

For whom and for what?

Exploring the question of ‘informed consent’ in treatment decision making processes

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Whose interests are preserved by a practice of informed consent? While the declared intention behind the introduction of this principle is clear enough, the question about how it actually works in specific, real-life situations can only be answered empirically. In this paper I draw on material from a research project on decision making processes regarding medical treatment for incurable cancer patients. The fieldwork for this has included observations of actual clinical consultations in a Norwegian hospital. On the basis of these I will explore the question of informed consent within two kinds of clinical encounters which regularly take place at two different stages in a diagnostic process. Each of these kinds of consultations followed their own set pattern, with striking contrasts regarding patients' involvement and consent. This disparity can hardly be explained by a difference in the gravity of the implications for the patients involved, and begs questions about the practice of informed consent in current clinical situations.

[end of life, doctor-patient communication, risk, uncertainty, responsibility, cultural scripts, Norway]

Among the four principles that for long have reigned as the pillars of ethics in medicine and health care (autonomy, beneficence, nonmaleficence, and justice), autonomy has held a paramount position (see e.g. O'Neill 2002; Beauchamp 1999; Faden & Beauchamp 1986). In accordance with a rising educational level and the development of a market orientation in society in general, the right to self determination, also in health care matters, has gained ground and challenged the paternalistic tradition that used to dominate the medical profession (see e.g. Katz 2002).

Intrinsically linked to the principle of autonomy, the institutional practice of informed consent is a central part of the ethical regulation within medicine. Depending on the stringency of the definition and the criteria applied, the origins of the practice of informed consent can be differently placed in history (Faden & Beauchamp 1986). Though examples of a demand for patients' consent can be found before that

(see e.g. Vollmann & Winau 1966), the Nürnberg processes is a frequently used reference point in connection with the historical background of informed consent (see e.g. Manson & O'Neill 2007; Ten Have & Clark 2002; Faden & Beauchamp 1986). This is indeed a sinister background: Extreme though it is, during the Nürnberg processes it was glaringly proved that the beneficence of medical professionals cannot be taken for granted. The code that was to follow, declared informed consent to be an irrefutable requirement for any medical research activity involving human subjects. Later on, what was introduced as a principle for medical research was made mandatory also for clinical ethics. Moreover, the stated information requirement developed into a demand for complete information, and an increasing degree of standardized specificity. This ideal, however, is neither attainable, nor necessarily beneficial for the patients concerned (Manson & O'Neill 2007). My intention in this article is to explore some of the dilemmas implicit in the issue of informed consent in clinical contexts, and the way it is practiced in some of the situations pertaining to these contexts.

The practice of informed consent is supposed to ensure that decisions about medical interventions are made in accordance with the patients' own preferences, and that nothing is done against their own interests. Inspired by Annemarie Mol's critical analysis of the emphasis on choice in health care (2008), and Sharon Kaufman's elucidatory description of the complexity of the consequences of this for patients at the end of life (2005), I have set out to explore the practice of informed consent in a Norwegian hospital context. My discussion is based on material from a project on patient involvement in decision making processes connected to medical treatment, which involved eighteen months of field work among seriously ill cancer patients in two different hospital wards. What, within this context, triggers a call for informed consent? What kind of logic is then applied? What implicit dilemmas are there, and how are they handled by those concerned?

I will approach these questions through the presentation of two cases, taken from two different kinds of doctor-patient consultations, and will draw on the concept *cultural script* as an analytical tool.

The stage and the framework: Hospital encounters and cultural scripts

This article is based on material from a research project on the role of patients and their relatives in treatment decisions when no curative measures are available. When lung cancer is detected with metastasis to other organs, or in a patient whose lung capacity is estimated to be too low to cope with the strain and the after effects of an operation, a surgical removal of the tumor is out of the question, and the prognosis is considerably worse than it otherwise would have been. Therapeutic measures like chemotherapy and radiation may be applied in the hope of achieving a temporary halting effect on the progression of the disease, and in the hope of a prolongation of life, limited though that may be. But the potential benefit is uncertain and the side effects may be considerable. This was also clearly stated to me at an early stage of the project, by one of the doctors who presented the situation like this:

Roughly speaking lung cancer patients can be divided into two main categories: non-small cell lung cancer, which is eighty per cent of the cases, and small-cell lung cancer, the remaining twenty per cent. The latter kind is the more aggressive one. The average life span without treatment is eight weeks. With chemotherapy this can be prolonged to an average of eight to ten months, but the side effects of the treatment are relatively severe. For non-small cell lung cancer the prospects are better to start with, with an average life span of twelve months without treatment. The possible gain from chemotherapy, however, is less. The life prolongation is on the average 2-3 months. But the treatment is somewhat milder.

For the last one and a half years I have been following inoperable lung cancer patients through the trajectory of their last stage in life. My contact with each patient started with attending their first consultation with a doctor about the results of tests carried out during a diagnostic process.¹ In most cases this first consultation was the occasion in which the patients were given their cancer diagnosis. For these patients this happened when the disease had already reached an incurable stage. Some patients, however, were called for a consultation before the diagnosis was available, in connection with a test that was necessary in order for a conclusion to be drawn.

In this article I will focus on the application of informed consent within these two kinds of clinical encounters, both of which followed a recurring pattern with remarkable similarities and differences. The encounters showed a striking contrast with regard to patient involvement in decision making processes and a difference in the demand for consent which can hardly be explained by a difference in the gravity of the implications for the patients concerned. One of these kinds of consultations, regarding the possibility of a surgical measure for investigative purposes with a minor chance of various complications, includes a written, statistical presentation of the risk implied and a standardized acquisition of informed consent. The other kind, concerning treatment options with notable side effects and poor chances of achieving what they are hoped to accomplish, does not.

In the attempt to decipher what this is about, I will draw on the concept of *cultural script* (Shore 1996) to see how far this can take us towards an understanding of the dynamics of these clinical consultations. I will base my discussion on examples of the two kinds of doctor-patient encounters mentioned above, primarily concentrating on a case of the first kind, which takes place while the diagnostication process is still going on. I selected these cases not because the patient concerned is a typical patient, but because of the way her encounter with the hospital doctors exposes the pattern of these consultations, including the application of informed consent. In spite of great variations in the individuals concerned, the evolvment of the encounters remains remarkably constant. While this cultural script can facilitate a consolidation of existing power relations, it also creates situations which affect and impair all those involved, the medical professionals included.

‘Cultural script’ is a concept with sociolinguistic roots, and has been defined as “highly codified and predictable exchanges with only minor individual variations” (Schank & Abelson, quoted in Shore 1996: 43). Schank and Abelson used the concept

for extensive studies of how restaurant guests interact with waiters to order their food, which clearly points to a functional purpose. My use of the term, however, is not semantic in the sense of referring to a word-by-word codified dialogical pattern, but is more in accordance with what Shore calls “a kind of foundational schema that can be realized with many variations and has room for spontaneous and individual variation as well” (op.cit: 66). I have used the term ‘cultural script’ for what I find to be a recognizable pattern in highly predictable behaviour in doctor-patient encounters in a hospital context.

The concept of cultural scripts implies a certain rationality² which pertains more to the larger institutional context than the judgements and deliberations made by the individual doctors. In adhering to the scripts, the doctors stand in alliance with the institution, partaking in and protected by the power that this institution possesses. At the same time they are captured by it, and though there is room for variation, deviating from the script in terms of its basic structure is not easily done.

The question of a biopsy in the midst of an investigation process: Alise and the unwelcome offer

The case of Alise concerns a consultation which took place in the midst of an investigation process. A medical examination meant to verify or discard a suspicion of lung cancer, is a process that varies considerably in duration and complexity. When other diagnostic measures like X-ray, computer tomography or bronchoscopy fail to provide sufficient basis for a conclusion, for some patients the next step is a biopsy of lung tissue, conducted during anaesthesia. This is one occasion that triggers the question of informed consent. There are certain risks attached to this surgical measure. Anaesthesia always implies the possibility of complications and operation wounds may give rise to infections. In this kind of consultations, patients are routinely asked to take a stand. Considering the risks involved, do they want this procedure to be done? In addition to the question posed in the consultation, patients are asked to sign an information form that states the risks in exact figures, to testify that they have been made aware of this.³

Few patients object to this procedure. But that does not make it unproblematic. Before going further into that issue, however, I will introduce you to Alise, a patient who did question the doctor’s approach, and by this throws light on the common practice.

In Alise’s case the cancer diagnosis is not the doctor’s main suspicion, though it is still a possibility which cannot be completely ruled out. The doctor has another diagnosis – sarcoidosis⁴ – as a main suspect, but that is not verified, and starting treatment on that suspicion alone is also problematic because of the side effects that this implies. There is no specific treatment for sarcoidosis. And the other suspect – lung cancer – faint as that might be, is a very serious possibility, and in case it should prove to be correct, early treatment can be crucial for the ultimate outcome.

This is a long consultation, of which I can only give a few limited extracts. Though Alise has gone through a lengthy diagnostication process, she meets this particular

doctor for the first time. She is a middle aged woman, divorced with two grown up children, and comes to the hospital alone. The doctor describes the medical findings at length, and explains the probable connection with the diagnosis of sarcoidosis. Then she says:

In medicine we sometimes deal with probabilities and let that suffice, and then we follow up. But if that is not – if you want to be sure and have a definite diagnosis, then we have chosen to offer you a surgical procedure.

She explains the procedure of a biopsy and how it involves full anaesthesia, and adds:

So it is a bit up to you, really, whether you want to just settle on the assumption that it probably is this disease, and be followed up with regular check-ups, or whether you want to know for sure.

The physician then proceeds to give more information about sarcoidosis, explaining that because it is a disease of unknown origin, the only available treatment is based on general immune-suppressing medicines that also have harmful effects. Besides the diagnostic operation with a purpose to investigate the possibility of lung cancer and the tentative treatment meant to deal with the eventuality of sarcoidosis, the patient is presented with a third option, that is to 'wait and see'. The patient responds by saying that that option might have been quite alright if she had been well, but not now, when she is sick. To which the doctor replies that she understands her patient very well. That is why she has offered her this operation, the doctor says, – and then she adds: "but in case something happens [i.e. if something goes wrong] it might be difficult to justify that it was done."

After another round of going through the options, in which the doctor repeats the reasons for each of these, and states, once more, that it is up to the patient to choose, the patient exclaims:

Alise (A): You know – what is a bit problematic for me, is this offer-approach, if you know what I mean. I mean: to be offered something is very nice – and this is all about me, I realize that, – but the way I think is that if someone offers this to me, they have to mean that it is not completely necessary. I mean, if you regarded it to be necessary, then you would not have presented it as an offer, – you would have just said that it was going to be done.

Doctor (D): But that is not how it is. I cannot take the full responsibility for you.

A: No, I understand that.

D: You have to do it yourself. From the information you get from me, it has to be a bit up to you, too. It is not as if you have someone who decides all you have to do here. That's how it is.

A: But then I am left with the consequence of saying "thank you very much, I turn down that offer."

D: No, no.

A: I have never – let me just tell you that: I have never been in a situation where I’ve had full anaesthesia.

The doctor apparently attempts to treat the patient as an equal party. She makes an effort to provide Alise with extensive background information regarding the surgical question, by supplying physiological and anatomical details about her condition. The patient can thus be said to be granted the right to self determination, in accordance with the principle of autonomy.

But the doctor’s approach hardly seems to lead to empowerment for this patient. This is not the kind of choice she can make on her own. On the basis of what could she do that? As quoted above, she refers to her lack of experience regarding anaesthesia, which, in spite of her long history of ailments and afflictions, she has never had before. Her understanding of what it implies depends on the explanation provided by the doctor. The power unbalance which is inherent to this relationship remains unchanged. It is still the doctor who selects and conveys the facts that are given, and whatever pieces of knowledge she has shared with the patient, the doctor knows a lot more. By providing these facts, but no clear recommendation, the doctor has left the patient half way: she has explained the danger, before leaving the choice to her. And the information sheet which spells out the risks of complications in numerical detail that is handed over for signature by the patient prior to the operation, comes on top of it all.

Alise is a patient who displays an eager and explicit interest in factual information about her sickness, a patient who keenly asks and probes about all test that are conducted, all symptoms that emerge. Having a long history of multiple, chronic diseases, she has learned not to take it for granted that the doctors she meets are fully cognizant about the complexity of her condition and she is used to giving reminders, supplying additional information and filling in the gaps.

In a later conversation with me, Alise explains how she understands her need for information:

Yes, I am a patient who wants a lot of information. Because my way of life is such that when I have enough information I can park it all on a sidetrack, and that is important to me. That is how I have done it for all my ailments. One of the doctors I met at the outpatient lung clinic commented on that. It is very rare that people with a condition like mine are working at all, he said. But that has never been an issue for me, for when I have been given an answer about what is wrong and an assurance that it is not deadly, then I find out how I can best live with it, and adjust to that. This is pretty much how it is: I now understand that if I ever dreamt about reaching Galdhøpiggen,⁵ then that time is passed, you know. But I don’t sit there thinking “Oh, my goodness, now I cannot go hiking in the mountains because I can hardly make it to the fourth floor.”⁶ Well, I will not be able to do that. But then I start thinking about how many flat landscapes there are. That one might enjoy even just looking at them – if you see what I mean? Thus, now when I am in such a bad shape, I could have just been sitting there thinking about all the holiday plans I have made without being able to realize them after all. But instead of that, I think about all the nice little walks I am still able to make [...] And I have talked to my boss, so when I

have those bad days I have started work at six o'clock, and left the place at half past one. That has been fine. You see? Then I adjust, and that works well. But I cannot do that with what I don't recognize and don't know how to relate to, and when I don't know what is going to happen. And therefore it is very important for me to get all the information – I mean, enough information to be able to work it into [my knowledge about] the rest of my problems. So that I can live with it. And I intend to keep doing that no matter what they [doctors] present to me.

Thus Alise is clear about why she demands extensive information from her doctors. She needs it in order to be able to make informed decisions. Decisions about how to handle the challenges of her everyday life; to what extent she may exert herself without deplorable repercussions and what limitations she has to yield to in order to make use of the action space that is actually available for her. Alise requires a medical understanding of the nature of her problems to make an effective coping strategy, and sort out her own guidelines for living. She does not ask for direct instructions about what to do. Rather, she wants a basis on which she can decide for herself. According to Alise, doctors have questioned her choice about remaining employed on a full time basis, and told her that this is rare for patients with a condition like hers. Alise is aware of this being a choice that involves a prioritization of some things above others. She has described to me how she often has gone right to bed when returning from work, having spent all her energy and with nothing left for other activities. But she was happy about being able to do something that she finds meaningful, and knows she does well.

So Alise wants medical information, and a lot of it, too, as a basis for making decisions. But she strongly objects to the doctor's proposal of her making a decision about the surgical question, i.e. a possible biopsy of her lymph glands. Alise struggles to interpret what this offer means in terms of risk and necessity. It obviously makes her feel insecure. While being a person who otherwise takes on a lot of responsibility and wants to do so, to Alise this doctor's proposal implies a responsibility she does not recognize as her own.

Making this offer or posing this question is not this particular doctor's idea. It is regular practice and handing out the information sheet for the patient's signature is part of a hospital procedure. This is a cultural script, a collective practice which functions as a form of institutionalization of 'informed consent' at the hospital. The information sheet is a text about risk, and is thus one way of dealing with the issue of uncertainty.

The presentation of treatment options after a conveyance of a serious diagnosis: Bjarne and the issue of assumed consent

The issue of uncertainty is also a crucial point in the other kind of consultations I have observed: those concerning the announcement of the outcome of the diagnostic process when this concludes with inoperable lung cancer; the disclosure of bad news.

These encounters also concern treatment decisions, but here there is no call for informed consent. The common pattern of these consultations includes a description of the upcoming treatment – chemotherapy – not as a question, but as a given fact. The attitude of the patient – his or her interest in the treatment in question – is taken for granted.

The case I have chosen as an example of this kind of consultations, also concerns a patient with a complex set of chronic conditions. Having suffered from COPD (Chronic Obstructive Pulmonary Disease) for many years and with several heart operations behind him, Bjarne is an experienced user of health care services. He comes to the consultation together with his wife, who is also a COPD patient, and sits in a wheelchair.

Like in the case concerning the question about a possible investigative measure, consultations about a conclusive diagnosis also typically begin with a systematic recapitulation of the tests that have been done. The investigation of this patient started with an x-ray of the lungs, and proceeded with a bronchoscopy. A CT-guided biopsy had also been booked after that, but this was cancelled prior to the consultation. This is the doctor's account to the patient:

We have received the results from the bronchoscopy that was conducted, and cancer cells were deducted in that specimen. So thus we have somehow got a diagnosis. A tumor has been seen on the left lung, and as we have found cancer cells in tests from the bronchoscopy from the lungs, we know that what we are talking about here is lung cancer. And the reason for cancelling this biopsy, then, is that we already know what kind of cells we are dealing with here. We have also conducted X-rays of the head and we have conducted X-rays of the stomach, and we have not seen anything then. So we are left with a tumor in the left lung. It is about five centimeter at the most in diameter. And then the question is what to do with this. We also see on the X-ray that you have a lot of emphysema. The lung capacity is overall fairly low. You also have a lesion on the other lung, which further reduces the lung capacity. Our assessment is thus that you will not be able to stand an operation. We would have to remove such an amount of lung tissue that it would be difficult for you to recover after the anaesthesia, and the remaining lung tissue would simply not be enough to cope. So what we are left with then, is chemotherapy and perhaps radiation. Chemotherapy is something we will try to get started in any case.

The consultation follows a given pattern, common to all the consultations of this kind (i.e. the disclosure of bad news) that I attended. The stable elements in this are a recapitulation of the conducted tests and their results, the announcement of the diagnosis, and a presentation of the upcoming treatment. All these points are obligatory, and the last point fills most of the time in these consultations.

Like in Alise's case, the medical findings are the starting point and a main feature throughout this consultation. The language is plain and straightforward. The diagnosis is presented with reference to the conducted tests: "Cancer cells have been detected in the lung tissue derived from bronchoscopy," and the tumor is described in exact terms with regard to size and location. After this brief review of the findings, and before

the patient has uttered anything else than short affirmative utterances like “yes” and “I see,” the doctor moves on to talk about treatment, the account of which occupies a major part of the consultation.

The commencement of treatment is presented as a decision which has already taken place. “We will in any case try to get started on this,” says the doctor in the quotation cited above, after having explained that the first choice – surgery – is out of question because of the state of the patient’s lungs. Another frequently used formulation is “What we now plan to do.” Even when this is differently phrased, like “We will now offer you,” the therapeutic measure is hardly posed as a question. Alternative options are not raised.

Reports from other cultural contexts have described a common and pervasive practice of avoidance of the word cancer (Elwyn et al. 2002; Mitchell 1998; Gordon & Paci 1997; Long & Long 1982). Extensive paraphrasing, vague language and euphemisms are widely used methods of protection of the patient, in the attempt of sparing him or her from a painful reality, as used to be the common practice in Norway too, until a few decades ago. As demonstrated above, this is no longer necessarily so. But whether the highly scientific language, strictly correct but stripped of references to practical implications for daily living (or dying) is in reality more open or direct, is not evident at all.⁷

Bjarne is mostly quiet during this speech by the doctor. He inserts a few comments about blood values and test results, indicating that he has made an effort to acquire some expert knowledge, before he moves on to talk about his previous experience as a patient in this hospital: a success story about survival against all odds.

The doctors could not understand how I could walk out from here on my own feet. They had written me off at least thrice during my stay here, but the doctor told me: “You have an extraordinary will power.” “Yes,” I said. “That’s right.” Without that concentration power I would be gone.

Bjarne tells about his failing heart, extensive operation and subsequent complications. It is a long and dramatic story about his stern determination to recover, no matter what, and his immense capacity to accomplish that in spite of serious health problems. It is a long and dramatic story, which the patient is allowed to complete till the end. The doctor refrains from interrupting, and tells me afterwards that he sees the story telling as a coping strategy. It cannot be taken for granted that a doctor lets a patient complete a story like that, long and fantastic as it is. The doctor thus shows a willingness to make space for this particular patient, by allowing a story about the successful mobilization of his own resources to occupy a major part of the consultation. But the adjustment to the individual patient seems to stop there. Little or nothing is done to check whether Bjarne has understood the message presented to him. His whole reaction, and his lengthy story, indicates that this is not the case. But before the patient begins his account of the situation, the doctor has not just conveyed the diagnosis in terms of accurate medical findings; he has also stated what is to be done in terms of treatment. There is no dwelling on that issue, no question posed. And while letting Bjarne

complete his story was probably important then and there, little or nothing is done to go into real dialogue about his understanding of the situation he is in. This happened neither in this consultation, nor later on. The basic pattern of the consultation, preparing a smooth pathway to the chemotherapeutic treatment, is undisturbed. The cultural script prevails, regardless of the particular characteristics of the individual patient.

The patient concerned is not disinterested in getting treatment. That has hardly been typical for other patients either. But when the treatment issue is presented immediately adjacent to the message about the diagnosis, emotionally loaded as that moment usually is, and with scarce discussion about the course of the disease and what can actually be expected from the treatment, the grounds for user participation is poor. And by that I do not mean to promote an extension of the standardized procedure of informed consent, from pre-surgery consultations to those concerning the announcement of a fatal diagnosis, or treatment options connected to that. I rather want to draw attention to the cultural script in the sense of a given pattern of the consultations, and the lack of flexible adjustment to particular patients that this implies, in spite of ideals about an individualized approach.

The awkward issue of medical uncertainty

The notion of informed consent apparently entails the provision of complete and comprehensive information to those affected by a decision – like Alise in the above mentioned case – based on the supposition that such information is available. But in real life any information is necessarily limited, the notion of exhaustive insight is a falsity, and a level of uncertainty is part of the human condition. Nevertheless, uncertainty is typically and predominantly perceived as a threat. While awareness of a lack of control over the course of events traditionally has been expressed as a belief in fate, a dominant trend in Western societies has been a movement from this notion to the concept of risk (see e.g. Giddens 1991: 107ff). Large investments are placed in risk assessments and measures applied for risk reduction – the ultimate expression of which is ‘zero-tolerance’.⁸

Accurate though the figures may appear to be, uncertainty is a predominant trait in all risk assessments, ultimately limiting what is calculable. Heyman and Henriksen have pointed out the great variations in lay person’s perceptions and interpretations of risk statistics, in terms of what it might indicate for their own prospects. Whether focus is held on the (dominant) likelihood of a positive result, or the (minor chance of) possible hazards, the same figures might trigger very different and unpredictable reactions (1998: 28).

Biomedical practitioners have a key role in risk assessments as well as in the implementation of manoeuvres aiming at risk reduction. Expectations of them being able to do so are high both within the discipline itself, and among those relying on these services. When the doctor in the first mentioned example speaks of “having to rely on probabilities” instead of definite evidence, she seems to do that with regret and discomfort. As something that is not how it should be.

Crucial as risk reduction and even risk elimination is to their vocation, dealing with persistent uncertainty and contingency is nevertheless an inescapable part of doctors' work. While this may appear to be stating the obvious, the denial of an awareness of uncertainty within medicine is not a new topic.⁹ As pointed out by Katz, the disregard of uncertainty serves a functional purpose: "It makes matters seem clearer, more understandable, and more certain than they are; it makes action possible. There are limits to living with uncertainty. It can paralyze action" (1984: 175). But the disregard of uncertainty can also be an obstacle to an appropriate implementation of medical measures. An intolerance of uncertainty can also lead to hasty decisions and conclusions about the diagnosis at a premature stage (see Groopman 2007).

The issue of uncertainty is deeply embedded in medical practice. But the implicit challenges attached are intensified in the context of patient communication. How and on the basis of what levels of detail should patients be informed about risks related to investigative and therapeutic measures? This dilemma can lead to a problematic movement between two opposite positions: either a complete appropriation or 'colonisation' of the responsibility, or a withdrawal from responsibility which leaves the patient alone. Alise is an example of the latter; Bjarne's case belongs to the first mentioned state of affairs.

In search of an embedded logic: On risks and accusations

The consultations with Alise and Bjarne follow two kinds of cultural scripts that are strikingly different when it comes to patient involvement in decision making and the call for informed consent. Why this difference? It is not that one of these types of consultations concerns a risky measure, while the other does not. They both do. The toxicity of the medicaments applied for chemotherapy may be very unpleasant, and not always endurable. In the worst case scenario they might even be life threatening – like the worst case scenario for operations in anaesthesia.

This comparison might seem unfair. There are obvious differences in the context of these two kinds of consultations. The biopsy question is treated according to a procedure adjusted to other surgical measures conducted in anaesthesia, where the starting point may well be a healthy patient, expecting to return to normality. The other starting point is an awareness of serious illness, involving an irreversible deterioration of the patient's condition. Expectations about the outcome will be very different, by all those involved. An element of unpredictability is nevertheless a unifying component for both.

The presence of risk – be it risky treatment or the risk of complications – does thus not in itself lead to a call for informed consent. Risks and uncertainty are there in both types of consultations referred to above, but it is dealt with differently by the doctors: In the last case, it hardly arises at all. In the first case, however, the issue of uncertainty is actively brought up by the doctor, but while doing that, she withdraws from responsibility and leaves it up to the patient to sort things out. Thus she is placing the burden of uncertainty on the patient. While insisting that the patient makes her own decision

about the question of surgery, the doctor points out that in case of complications, it might be difficult to justify that this operation is done. This indicates another kind of risk, obviously thought of by the doctor: the risk of accusation.

Patients seldom submit complaints. But over the last decades the number of complaints about treatment outcomes in Norwegian hospitals has been steadily increasing.¹⁰ This follows a growing awareness about customers' rights and the establishment of institutions pertaining to that, in accordance with a corresponding development in other Western countries. The introduction of a standardised procedure about informed consent prior to surgical measures is also part of an international trend. It is a widely applied cultural script which is enacted by individual doctors, but not designed by them. Neither is this script developed by doctors alone. A cultural script refers to an interaction, and is not worked out unilaterally by one party to this. This is also true for what has been described above. Though my attention has primarily been on doctors' scripts, these have also been influenced by the voices of patients. When Bjarne's doctor follows a script that assumes that patients prefer treatment in case of cancer, it has an empirical base. Most patients do. But doctors and patients are not equal parties. There is a power imbalance at work here, and institutional interests have also been involved in the evolvement of medical professionals' cultural scripts.

Informed consent: A question of *how* rather than *if*

Inviting patients to participate in treatment decision making processes has no long tradition for doctors. According to Katz patient self-determination is "an idea alien to medicine" (2002: 104). But there is no turning back to the era before autonomy was set on the agenda. A return by the doctors to the paternalistic style is neither possible nor desirable. Autonomy for patients in the sense of providing them with the possibility of having a say in questions regarding their own treatment is an essential value, and is there to stay. More than *if*, informed consent in treatment decision making is a question of *how*.

As implicit in the coining of the term itself, a patient's understanding of the issue is a basic prerequisite for a practice of informed consent. Information and communication are at the crux of the matter. But what kind of information is required? In both the cases presented above, patients are provided with exact and excessive information on the medical findings concerning their case. But how far does this promote an understanding of what is at stake? Ethical gatekeepers, preoccupied with a standardisation of informed consent, have focused much on the amount of information; concerned that it should not be scanty or incomplete. But as Alise makes clear, too much information, or too much choice, is another disadvantageous possibility. More than what is *enough*, the question of information is a question of what is *adequate* (cf. The 2002).

A judgement about the ethics of any medical deliberation, or the answer to the question about the protection of patients' interest in a decision making process, cannot simply depend on whether or not that process has included an acquisition of formalised informed consent. Obtainment of 'informed consent' can be practised in many

ways, including ways that are disadvantageous and even abusive to the patient. If the right to self determination is granted without a recognition of the structural inferiority of the patient and the asymmetrical relations between her and the doctor, the patient risks being subject to abandonment, rather than being empowered.

Unless it takes place with a sensitive adjustment to the individual patient, with information that relates to his or her values and life situation, the demand for informed consent risks leading to empty and impossible choices. The way this is practiced, however, depends on more than the individual physician. By means of the notion of cultural script I have wanted to draw attention to that.

Notes

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- 1 In accordance with international ethical guidelines, the design of the study was also based on informed consent. Patients were recruited at the onset of the investigation process, i.e. at a point when noone knew who among them would eventually be given a cancer diagnosis.
- 2 This use of the term is inspired by Annemarie Mol (2008).
- 3 Several kinds of risks are mentioned in this sheet: 1) severe breathing difficulties, the risk of which is said to be very small"; less than 1 per 1000 examinations. 2) major bleeding, the risk of which is also said to be "very small," less than 1 per 1000 examinations. 3) bleeding that leads to a need for blood transfusion, the risk of which is "very small"; less than 1 per 200 examinations. 4) lesions in the lung; "a complication we sometimes see." 5) collapse of the lung; which happens "in some cases." No statistics are mentioned for the last two complications, but a concluding remark characterizes them all as "minor accidents," "practically never seen to lead to permanent damage." The reader is also assured that these measures are only conducted when necessary for diagnosis or treatment, and is encouraged to contact a doctor in case something remains unclear.
- 4 A disease with unknown etiology, with some resemblances to tuberculosis. There is no cure for sarcoidosis, but many patients develop only mild symptoms and get better without treatment. Corticosteroids are otherwise the common treatment used to control the symptoms and the progression of the disease.
- 5 The highest mountain in Norway.
- 6 A reference to our meeting place for this interview, which took place on the fourth floor, and her breathing problems when climbing the stairs.
- 7 This development is not a unique to Norway. An outstanding account of a similar and comparable situation in a Dutch context has been made by Anne-Mei The (2002). When The describes the physicians she met as "champions of veiled language" it is not because of a use of euphemisms, but because of an unfamiliar language that fails to convey the seriousness of the patients' condition (p. 69). For further discussion about the relationship between medical language and the language of daily life, and the implications of doctors not attending to the latter, see Theda Rehbock (2009).

- 8 An example of a contribution to the discussion about the implications of this for public health and medical care within a Norwegian context is the zealous statement and depiction by Per Fugelli (2003).
- 9 Early examples, also mentioned by Bosk (1979), are the works of Fox (1957) and Davis (1960).
- 10 According to the statistical records by NPE, the Norwegian Association for Patient Compensation, founded in 1988, the figures show a steady increase in the annual number of cases, from a couple of hundred in the first year, rising to nearly four thousand in 2009 (NPE's annual report 2009). Patients complain about lack of treatment, and treatment started too late. Maximum treatment, however, even if this is on weak grounds, hardly seems to be an issue leading to legal pursuit.

References

- Beaucamp, Tom L. & James F. Childress
 1994 *Principles of biomedical ethics* New York: Oxford University Press.
- Beecher, Henry K.
 1966 Ethics and clinical research. *New England Journal of Medicine* 274 (24): 1354-60.
- Bosk, Charles
 1979 *Forgive and remember: Managing medical failure*. Chicago: University of Chicago Press.
- Davis, Fred
 1960 Uncertainty in medical diagnosis: Clinical and functional. *American Journal of Sociology* 66: 41-47.
- Elwyn, Todd S. et al.
 2002 Responsibility and cancer disclosure in Japan. *Social Science & Medicine* 54 (2): 281-93.
- Faden, Ruth R. & Tom L. Beauchamp
 1986 *A history and theory of informed consent*. New York and Oxford: Oxford University Press.
- Fugelli, Per
 2003 *0-visjonen. Essays om helse og frihet* [The 0-vision. Essays on health and freedom] Oslo: Universitetsforlaget.
- Fox, Renée C.
 1957 Training for uncertainty. In: Robert K. Merton et al. (eds), *The student-physician*. Cambridge: Harvard University Press, pp. 207-41.
- Giddens, Anthony
 1991 *Modernity and self-identity: Self and society in the late modern age*. Stanford: Stanford University Press.
- Gordon, Deborah R. & Eugenio Paci
 1997 Disclosure practices and cultural narratives: Understanding concealment and silence around cancer in Tuscany, Italy. *Social Science and Medicine* 44 (10): 1433-52.
- Groopman, Jerome
 2007 *How doctors think*. Boston and New York: Houghton Mifflin Company.

- Heyman, Bob & Mette Henriksen
 1998 Probability and health risks. In: Bob Heyman (ed.), *Risk, health and health care*. London: Arnold, pp. 27-64.
- Ingelfinger, Franz J.
 1972 Informed (but uneducated) consent. *New England Journal of Medicine* 287 (9): 465-66.
- Katz, Jay
 2002 *The silent world of doctor and patient*. Baltimore and London: Johns Hopkins University Press.
- Kaufman, Sharon
 2005 *... and a time to die. How American hospitals shape the end of life*. Chicago and London: University of Chicago Press.
- Long, Susan O. & Bruce D. Long
 1982 Curable cancers and fatal ulcers: Attitudes towards cancer in Japan. *Social Science & Medicine* 16 (24): 2101-08.
- Manson, Neil C. & Onora O'Neill
 2007 *Rethinking informed consent in bioethics*. Cambridge: Cambridge University Press.
- Mitchell, Jill L.
 1998 Cross-cultural issues in the disclosure of cancer. *Cancer Practice* 6 (3): 153-60.
- Mol, Annemarie
 2008 *The logic of care: Health and the problem of patient choice*. London & New York: Routledge.
- O'Neill, Onora
 2002 *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press.
- Rehbock, Theda
 2009 Person und Sprache. Zur Bedeutung philosophischer Sprachkritik für die Ethik. In: Hans Werner Ingensiep & Theda Rehbock (eds), *Sprache und Sinn in Grenzsituationen* Würzburg: Königshausen & Neumann, pp. 39-58.
- Shore, Bradd
 1996 *Culture in mind. Cognition, culture, and the problem of meaning*. New York & Oxford: Oxford University Press.
- Ten Have, Henk & David Clark (eds)
 2002 *The ethics of palliative care*. Buckingham: Open University Press.
- The, Anne-Mei
 2002 *Palliative care and communication. Experiences in the clinic*. Buckingham: Open University Press.
- Vollmann, Jochen & Rolf Winau
 1966 The Prussian regulation of 1900: Early ethical standards for human experimentation in Germany. *IRB: Ethics & Human Research* 18 (4): 9-11.
- Wilkinson, Iain
 2010 *Risk, vulnerability and everyday life*. London: Routledge.

