan på bakgrunn av dette ikke se at et samtykke om deltakelse praktisk sett kan være umulig å innhente. Videre vil De kunne komme opp i en situasjon hvor pasienter vil nekte å delta uten på forhånd å ha blitt spurt. Slik nektelse i forbindelse med informasjon måtte respekteres som et avslag på en deltakelsesforespørsel. Noe annet vil være en klar krenkelse av pasientens integritet. Direktoratet vil også påpeke betenkelighetene ved at De i forkant ikke vet hvilke pasienter og situasjoner som vil bli observert, da dette medfører at De heller ikke kan vite hvilke- og hvor sensitive pasientopplysninger De vil få tilgang til.

Direktoratets har vurdert det slik at studien kan generere kunnskap som kan være av betydning i legers grunn- etter- og videreutdanning. Det er imidlertid for det foreliggende prosjektet tale om observasjon av samtykkekompetente pasienter. Etter direktoratets vurdering, vil innvilgelse av dispensasjon fra taushetsplikten i slike tilfelle innebære et så stort inngrep i den enkelte pasients integritet at det vil være i strid med legalitetsprinsippet. Taushetsplikten kan således bare oppheves gjennom samtykke fra den enkelte pasient. Dersom samtykke ikke er praktisk mulig å innhente fra de aktuelle pasienter, vurderer Direktoratet prosjektet som ikke praktisk gjennomførbart.

For hvilke krav det stilles til et gyldig avgitt samtykke vises det til Direktoratets vedtak av 22.12.05.

Direktoratet kan med dette ikke omgjøre sitt vedtak av 22.12.05, vedrørende dispensasjon fra taushetsplikten for tilgang til opplysninger som fremkommer under deltakelse på visittrunder. Klagen oversendes dermed til Helse- og omsorgsdepartementet som rette instans.

Dispensasjon for deltakelse i interne møter
Sosial- og helsedirektoratet har, på bakgrunn av Deres klage, vurdert saken på nytt og kommet til vedtaket vedrørende dispensasjon fra taushetsplikten for deltakelse i interne møter omgjøres.

Vedtak:
Med hjemmel i hlspl. § 29 og fvl. § 13 d innvilger Sosial- og helsedirektoratet søknad om dispensasjon fra taushetsplikt i forbindelse med deltakelse i interne helsepersonellmøter, hvor det fremkommer taushetsbelagte opplysninger om innlagte pasienter.

Direktoratets dispensasjon gis på følgende vilkår:
- at taushetsplikten etter fvl. §§ 13 til 13 e og helsepersonelloven overholdes, jfr. helseregisterloven § 15
- at opplysningene behandles og oppbevares strengt konfidensielt
- at prosjektet gjennomføres i samsvar med prosjektbeskrivelsen

- at personidentifiserbare data slettes straks det ikke lenger er behov for dem og senest ved prosjektets avslutning den 31.12.08
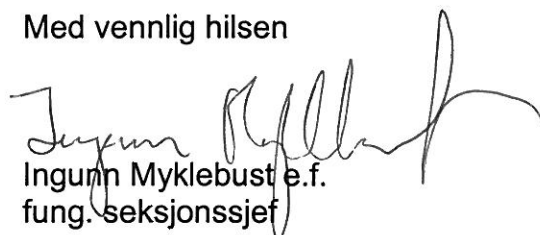- at publikasjoner gis i en slik form at enkeltpersoner ikke kan gjenkjennes

Dispensasjonen gjelder prosjektleder Kari Milch Agledahl og prosjektmedarbeider Åge Wifstad. Direktoratet gjør oppmerksom på at dispensasjonen kun gjelder de navngitte personer og at prosjektleder er ansvarlig for at dette overholdes.

Det forutsettes at innhenting, oppbevaring og sletting av opplysninger er i overensstemmelse med Datatilsynets bestemmelser, samt at Regional etisk komité (REK) har vurdert og tilrådet prosjektet.

Direktoratet gjør videre oppmerksom på at brudd på taushetsplikten kan være straffbart i medhold av fvl. § 13 e tredje ledd, hlspl. § 76 og hlsregl. § 34.

Sosial- og helsedirektoratets vedtak er å anse som et enkeltvedtak i henhold til forvaltingsloven (fvl) § 2 b. Vedtaket kan påklages og klagefristen er tre uker fra mottakelsen av dette brev, jfr. fvl. §§ 28 og 29. Klageinstans er Helse- og omsorgsdepartementet, men en eventuell klage skal rettes til Sosial- og helsedirektoratet. Det følger av fvl. § 18 at en part har rett til å gjøre seg kjent med sakens dokumenter, men mindre annet følger av de unntak loven oppstiller i §§ 18 og 19.

Med vennlig hilsen

Ingunn Myklebust e.f.
fung. seksjonssjef

Ida Marie Pedersen
førstekonsulent

DET KONGELIGE
HELSE- OG OMSORGSDEPARTEMENT

Kari Milch Agledahl
Postboks 7000 St. Olavs plass
0130 OSLO

Deres ref	Vår ref	Dato
	200603889-/ASD	28.7.2006

Klage - Avslag på søknad om dispensasjon fra taushetsplikten i forbindelse med forskningsprosjektet "Klinikkens skjulte verdier"

Det vises til klage vedrørende ovennevnte datert 22. januar 2006 på vedtak fattet av Sosial- og helsedirektoratet 21. desember 2005.

Sosial- og helsedirektoratet gir i vedtaket 21. desember avslag på søknad 8. september om dispensasjon fra taushetsplikt for å kunne gjennomføre prosjektet "Klinikkens skjulte verdier". Prosjektet innebærer at forsker gjennom deltakende observasjon følger ulike leger i deres vanlige kliniske arbeid, supplert med avklarende spørsmål underveis.

Sosial- og helsedirektoratet begrunner avslaget med at i det aktuelle forskningsprosjektet vil forskeren, gjennom observasjon av konsultasjoner, få kjennskap til svært sensitive opplysninger om et stort antall pasienter. Direktoratet uttaler at pasientene vil befinne seg i en svært sårbar situasjon, ikke bare med hensyn til innholdet i opplysningene som kommer frem, men også som en naturlig konsekvens av pasientrollen. Videre uttales: "De som forsker vil være en ukjent person for pasientene, og skal overvære lukkede, private lege-pasientsamtaler og sengeposter. Denne tilstedeværelsen vil kunne forrykke den trygghet og tillit som et pasient/behandlerforhold er avhengig av."

Direktoratet kan ikke se at det aktuelle forskningsprosjektet vil være til så stor fordel eller interesse for forskningsdeltakerne selv, og de pasientgrupper de tilhører, at et inngrep av en slik art og størrelse kan tillates. Etter direktoratets vurdering vil en dispensasjon fra taushetsplikten innebære et så stort inngrep i den enkelte pasients integritet at det vil være i strid med legalitetsprinsippet. Direktoratet gjør oppmerksom

på at eventuell tilgang til taushetsbelagte opplysninger praktisk kan hentes inn ved at helsepersonell som allerede har tilgang til opplysningene i medhold av helsepersonelloven, og ikke forskeren, kan stå for førstehåndskontakten med pasienten.

I klagen presiserer og utdyper klager fremgangsmåten i den planlagte studien. Det presiseres at studien består av en samtykkebasert del og en ikke-samtykkebasert del. Den samtykkebaserte delen omfatter de personlige lege-pasient konsultasjonene (en til en konsultasjonene), og denne delen av studien vil derfor ikke nødvendiggjøre dispensasjon fra taushetsplikt, da pasientene vil bli forespurt om deltakelse i prosjektet, og samtykke vil bli innhentet.

Studiens ikke-samtykke baserte deler omfatter deltakelse i interne møter, som morgenmøter, previsitter, undervisningsmøter og personalmøter, samt visittrunder på sengepostene. Det presiseres at forsker ikke aktivt skal innhente pasientopplysninger, og personidentifiserbare data heller ikke vil bli nedtegnet eller registrert i noen form. Forsker ønsker ikke innsyn i pasientjournaler, prøvesvar eller andre pasientdata. Målet for forskningsprosjektet er å studere legene i deres vanlige kliniske arbeid, supplert med avklarende spørsmål underveis.

På bakgrunn av klagebrevet har Sosial- og helsedirektoratet vurdert saken på nytt. Direktoratet har kommet til at vedtaket vedrørende dispensasjon fra taushetsplikt for deltakelse i interne møter omgjøres.

Klagen slik den foreligger for departementet gjelder dermed avslaget på søknaden om forskerens adgang til å kunne delta på legenes visittrunder.

Departementets vurderinger
Det foreligger klagerett etter forvaltningsloven § 28. Departementet legger til grunn at klagen er fremsatt innen fristen i henhold til forvaltningsloven § 29, jf. brev av 4. mai 2005 fra direktoratet. Helse- og omsorgsdepartementet er rette klageinstans. Klageinstansen kan etter forvaltningsloven § 34 fjerde ledd selv treffe nytt vedtak i saken eller oppheve det og sende saken til underinstansen til helt eller delvis ny behandling.

Ved behandling av klagen har departementet lagt til grunn de opplysninger som fremgår av sakens dokumenter.

Departementet har kommet til at direktoratets vedtak bør omgjøres. En forutsetning for dette er at pasientene på den aktuelle avdelingen på forhånd blir informert om forskningsprosjektet, og at de gis adgang til å reservere seg mot at forskeren som observatør deltar på visitten.

Side 2

Det er videre en forutsetning at Regional komité for medisinsk etikk tilrår at prosjektet gjennomføres. I følge klagen har forsker diskutert prosjektet med leder for den regionale komité for medisinsk forskningsetikk i Nord-Norge, som anser at studien ikke kommer inn under REK's mandat, da dette ikke dreier seg om biomedisinsk forskning. Departementet vil vise til mandatet for De regionale etiske komiteer for medisinsk forskningsetikk kapittel 2 punkt 3 der det fremgår at mandatet også omfatter forskningsprosjekter der det inngår mennesker og identifiserbare eller anonyme data. Departementet antar at spørsmålet om en forsker i et bestemt forskningsprosjekt skal kunne delta på legevisitter eller ikke angår den enkelte pasient på en slik måte at spørsmålet må underlegges en etisk vurdering. Departementet viser også til at direktoratet i brev 4. mai 2005 har satt tilråding fra Regional etisk komité som vilkår for å dispensere fra taushetsplikten for forskers deltakelse i møter.

Det rettslige utgangspunkt er som direktoratet anfører at pasientopplysninger er underlagt lovbestemt taushetsplikt, jf. helsepersonelloven (hlspl.) § 21 og forvaltningsloven § 13. Dette innebærer at helsepersonell skal hindre andre i å få adgang eller kjennskap til opplysninger om folks legems- eller sykdomsforhold eller andre personlige forhold som de får vite om i egenskap av å være helsepersonell. Plikten til å sikre opplysningenes konfidensialitet gjelder også ved innsamling av opplysningene. En forutsetning for at en forsker skal kunne delta på en leges visittrunder vil derfor være at det foreligger et lovhjemlet unntak fra taushetsplikten.

Etter direktoratets vurdering vil innvilgelse av dispensasjon fra taushetsplikten innebære et så stort inngrep i den enkelte pasients integritet at det vil være i strid med legalitetsprinsippet. Taushetsplikten kan etter direktoratets vurdering bare oppheves gjennom samtykke fra de aktuelle pasienter, det vil si en frivillig, uttrykkelig og informert erklæring fra den registrerte om at han eller hun godtar at helseopplysninger om seg selv blir behandlet.

Departementet har lagt vekt på at studien kan generere kunnskap som kan være av betydning i legers grunn- etter- og videreutdanning.

Departementet har videre lagt vekt på at ingen personidentifiserbare pasientopplysninger vil bli nedskrevet eller oppbevart.

Departementet mener at pasientenes integritetsvern er ivaretatt ved at pasientene blir informert om prosjektet, herunder at de kan reservere seg mot deltakende observasjon/indirekte observasjon fra forskeren sin side.

Oppsummering:
Med hjemmel i helsepersonelloven 29 og forvaltningsloven § 13 d innvilger departementet søknad om dispensasjon fra taushetsplikt i forbindelse med deltakelse på visittrunder, jf. søknaden.

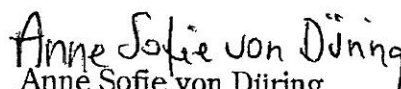Dispensasjonen gjelder prosjektleder Kari Milch Agledahl

Dispensasjonen gis på følgende vilkår:
- Pasientene på den aktuelle avdelingen må på forhånd ha blitt informert om det aktuelle forskningsprosjektet, og at de kan reservere seg mot deltakende observasjon/indirekte observasjon fra forskeren sin side.
- Regional komité for medisinsk forskningsetikk tilrår at prosjektet gjennomføres.
- Taushetsplikten etter helsepersonelloven og forvaltningsloven overholdes.
- Publikasjoner gis i en slik form at enkeltpersoner ikke kan gjenkjennes.
- Prosjektet gjennomføres i samsvar med prosjektbeskrivelsen.

Med vennlig hilsen

Elisabeth Salvesen e.f.
Fung. ekspedisjonssjef

Anne Sofie von Düring
seniorrådgiver

Kopi:
Sosial- og helsedirektoratet
Den nasjonale forskningsetiske komité for medisin
Regional forskningsetisk komité for medisin Nord Norge

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Deres ref.:   Vår ref.: 200604410-3/MRO/400   Dato: 22.09.2006

P REK NORD 90/2006 KLINIKKENS SKJULTE VERDIER - TILBAKEMELDING FRA FORSKNINGSETISK KOMITÉ

Prosjektet ble lagt frem for Regional komité for medisinsk forskningsetikk (REK Nord) i møte 31.08.06. I referatet heter det:

"Målsettingen for denne kvalitative studien er å utvikle forståelsen av hva det vil si å være lege i et moralsk perspektiv. En vil forsøke å kartlegge og synliggjøre legers etiske resonneringer og valg i vanlig klinisk arbeid. Hvordan handler og beslutter de rent faktisk i moralske problemstillinger? Hvilke idealer eller prinsipper er det de forsøker å handle i tråd med? Og hvilke faktorer vektlegges av legene selv i verdimessige valgsituasjoner? For å framskaffe kunnskap om dette vil forskeren ved deltakende observasjon studere sykehusleger gjennom arbeidsdagen, både på morgenmøter, visitt og i samtale/konsultasjon med pasienter. Det er ikke legens samhandling med pasientene *per se* som er fokus for studien, men legenes resonneringer og valg gjennom hele arbeidsdagen. Imidlertid vil forskeren gjennom dette studiedesignet få tilgang til sensitive og taushetsbelagte opplysninger om den enkelte pasient. Der forskeren er til stede ved konsultasjoner, vil det bli innhentet informert samtykke fra pasientene. For informasjon som kommer fram på morgenmøter, røntgenmøter, previsitt og visitter, er det søkt om dispensasjon fra taushetplikten

Til dagens møte forelå også prosjektleders e-brev av 22.8.2005 til REK Nord, svar til prosjektleder fra REK Nord i brev av 1.9.2005, prosjektleders utfylte skjema for søknad til Sosial- og Helsedirektoratet om dispensasjon fra taushetsplikt (feilaktig datert 23.8.2006?), svar til prosjektleder fra Sosial- og Helsedirektoratet i brev av 22.12.2005, klage fra prosjektleder til Sosial- og helsedirektoratet i brev av 22.1.2005, svar til prosjektleder fra Sosial- og helsedirektoratet i brev av 4.5.2006, samt svar til prosjektleder fra Helse- og omsorgsdepartementet av 28.7.2006.

Regional komité for medisinsk forskningsetikk, Nord-Norge (REK Nord) har tidligere vurdert spørsmålet om prosjektet "Klinikkens skjulte verdier" er framleggingspliktig for REK. Prosjektleder ble i brev av 1.9.2005 fra REK Nord meddelt at komiteen fant at prosjektet falt utenfor komiteens mandat. Vedtaket ble gjort av komiteens leder med tilslutning fra samlet komité i møte 29.9.2005.

Prosjektleders søknad om dispensasjon fra taushetsplikten ble avslått fra Sosial- og helsedirektoratet. Etter klage er vedtaket omgjort av Helse- og omsorgsdepartementet, Helse- og omsorgsdepartementet uttaler imidlertid at "Departementet antar at spørsmålet om en forsker i et

bestemt forskningsprosjekt skal kunne delta på legevisitter eller ikke angår den enkelte pasient på en slik måte at spørsmålet må underlegges en etisk vurdering." og setter som forutsetning for dispensasjonen at prosjektet er tilrådd av Regional komité for medisinsk forskningsetikk. I realiteten innebærer dette et krav om omgjøring av REK Nords tidligere vedtak.

Vedtak:

REK Nord har på nytt vurdert prosjektet opp mot komiteens mandat, som omfatter biomedisinsk forskning på mennesker. I prosjektet skal det forskes på mennesker, i dette tilfellet leger. Det er aspekter ved legers yrkesutøvelse som skal studeres og det innhentes ingen biomedisinske opplysninger om personene det forskes på. Forskeren kan gjennom prosjektet få tilgang til personidentifiserbare pasientopplysninger, men disse vil ikke inngå som data i forskningen. At forskningsarbeidet innebærer at forskeren får tilgang til helseopplysninger om personer som ikke inngår i forskningsprosjektet, har etter komiteens mening ikke betydning for forståelsen av hva slags type forskning dette er.

Komiteen opprettholder sitt tidligere vedtak om at prosjektet ikke er å betrakte som biomedisinsk forskning i henhold til mandatet for de regionale komiteer for medisinsk forskningsetikk.

Departementet anfører at spørsmålet om en forsker i et bestemt forskningsprosjekt skal kunne delta på legevisitter eller ikke angår den enkelte pasient på en slik måte at spørsmålet må underlegges en etisk vurdering. REK Nord slutter seg til dette, men anser at nødvendig etisk vurdering i dette tilfellet er ivaretatt av departementets vurdering når det gjelder dispensasjon fra taushetsplikt.

På bakgrunn av departementets forutsetning for å innvilge dispensasjon fra taushetplikt og av hensyn til framdriften i prosjektet, vil REK Nord uttale at komiteen ikke ser at prosjektet reiser etiske betenkeligheter av en slik karakter at komiteen ville ha frarådd prosjektet, hvis det hadde falt innenfor mandatet."

For ordens skyld gjør vi oppmerksom på at komiteens virksomhet er underlagt lov om offentlighet i forvaltningen (offentlighetsloven). Dette betyr at alle saksdokumenter er offentlige, med mindre det er gjort unntak i lov eller i medhold av lov. Et eventuelt krav om unntak fra offentlig innsyn må derfor begrunnes med henvisning til lovbestemmelser. Vi viser spesielt til offentlighetslovens §§ 2, 5a og 6 og forvaltningslovens § 13.

Når det gjelder lov om behandlingsmåten i forvaltningssaker (forvaltningsloven) gjelder kap I-III (lovens område, regler om habilitet og alminnelige regler om saksbehandlingen) og §§ 18-20 (om partsinnsyn) for komiteenes virksomhet.

Vennlig hilsen

May Britt Rossvoll
førstekonsulent

Appendix II

Study I: Information to doctors and patients

Informasjon om forskningsprosjektet *Klinikkens skjulte verdier*

- **Målsetning**: Prosjektet går ut på å synliggjøre legers etiske resonneringer og valg i vanlig klinisk arbeid. For å oppnå dette ønsker jeg å ta for meg legenes konkrete omgang med verdispørsmål i klinikken, for å se og høre hvordan de faktisk handler og beslutter i moralske problemstillinger. Jeg vil ikke vurdere legenes medisinske avgjørelser, og heller ikke evaluere legenes handlinger i forhold til moralsk rett og galt. Jeg ønsker å få tak i hva som ligger til grunn for legenes verdimessige resonnering.

- **Metode**: Den planlagte studien går ut på å følge legers arbeidshverdag, i første omgang allmennlegene. Det vil si at jeg vil være med på morgenmøte, pasientkonsultasjoner, evt. kommunale oppgaver og tverrfaglige møter. I tillegg håper jeg legen har mulighet til å avsette tid til et 20-30min intervju på slutten av dagen. Intervjuet vil da i hovedsak dreie seg om dagens hendelser, og legen vil få mulighet til å utdype sine egne handlinger hvis ønskelig.

- **Taushetsplikt**: Jeg er selv lege og vant til å forholde meg til taushetsbelagt informasjon. Som forsker har jeg imidlertid ikke tilgang til pasientdata ettersom jeg ikke er involvert i behandlingen av pasientene. Jeg vil derfor innhente samtykke av alle pasientene som kommer til konsultasjon hos den legen som observeres. Dersom pasienten ikke samtykker, vil jeg ikke være til stede i den aktuelle konsultasjonen. Jeg har ikke tilgang til pasientens journal utover opplysninger om den aktuelle problemstillingen.

- **Datainnsamling**: Det vil ikke bli foretatt noen opptak av observasjoner eller intervju, registrering vil kun skje i form av notater underveis og etter observasjonen og intervjuet. For å forstyrre konsultasjonen minst mulig vil jeg unngå å ta notater når pasienten er tilstede.

- **Konfidensialitet**: Jeg vil ikke nedtegne noen personidentifiserbare opplysninger om verken pasientene eller legene. Legene som observeres vil anonymiseres i materialet, og ikke være direkte eller indirekte identifiserbare i fremtidige artikler.

- **Prosjektets omfang**: Studien av allmennlegenes kliniske hverdag er en del av en større studie hvor også sykehusleger inngår. I utgangspunktet er det planlagt observasjon og intervju med ca 30 leger, men dette må avpasses i forhold til den fortløpende analysen av datamaterialet. Studien inngår i et doktorgradsprosjekt ved Universitetet i Tromsø og skal avsluttes vår 2010.

- **Finansiering**: Prosjektet er finansiert av forskningsmidler fra Helse Nord.

- **Prosjektansvarlig**: Undertegnede er prosjektansvarlig og ansvarlig for innsamling og behandling av data. Veileder for prosjektet er Åge Wifstad, førsteamanuensis ved ISM, UiT. Biveileder er Reidun Førde, professor II ved seksjon for medisinsk etikk, UiO.

Vennlig hilsen

Kari Milch Agledahl
Institutt for Samfunnsmedisin
Medisinsk fakultet
Universitetet i Tromsø
9037 Tromsø
Tlf: 776 44811 (41 55 04 46)

Forespørsel om samtykke

Deltakelse i prosjektet er frivillig. Samtykket kan trekkes tilbake på et hvilket som helst tidspunkt uten å oppgi grunn. Dersom deltageren ønsker å få tilsendt fremtidige artikler publisert på bakgrunn av denne studien, må deltagerens navn og adresse registreres. Personinformasjonen vil ikke kunne knyttes til datainnsamlingen.

☐ Jeg har mottatt skriftlig og muntlig informasjon om prosjektet *Klinikkens Skjulte Verdier*. På grunnlag av dette er jeg villig til å delta i studien.

☐ Jeg ønsker å få tilsendt artiklene som baseres på studien.

.

Navn:_____

Adresse:_____

Postnummer:_____   Sted:_____

Signatur:_____   Sted:_____   Dato:_____

Forespørsel om deltagelse i forskningsprosjektet
Klinikkens Skjulte Verdier

Dr .... deltar i dag i et forskningsprosjekt i medisinsk etikk. Det medfører at han blir fulgt gjennom hele arbeidsdagen av undertegnede, *Kari Milch Agledahl*, som selv er lege og forsker. Prosjektet fokuserer på de verdimessige sidene av medisinen, og målet er å synliggjøre hvordan leger faktisk håndterer verdispørsmål i arbeidet sitt.

Ettersom du er pasient hos denne legen i dag, ønsker jeg om å be om tillatelse til å være til stede under legetimen. Jeg har taushetsplikt om alle pasientopplysninger, og ingen identifiserbar informasjon vil bli nedtegnet eller brukt i studien. Selv om du samtykker til studien, har jeg ikke tilgang til din pasientjournal.

All deltakelse i prosjektet er frivillig. Dersom du ikke ønsker å delta i studien, vil legetimen forløpe som normalt, og det har ingen negative følger for deg som pasient. Selv om du samtykker til deltagelse, kan samtykket trekkes tilbake på et hvilket som helst tidspunkt uten at du trenger å oppgi grunn.

Ytterligere informasjon om studien finnes på neste side.

Vennlig hilsen

Kari Milch Agledahl

Institutt for Samfunnsmedisin
Medisinsk fakultet
Universitetet i Tromsø
9037 Tromsø

Jeg har mottatt informasjon om forskningsprosjektet *Klinikkens Skjulte Verdier*.

Jeg er **villig** til å delta i studien. ☐

Jeg er **ikke villig** til å delta i studien. ☐

Signatur:_____

Informasjon om studien

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- **Målsetning**: Prosjektet går ut på å synliggjøre legers etiske resonneringer og valg i vanlig klinisk arbeid. Fordi legers avgjørelser ofte har stor betydning for pasientenes liv og helse, er medisinske overveielser tett knyttet til verdivurderinger. Kjennskap til hvordan verdiene er infiltrert i medisinsk praksis kan bedre legenes forståelse av de etiske sidene av faget, og på denne måten hjelpe legene til å treffe kyndige medisinske avgjørelser og bli bedre leger. For å oppnå dette ønsker jeg å ta for meg legenes konkrete omgang med verdispørsmål i klinikken, for å se og høre hvordan de faktisk handler og beslutter i moralske problemstillinger.

- **Taushetsplikt**: Jeg er selv lege og har vanlig taushetsplikt. Som forsker har jeg imidlertid ikke tilgang til informasjon om pasienter siden jeg ikke er involvert i den medisinske behandlingen. Alle pasientene som kommer til konsultasjon hos den legen som observeres blir derfor spurt om samtykke. For pasienter som samtykker har jeg ikke tilgang til pasientjournalen utover opplysninger om den aktuelle problemstillingen. Dersom pasienten ikke samtykker, vil jeg ikke være til stede i den aktuelle konsultasjonen.

- **Datainnsamling**: Det vil ikke bli foretatt noen form for opptak av observasjoner, registrering vil kun skje i form av notater. For å forstyrre konsultasjonen minst mulig vil jeg unngå å ta notater når pasienten er tilstede.

- **Konfidensialitet**: Jeg vil ikke notere eller bruke noen identifiserbare opplysninger om pasientene og legene. Legene og pasientene som observeres vil bli fullt anonymisert i fremstillingen av studien.

- **Prosjektets omfang**: I utgangspunktet er det planlagt observasjon og intervju med ca 30 leger. Studien inngår i et doktorgradsprosjekt ved Universitetet i Tromsø som skal avsluttes våren 2010.

- **Finansiering**: Prosjektet er finansiert av forskningsmidler fra Helse Nord.

- **Prosjektansvarlig**: Undertegnede er prosjektansvarlig og ansvarlig for innsamling og behandling av data. Veileder for prosjektet er Åge Wifstad, førsteamanuensis ved Institutt for Samfunnsvitenskap, Universitetet i Tromsø. Biveileder er Reidun Førde, professor II ved seksjon for medisinsk etikk, Universitetet i Oslo.

Forespørsel om deltagelse i forskningsprosjektet
Klinikkens Skjulte Verdier

Medisinsk avdeling deltar denne uken i et forskningsprosjekt i medisinsk etikk. På grunn av dette følges Dr .... gjennom arbeidsdagen i dag av undertegnede som selv er lege og forsker.

Siden du er pasient hos denne legen i dag, ønsker jeg om å be om tillatelse til å være til stede under legetimen. Hvis du ikke ønsker min tilstedeværelse, har det ingen negative følger for deg som pasient. Selv om du samtykker nå, kan du ombestemme deg når som helst uten at du trenger å oppgi grunn.

Ytterligere informasjon om studien finnes på neste side.

Vennlig hilsen

Kari Milch Agledahl

Jeg har mottatt informasjon om forskningsprosjektet Klinikkens Skjulte Verdier.

Jeg **samtykker** til at forsker er til stede. ☐

Jeg **samtykker ikke** til at forsker er til stede. ☐

Signatur:_____

Informasjon om studien

.

- **Målsetning**: Prosjektet går ut på å synliggjøre legers etiske resonneringer og valg i vanlig klinisk arbeid. Fordi legers avgjørelser ofte har stor betydning for pasientenes liv og helse, er medisinske overveielser tett knyttet til verdivurderinger. Kjennskap til hvordan verdiene er infiltrert i medisinsk praksis kan bedre legenes forståelse av de etiske sidene av faget, og på denne måten hjelpe legene til å treffe kyndige medisinske avgjørelser og bli bedre leger. For å oppnå dette ønsker jeg å ta for meg legenes konkrete omgang med verdispørsmål i klinikken, for å se og høre hvordan de faktisk handler og beslutter i moralske problemstillinger.

- **Taushetsplikt**: Jeg er selv lege og har vanlig taushetsplikt. Som forsker har jeg imidlertid ikke tilgang til informasjon om pasienter siden jeg ikke er involvert i den medisinske behandlingen. Alle pasientene som kommer til konsultasjon hos den legen som observeres blir derfor spurt om samtykke. For pasienter som samtykker har jeg ikke tilgang til pasientjournalen utover opplysninger om den aktuelle problemstillingen. Dersom pasienten ikke samtykker, vil jeg ikke være til stede i den aktuelle konsultasjonen.

- **Datainnsamling**: Det vil ikke bli foretatt noen form for opptak av observasjoner, registrering vil kun skje i form av notater. For å forstyrre konsultasjonen minst mulig vil jeg unngå å ta notater når pasienten er tilstede.

- **Konfidensialitet**: Jeg vil ikke notere eller bruke noen identifiserbare opplysninger om pasientene og legene. Legene og pasientene som observeres vil bli fullt anonymisert i fremstillingen av studien.

- **Prosjektets omfang**: I utgangspunktet er det planlagt observasjon og intervju med ca 30 leger. Studien inngår i et doktorgradsprosjekt ved Universitetet i Tromsø som skal avsluttes våren 2010.

- **Finansiering**: Prosjektet er finansiert av forskningsmidler fra Helse Nord.

- **Prosjektansvarlig**: Undertegnede er prosjektansvarlig og ansvarlig for innsamling og behandling av data. Veileder for prosjektet er Åge Wifstad, førsteamanuensis ved Institutt for Samfunnsvitenskap, Universitetet i Tromsø. Biveileder er Reidun Førde, professor II ved seksjon for medisinsk etikk, Universitetet i Oslo.

STUDIE I MEDISINSK ETIKK

Medisinsk avdeling deltar denne uken (uke 12) i et forskningsprosjekt i medisinsk etikk. Enkelte av legene ved avdelingen vil derfor bli fulgt av Kari Milch Agledahl, som selv er lege og forsker. Studien fokuserer på legene og deres arbeid og ikke primært på pasientene, men du som pasient vil også kunne bli observert hvis du er i kontakt med legen som følges den arbeidsdagen. Det vil imidlertid ikke bli brukt noen identifiserbare opplysninger om deg som pasient. Hvis du ønsker det, kan du reservere deg mot å bli observert i forbindelse med studien. Gi da beskjed til avdelingssykepleier.

Ytterligere informasjon om studien fås ved henvendelse til sykepleierne.

Appendix III

Study II: Documentation of approval

UNIVERSITETET I OSLO

DET MEDISINSKE FAKULTET

Pål Gulbrandsen
Akershus universitetssykehus
HØKH
Postboks 95
1478 Lørenskog

Regional komité for medisinsk og helsefaglig
forskningsetikk Sør-Øst C (REK Sør-Øst C)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 84 46 67
E-post: t.e.svanes@medisin.uio.no
Nettadresse: http://helseforskning.etikkom.no

Dato: 08.09.09
Deres ref.:
Vår ref.: 2009/913 (oppgis ved henvendelse)

Å ivareta pasienten.

Vi viser til søknad mottatt til frist 03.08.09 om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden er blitt vurdert av Regional komité for medisinsk og helsefaglig forskningsetikk i henhold til lov av 20. juni 2008 nr. 44, om medisinsk og helsefaglig forskning (helseforskningsloven) kapittel 3, med tilhørende forskrift om organisering av medisinsk og helsefaglig forskning av 1. juli 2009 nr 0955.

Prosjektet skal synliggjøre legers etiske valg i vanlig klinisk arbeid, for å bedre forstå den verdimessige betydningen av klinisk praksis. Første del av prosjektet inkluderte observasjon og intervju av 15 leger, hvor man fant at legenes kliniske tilnærming systematisk vektla visse moralske verdier. I denne delstudien ønsker man å utdype disse resultatene ved å studere opptak av lege-pasient møter, for å se i hvilken grad legene ivaretar pasientene utover det medisinske, som medmennesker.

Komiteen har ingen innvendinger til at studien gjennomføres.

Vedtak:
Prosjektet godkjennes.

I tillegg til vilkår som fremgår av dette vedtaket, er tillatelsen gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Komiteens avgjørelse var enstemmig.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jfr. helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK Sør-Øst C (jfr. forvaltningsloven § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. forvaltningsloven § 29

Med vennlig hilsen

Arvid Heiberg (sign.)
professor dr. med.
leder

Tor Even Svanes
komitésekretær

Vi ber om at alle henvendelser sendes inn via vår saksportal: http://helseforskning.etikkom.no
eller på e-post til: post@helseforskning.etikkom.no
Vennligst oppgi vårt saksnummer/referansenummer i korrespondansen.

Appendix IV

Study II: Information to doctors and patients

Erklæring om samtykke – leger

Undersøkelse av kvaliteten på legers samtale med pasienter

Jeg har lest skriftlig informasjon og fått muntlig informasjon om undersøkelsen som handler om hvordan kvaliteten på legers samtale med pasienter kan forbedres. Jeg godtar at mine konsultasjoner videofilmes som ledd i dette forskningsprosjektet, så fremt pasienten har avgitt informert samtykke.

Jeg er kjent med at jeg når som helst kan trekke tilbake mitt samtykke til oppbevaring av videoopptakene. Jeg er videre kjent med at videoopptakene kun vil bli brukt til forskning på kommunikasjon mellom leger og pasienter, og at jeg og involvert(e) pasient(er) vil bli kontaktet for ev. å avgi samtykke til bruk av et videoopptak i forbindelse med undervisning av leger eller medisinstudenter dersom det blir aktuelt.

☐ Jeg gir samtykke til at videoopptakene lagres ved Universitetet i Oslo til bruk for forskning på kommunikasjon mellom leger og pasienter til og med år 2020. Ev. nye prosjekter vil bli vurdert av Regional komité for medisinsk forskningsetikk.

☐ Jeg gir kun samtykke til at videoopptakene lagres ved Universitetet i Oslo til bruk for det aktuelle prosjektet, der effekten av et kurs i klinisk kommunikasjon skal vurderes, dvs. lagring til og med år 2011.

Lørenskog, _____

          (dato)

Navn: _____ Fødselsdato: _____

_____

Underskrift lege

Pasientinformasjon for forskningsprosjekt "Bedre samtaler med pasienter og pårørende"

Vi spør deg med dette om du som pasient/pårørende ved Akershus universitetssykehus vil være med på et forskningsprosjekt. Formålet med prosjektet er å studere legers samtaler med pasienter og/el. pårørende. <u>Det er frivillig å delta.</u>

Legene får et kurs i hvordan de bør føre samtaler. Vi videofilmer samtaler med pasienter/pårørende før og etter kurset. Kameraet vil være stilt slik at vi ser legens ansikt tydelig, og ditt ansikt hvis det er mulig. Om du må kle av deg, vil det ikke bli filmet, men mikrofonen vil oppfatte samtalen likevel.

Du får et lite spørreskjema før samtalen, og to små spørreskjemaer etter.

<u>Enten du vil være med eller ikke, får du samme medisinske behandling.</u> Hvis du velger å være med, men ombestemmer deg senere, vil videoen og alle andre opplysninger om deg bli slettet så fort du gir oss beskjed. Det får ingen konsekvenser for din behandling, ditt forhold til legen eller sykehuset.

Datafiler som er opprettet med utgangspunkt i materialet, men der ingen opplysninger kan føres tilbake til deg, vil ikke bli fjernet. I disse filene finnes verken videobilder eller andre data som indirekte kan knytte informasjonen til deg. Du har ellers rett til å kreve innsyn i all informasjon som handler om deg.

Videoen vil kun bli sett av forskere med taushetsplikt. Taushetsplikten tillater ikke bruk av informasjonen til noe annet formål, selv ikke om det kunne vært til din fordel (for eksempel i forbindelse med en rettssak). Videoen blir lagret forskriftsmessig ved Universitetet i Oslo slik at uvedkommende ikke kan få tak i den. Det aktuelle prosjektet varer til 2011, men det kan være aktuelt å bruke videoene til flere studier av legers samtaler med pasienter/pårørende. Vi vil derfor be om ditt samtykke til lagring til og med 31. desember 2020, men du kan også velge å gi samtykke til lagring bare til og med 31. desember 2011.

Vi trenger ditt navn, adresse og telefonnummer av tre grunner. Vi ønsker å kontakte deg per telefon (eller personlig hvis du fortsatt befinner deg i sykehuset) ett døgn etter videoopptaket for å forsikre oss om at du fortsatt er villig til å delta. Dersom du ber oss slette videoene og/eller andre opplysninger, må vi være sikre på at vi fjerner riktig materiale. Dersom lovverket endres, slik at det stilles krav til lengre lagring av forskningsmateriale enn det som gjelder i dag (det er foreslått 10 år), må vi kunne kontakte deg for å opplyse deg om dette.

Følgende person er databehandlingsansvarlig for prosjektet og fungerer som kontaktperson:
Avdelingssjef/1. amanuensis og lege **Pål Gulbrandsen**
HØKH, Postboks 95, Akershus universitetssykehus/Universitetet i Oslo, 1478 Lørenskog.
Telefoner: 67929461 (arbeid), 95827288 (mobil), 67971277 (privat).

Navn og kontaktopplysninger på to andre kontaktpersoner:
Professor/psykolog **Arnstein Finset**, Avdeling for atferdsfag, Universitetet i Oslo. Telefon 22851435.
Stipendiat/lege **Bård Fossli Jensen**, Akershus universitetssykehus. Telefon 91100522.

Erklæring om samtykke

Jeg har mottatt skriftlig og muntlig informasjon og er villig til å delta i studien.

☐   Jeg gir samtykke til at opplysninger om meg, inkludert videoopptak, lagres ved

Universitetet i Oslo til bruk for forskning på samtaler mellom leger og

pasienter/pårørende til og med 31.12.2020.

☐   Jeg gir <u>kun</u> samtykke til at opplysninger om meg, inkludert videoopptak, lagres ved

Universitetet i Oslo til bruk for det aktuelle prosjektet, dvs. til og med 31.12.2011.

Lørenskog, _____

               (dato)

Navn pasient/pårørende:_____

Ev. den pårørendes familieforhold til pasient:_____

Navn pasient:_____

_____

Underskrift pasient/pårørende

Jeg har gitt muntlig informasjon om undersøkelsen til pasienten/pårørende.

Underskrift lege/prosjektmedarbeider