

Shared decision-making in decisions on treatment

Legislation entitles patients to be involved in decisions on treatment that apply to themselves (shared decision-making). This sounds reasonable, and few will question this principle today. In reality, this is a complex and time-consuming process that requires guided training, in part because patients' need for involvement depends on their own personal characteristics as well as the situation.

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The Patients' Rights Act states that patients are entitled to have a say in the choice between available and medically sound methods of examination and treatment. Furthermore, the provision of services should as far as possible be designed in cooperation with the patient, and considerable weight should be given to the patient's opinion. Moreover, the Act states that patients should be provided with the information necessary to gain insight into their health condition and the content of the health assistance, as well as possible risks and adverse effects (1). However, doctors and patients face each other in a wide variety of situations, and patients differ considerably in terms of their level of knowledge and understanding of health issues, as well as in their willingness and interest with respect to being involved. How can the doctor comply with the requirements stated in the Act? We will restrict this discussion to decisions on treatment. Decisions pertaining to the choice of examinations, including screening tools, may be even more complicated.

The requirement to include patients in decisions on treatment whenever possible is based on an ethical imperative: respect for patient autonomy (2). Half a century ago, this was not so. The emergence of the current ideal is a result of a continuous improvement in the educational level of the population (3), supported by the persistent efforts of patient organisations and some idealists in the profession. Shared decision-making is an essential element of patient-centred communication, which has been promoted since the 1970s (4, 5). Most of the research on doctor-patient communication has been undertaken by adherents of

this method of communication. As a rule, this research has been of a descriptive character, although with some clearly normative elements. Few critical voices have been heard. In 2011, after a thorough analysis, Pilnick and Dingwall concluded that the fundamental asymmetry of the doctor-patient relationship persists in spite of decades of training programmes in patient-centred communication, and that the appropriateness of this method should be questioned (6). A Cochrane review from 2012 showed that patient-centred communication provides mixed results in terms of patient satisfaction, behaviour and health outcomes (7). This has spurred a growing interest in which details of the general concept of patient-centred communication actually work or do not work. Poorly elucidated areas include the information exchange itself and the conferring with patients. There is no disagreement that patients are concerned with receiving adequate information (8–10).

The importance of trust

In conversations between colleagues we constantly hear that when doctors attempt to confer with the patient regarding choice of treatment, they often receive a friendly rebuff, with statements such as: «Aren't you the doctor here?» Alternatively, the patient turns the question back to the doctor: «What do you mean?» Such experiences are seen as confirming that involvement of the patient often fails to work, and is therefore almost entirely a waste of time. In an article on the connection between trust, risk and power, the Norwegian philosopher Harald Grimen has undertaken a good analysis of the dynamic of these situations (11). Grimen claims that these three concepts are inextricably linked in the health services. The ill person experiences some degree of risk and needs help to reduce it. The doctor is the person who is able to assess this risk and hopefully has the power to address it. In this vulnerable situation, the doctor must be trusted. If the

doctor in this situation invites the patient to participate in the decision or even make the decision, this may give rise to confusion or a sense of insecurity. Because this balance is so delicate, the doctor needs to think through the kinds of decisions in which to involve the patient and handle the situation with great care.

Two of the authors have detailed knowledge of a material consisting of 380 video recordings from Akershus University Hospital. This material includes only a handful of situations where the patient is meaningfully involved in decision-making. Attempts are made to include patients in a number of decisions without them having been provided with the necessary preconditions, while in other situations they are frequently not consulted when this would be highly appropriate. These observations are in the process of publication, but we wish to raise this issue in our article at this point since there is a critical gap between prevailing practice and legal requirements, and we wish to draw attention to this fact and spark a debate.

The doctors should not be blamed, since no training and guidance have been available. However, the overriding belief is that regular interpersonal conversation skills or the basic training provided to medical students will suffice. This is equivalent to believing that if you can slice a loaf of bread, you will also know when to cut open an abdomen and take the knife in your hands.

No shared decision-making in spite of clear guidelines?

Today, there is no international consensus regarding the kinds of decisions in which the patient ought to be involved. Many believe that wherever there are clear guidelines for treatment, meaning that the Act's concept of «medically sound treatment method» is covered by a written procedure, it is unnecessary to involve the patient in the decision. However, this assumption is not in line with new standards for professional guidelines (12).

A lack of patient shared decision-making

is clearly evident in the field of cardiology. Even in cases of invasive cardiac medicine, little time is devoted to patient involvement (13). Patients in this situation have great confidence in the doctor's decision-making skills, but nevertheless appreciate being consulted (13). In Norwegian hospitals, patients with myocardial infarction are regularly prescribed a series of drugs that must be used over long periods, some of them even for life, without this being subject to discussion.

We wish to raise two fundamental objections to such a practice. First, drugs represent an active manipulation of the patient's body, which may have consequences equal to those of a surgical intervention. Surely, it would seem obvious to provide some information about the effects of each drug and how the patient will experience these effects. Second, it rarely occurs in medicine that a drug has such an extreme effect as to preclude any weighing of benefits against adverse effects. Studies have shown that one-third of all patients with cardiovascular disease harbour major concerns about their drug-based treatment (14), and a large proportion discontinue their treatment within a month after their discharge following a myocardial infarction (15). Perhaps more patient involvement could have an effect on this? When prescribing six different drugs, it is understandable that time can be saved by leaving out the details – but is it correct to do so?

New immunomodulating drugs for multiple sclerosis (MS) also illustrate key fundamental issues regarding the limits to patient involvement. In general, it appears that drugs which most effectively suppress the disease also carry the greatest risk of serious adverse effects (16). In such situations, guidelines alone cannot determine the choice of treatment. Weighing effects against risks involves choices in which the patients ought to be involved. However, there are also legitimate reasons to restrict the patient's (and the doctor's) right to choose freely. For example, some drugs used for multiple sclerosis cost more than NOK 200 000 per year, while the alternatives cost less than one-third of this amount. The choice therefore entails consequences that apply not only to the patient alone. Speaking with patients about societal priorities and personal risk under conditions of great uncertainty is a communicational tightrope walk that entails a large risk of a wrong move if the doctor is not well prepared and trained.

Ideal and reality

If it is the case that decisions must be discussed with patients only when the doctor is uncertain of the right choice, this may

Table 1 Sequence of tasks in the conversation when patients are to be involved in decisions. After Glyn Elwyn and collaborators (22)

Justification	The doctor shows that a choice needs to be made, and that this requires attention and discussion.
Community	The doctor assures the patient of support in the discussion and in making the choice, including that the patient will not be left to his/her own devices.
Alternatives	The doctor provides information on the advantages and disadvantages of relevant alternatives.
Preferences	The doctor seeks to elicit the patient's views, preferences and priorities, in light of the information at hand.
Integration	The patient's preferences are included in a total assessment, which also includes clarification of the patient's wishes regarding who will make the final decision.

produce unintended effects. At the annual conference of the Society for Medical Decision Making in Chicago in 2011, the following rhetorical question was asked: «Why is it that patients are consulted only when the doctor is in serious doubt?» Patients may perceive this as doctors renouncing their responsibility. The doctor, on the other hand, may fear that a decision that fails to produce the desired result will cause the patient to lodge a complaint. Some of USA's foremost experts in communication with patients who are seriously ill, authors of the book *Mastering communication with seriously ill patients* (17), have developed instructional videos in oncology and posted them on the Internet (18). The videos appear to recommend that the patient *must* choose, and that this is only a matter of providing sufficient information. Whether this results from a strong emphasis on patient autonomy or a «cover-my-backside» attitude will be left unsaid.

Those researchers who focus most on the involvement of patients in decision-making concentrate on such difficult choices (19–21), and their studies most often include identification of a crucial decision for more detailed scrutiny. In our video material there are on average more than ten decisions on the table in each doctor-patient meeting, and it is obvious that all of these cannot or should not be raised with the patient, since this would cause the activity to stall completely. Our general impression is that the doctors fail to implement the shared decision-making process as described by the ideal (Table 1) (22). Some of the most time-consuming passages concerning decisions in which the patient is involved pertain to setting a date for the next meeting. It is therefore unsurprising that some of the most frequent causes of complaints lodged in the health enterprises and the patient ombudsman's offices relate to a lack of information and to not having been heard.

What can be done?

The requirements defined by legislation are strict, even in light of a cautious interpretation of terms such as «participate», «as far as possible» and «the information necessary». In our opinion, compliance with the legal requirement will necessitate a change in culture. It will require a nationwide training effort, which in turn will require patience and a long-term view. The proposal to introduce mandatory communication training in post-graduate training is a promising feature (23). Another feature that may prove useful is the preparation of Internet-based decision-making tools that the doctor and patient can use jointly or the patient can study at home with his or her relatives (24). To date, these have had some limitations in terms of their knowledge base, practical availability and the possibility to involve both the therapist and the patient in the choices to be made. Professional guidelines are subject to the same flaws. An international research and innovation programme called MAGIC (<http://www.magicproject.org/share-it/>) is therefore developing a new generation of professional guidelines and tools that doctors and patients can use jointly to share knowledge about the advantages and disadvantages of treatments. These tools are available on tablet computers, and their purpose is to act as an aid in conversations. User testing of the presentation formats is currently underway in several countries (25).

A somewhat less sophisticated, but easily available variant can be found at www.optiongrids.org. The Health Library and Innlandet Hospital are cooperating to develop a tool that can assist in discussions on long-term treatment for bipolar disorder (Øystein Eiring, personal communication). However, these tools will not be able to cover all possible situations involving clinical decision-making in the foreseeable future, and at worst, they may turn the conversation into an exercise in technology. Their possible uses should therefore not

be regarded with undue optimism. It also deserves mention that the challenges we are facing are of an international nature. An article in JAMA showing how Kahneman and Tversky's theory of choice can be applied in difficult clinical situations stated that doctors receive little training to help them understand how people make decisions (26).

Achieving this change in culture requires more research, dissemination, training, development of tools and local adaptation. Research ought to focus on optimal methods to succeed in patient involvement in various kinds of decisions, since many aspects remain unexplored. The most important pitfalls must be addressed in supplementary training courses in communication, and provisions should be made for active workplace-based training and guidance. The knowledge base and capacity for guidance must be developed first, and it is therefore unrealistic to expect a quick improvement in this situation. The development of tools will take place in Norway as well as internationally. In this country it ought to be driven forward by relevant professional groups, and should most likely be coordinated by the Norwegian Knowledge Centre for the Health Services.

Local adaptation will be necessary due to the variations in organisation and availability of treatment options. There is also a need for discussions between professionals and user representatives at regular intervals regarding the information that should be given priority for transferring to patients for major decisions in each field. These efforts to build a culture must be pursued by each health enterprise, in order to ensure that the information is relevant in the catchment area in question, as well as to keep attention focused on shared decision-making as a key function in the health services. At some point in the future, doctors will hopefully associate their professional identity as strongly with their mastery of this art as with their ability to handle a scalpel and stay informed about the knowledge base in their field.

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