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Patient involvement between ideals and reality - an empirical study of shared decision making and ordinary encounters between patients, doctors and nurses; Summary

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Summary

Research shows that patient involvement has a positive effect on clinical outcome as well as on patient satisfaction. Patients who have received information about their treatment comply with their treatment to a higher extent, are more satisfied with the treatment, and have better treatment results, and people who consider themselves in control of events respond better to treatment. In addition to this, improved clinical outcome is positively associated with good communication between health care professionals and patients. For these reasons, patient involvement is seen as an essential factor in the attempts to improve the quality of treatment internationally, as well as in the Danish health care system.

In the National Strategy for Quality Development in the Health Care System, encouragement of the patient perspective is a central focus area, and ways of establishing better conditions for active involvement of patients and relatives are sought. This report is intended as an input to the discussion on how this can be done.

The purpose of the study

The purpose of this study is to open a debate with health care professionals and decision makers about how patient involvement can be shaped and developed.

The report gives two contributions to the discussion on the design of patient involvement: Firstly, it introduces a special model for patient involvement called Shared Decision Making. Secondly, it presents an empirical case study of patient involvement in treatment decisions in two treatment settings in the Danish health care system. The study investigates approaches, conceptions, and interests of patients and health care professionals concerning patient involvement, understood as patients having influence on their treatment. Furthermore, it is a study that discusses the dilemmas and barriers for patient involvement that arise in everyday clinical encounters.

Shared Decision Making – a model for patient involvement

Shared decision making is one of the most recent models fostered by health care research to denote patient involvement. The model describes how decisions should be made. It is centred on the idea that the doctor communicates medical knowledge to the patient, and that the patient's perspectives, preferences and rights are included in the clinical conversation.

In its own understanding, shared decision making aims at the establishment of a partnership between health care professional and patient. Through dialogue, health care professional and patient must reach a consensus about which treatment is the better and should be carried out. The exchange of knowledge and information is one of the most important preconditions to carry out shared decision making in clinical practice.

In Denmark, the interest in shared decision making has yet to be developed in full. The basic ideas of the model, however, still seem to be gaining more attention in the Danish health care system. Among these are the ideas that the patient has resources which should be appreciated, that the patient should be involved in decisions, and that patients' preferences are important.

However, reality is often a lot more complex and the literature points out that shared decision making is an idealized model, which can only rarely be found in practice.

From model to patient involvement in everyday practice

The hypothesis of this study is that increased patient involvement in Denmark presupposes insight into how patient involvement takes place in everyday clinical practice - and a willingness to learn from this knowledge. In an attempt to fill out our knowledge gaps, we have carried out this empirical study, which aims to describe how treatment decisions are made in two out-patient units for chronic patients: a heart rehabilitation unit and an arthritis unit.

The empirical study is not an examination of shared decision making. However, the study reflects the model in that it has a special focus on dialogue in the consultation, roles of patients and health care professionals, exchange of information, and decision making processes.

Methods of the study

The empirical study is a qualitative case study. At the units for heart rehabilitation and arthritis treatment, we have observed a number of consultations and chosen 50 all together for further analysis. In addition, we have carried out 21 qualitative interviews with patients and 17 with their nurses and doctors. The interviews have been carried out and analysed in a narrative perspective. The observations have been analysed with special attention to how knowledge is exchanged between patient and health care professional, and how the courses of treatment and treatment decisions are affected by and shaped by the dialogue.

The results of the empirical study

Patient involvement in decision making is affected by several parameters. The report shows that patient involvement in everyday clinical practice depends on:

1. Expectations of patients and health care professionals
2. The specific, clinical situation
3. Type of treatment and treatment decisions.

The correlation between these parameters create possibilities as well as barriers for patient involvement – and the meeting between patient and health care professional is shaped in the interplay between these parameters. An understanding of the interplay between these parameters as it is shaped in the context of each department and clinic is thus a necessary preclusion for the creation of more patient involvement. This conclusion is substantiated by a number of empirical analyses, which illustrate how this interplay is shaped in the heart rehabilitation and arthritis clinics respectively.

A comparison of the two departments illuminates how:

Expectations of the parties to one another, types of treatment, and the clinical situation together form each clinic's particular approach to patient involvement:

- Patient involvement in decision making is closely connected to the distribution between patient and health care professional of knowledge, responsibility, and agency. Shared decision making is best made when these domains overlap
- The dialogue between patients and health care professionals is shaped by – but also underpins – the level of patient involvement and the way this is practiced in the department in question
- A number of factors not directly related to the interaction between staff and patient in the consultation influence the form and degree of patient involvement. The empirical study analyses two of these: First, the many considerations that the health care workers pay regards to along with the consideration for patient involvement, and second, the role of the relatives.

Dilemmas of the health care professionals

Treatment decisions involve considerations of many things: clinical evidence, medical expert opinion, economic limits, as well as acceptance of the patient. Thus the doctor treatment choices often represent a dilemma, where he must choose which part of his responsibility he will act on in a given situation. However, some areas of responsibility weigh more than others.

The structuring of the medical conversation and the way the information is given are important with regards to whether and how patients get influence on their treatment. This study shows how involvement of the patient's preferences and wishes do not have a natural space in the conversation between patient and doctor. The patient's preferences come to the fore before or after the core of the conversation, but seldom play an integrated part of the conversation. In those contexts where health care professionals talk with each other, patient preferences only really play a part when they can be portrayed as extraordinary.

The influence of next-of-kin on the knowledge level of patients

The patients in this study draw attention to the fact that prior knowledge about their disease is a precondition that enables them to ask health care professionals any questions. Through an active search for information on the Internet and via relatives, the arthritis patients obtain the necessary knowledge.

Heart patients, on the other hand, do not ask much about the medical treatment in the consultations. Instead they let this area of knowledge remain solely the domain of the doctor. However, some heart patients ask family members, friends, or the acquaintances of their friends about their medical treatment or operational procedures. Although the health care professional in charge of their treatment should be considered the more qualified with regards to this type of knowledge, patients systematically turn elsewhere for this knowledge, and primarily find it outside the closed circle of the consultation.

From the observed consultations with patients who were later interviewed, we clearly see that apart from the questions directly occasioned by the doctor, all the patients' questions could be referred back to knowledge obtained from a relative or an acquaintance. Thus relatives and acquaintances become important actors in that it is through them that patients obtain basic knowledge, which enable them to ask questions to the health care professionals.

Contribution of the empirical findings to the model of shared decision making

As mentioned, the empirical study examines a number of areas addressed by the model for shared decision making. These are:

1. How treatment related decisions are made
2. The significance of explicitly involving preferences as well as knowledge in the decision
3. The exchange of information
4. The role of the patient as an active partner.

How are treatment related decisions made?

Shared decision making places the process of decision making at the centre of interest. The model has been developed to take into account the built-in dilemmas and imperfect basis of knowledge of medical everyday practice, but is still in line with what organisational theorists have called a rational paradigm for decision making. The model rests on the idea that decisions are made on the basis of knowledge; that decisions can be confirmed and demarcated in time; and that the actions of participating parties are steered by an effort to obtain the best possible choice of treatment. Furthermore it is anticipated that patient and health care professional make the choice on the basis of a joint balancing of treatment alternatives and their consequences.

The empirical study presents another picture of how treatment related decisions are made. Decision making follows different models depending on the type of treatment and the primary agendas of patients and health care professionals.

At the arthritis out-patient clinic, health care professionals and patients search for valid occasions for making decisions, which can link together known solutions, problems perceived by the patient (invalidity or pain), and results from clinical tests. Negotiations concerning the validity of decision making occasions seem to colour the process of decision making. Seen from this perspective, patient involvement centres on how occasions for making decisions are sought, defined and negotiated between doctor and patient – and around the rules for this negotiation.

In the heart rehabilitation unit treatment related decisions seem to take the shape of continuous narratives which follow the motto ‘the road appears as we go along’. No distinctive occasions for making decisions are sought. The dialogues in the consultations do not take the form of decision processes with a clear acknowledgement of the problem at hand, and a clear wording of solutions and explicit evaluation of alternatives and the consequences of different actions. It is more a question of patients and health care professionals being in a continuous state of inquiry, which imply that they keep many options open for a long period of time. Implicitly, they make a lot of small, partial choices through acting – or not acting – and in this way the course of treatment moves forward.

Patient involvement in the sense of co-participation must also be possible in cases like the above mentioned, where the decision processes do not follow a rational paradigm. But the present model for shared decision making does not include this.

Patient preferences and the knowledge of health care professionals

The central idea of the shared decision making model is that better treatment decisions are made when both medical knowledge, treatment preferences of the parties, and other patient preferences are included in the decision making.

Patient preferences primarily mean those objective conditions in the life of the patient, which are decisive with regards to what will be the best treatment for exactly this patient, secondly the patient's subjective assessment of what is more important for him (for instance keeping his job as a truck driver, future health risks or immediate side effects). This reasoning leads to a division of knowledge into two kinds: one associated with the health care professional and one associated with the patient. But in real consultations both parties make use of both kinds of knowledge.

This becomes especially clear in the consultations at the arthritis out-patient clinic. Here the patients often refer to medical knowledge when explaining their wishes for the treatment. The doctors often make use of knowledge about the lived life of the patients when they argue for the treatments they prefer to employ. Thus both parties make use of the kinds of arguments they expect the other party to stress more.

The report also shows that either patient preferences are not given enough space in the consultation to become a serious parameter in the choice of treatment – or if they are included, fights for their legitimacy often arise. When patients actively engage in the decision making process, power relations between patient and health care professional are challenged.

In principal, conflict can be seen as an inevitable consequence of the kind of explicit communication that follows from involving patients in decision making. But as demonstrated in other studies of the Danish society and health care system, there seems to be a tendency to consider conflict problematic and to avoid dialogue, which can lead to disagreement. This is due to the fact that disagreement is associated with those aspects of inter-human relations which are not popular (inequality, conflict). Disagreement between doctor and patient demonstrates the unequal power relations between them. And reversely, agreement demonstrates equality.

Shared decision making is a model which attempts to balance traditional, hierarchical power relations between patient and doctor by creating more equality. But this is attempted through an explicit dialogue, which exposes disagreements and inequality. In this way, the model seems to collide with some of the ways equality is employed by patients and health care professionals.

To give and search for information

According to the model of shared decision making, decisions must be based on an exchange of all relevant information. This renders information exchange a crucial part of the decision making process.

Patients in this study express clear wishes to be informed about the course of treatment, disease and treatment options. For the health care professionals it is an institutionalized practice to inform about these matters. 'To give' information has become an act which is expected by both patients and health care professionals themselves. Patients are also expected to search for information, and to a still higher extent. The modern technologies of the information society, not least the Internet, reinforce the idea that information is an independent entity, which is 'out there' and which can be 'searched for'.

However, the terms 'giving' and 'searching for' information too easily lead to a perception of information as units or 'things', which shift hands between the expert and the layman. The terms thereby prevent us from seeing how information plays a role in the

interaction between people and between people and the media. In reality, information is exchanged as part of a dialogue, which includes a large amount of interpretation and weighing of what kinds of actions are appropriate with this exact person. Bearing this in mind, the report illustrates what patients and health care professionals actually 'do', when they give or search for information, and how the information become a part of the dialogue in the consultations.

Rather than 'giving' information neutrally and independently from the context, health care professionals balance agendas, time frames, necessary levels of information about side effects with other information that at a given time is presumed to be intelligible to the patient in question. But it follows from this well-meant consideration that patients can inadvertently send out signals – by means of their looks, age, or behaviour – which by the doctor is taken to mean that they do not wish or are not capable of understanding certain information. Furthermore, their empathic timing of information can imply that a number of treatment decisions are made before the patient has enough knowledge to be able to participate in them. In fact, information is often given so that it does not become an important factor in the process of medical decision making.

Moreover, the health care professionals' information giving is consistent with their understanding of what is basically at stake in their area of treatment. The way patients search for information is in line with these understandings of what is at stake in the consultations and the way information is given. The arthritis patients search for information after a treatment choice has been made or medical treatment has been initiated, and they use the information to obtain confirmation that the choice was the correct one. Heart patients on the other hand seem to be caught in the same information dilemma when searching for information as the health care professionals experience when informing them. For the health care professionals, the issue at hand is not to make the patients feel unsafe through informing them, the issue at hand for the patients is not to become unsafe. Several patients state that because of this concern, they have avoided searching for information about their disease altogether.

The patients' reasons not to ask are connected to their evaluations of the situation at hand and the distribution of roles between themselves and the health care professional in charge of their treatment. The interpretation of the situation and the interplay of patient and health care professional thus seem to determine whether or not the patient asks the health care professional in charge of their treatment to provide information – and whether or not the information they search for will be employed in the consultations. Ultimately, the patient's interpretation of what is expected by him or her determines whether or not patient involvement in treatment decisions becomes possible.

Shared decision making and human agency

In the literature about patient involvement and shared decision making, and in the interviews with health care professionals in this study, it is emphasized that there are patients who behave very passively with regards to their treatment, while others are very active and wish to be involved. Of course, involvement in decision making must not go against the wish of the patient, and thus the doctor must shape the consultation in accordance with the patients' wishes concerning involvement. The literature about shared decision making has as its ideal human agency, but both literature and the health care workers in this empirical study recognize the right of humans not to take an active role in decision making.

However, the division between active and passive agents is challenged by this study. For the narratives of the interviewed patients show that patients are only rarely completely passive with regards to their treatment. On the contrary, they seem to have in common that they act upon notions about how they can obtain the best possible treatment. The many and sometimes very imaginative ways in which patients act upon their treatment can be invisible to the health care professionals and therefore be interpreted as passiveness. However, this large amount of work on behalf of the patients, whether they are involved in the process of decision making or not, must invite reflection for those who wish to work towards more patient involvement.

An evaluation of the potential of the model for shared decision making

The empirical study has pointed to the fact that when working with patient involvement, we must take the more difficult road. We cannot just implement a model. We need to take as our point of departure the dynamics of each specific department and treatment to create more patient involvement.

With this report we have attempted to sow seeds of reflection in the minds of the people who are looking for ways of increasing patient involvement in their department or at their hospital. We have pointed to some areas which should be specifically addressed. And we have proposed ways of affecting the dialogue between patient and health care professional.

Seen in this light, increased patient involvement cannot rely solely on directives from outside or knowledge of models, but requires a fundamental change in all the minor everyday routines, which will then affect the way the patients and health care professionals interact, interpret and speak with each other.

One place to start the change of minor routines can be to evaluate the preconceptions about human agency – of health care professionals and patients respectively – that the treatment is based on. Are agency, responsibility, and knowledge distributed in a way that makes shared decision making meaningful? Can something be done to create a distribution which makes shared decision making relevant? And what kinds of concrete actions or exchanges of knowledge are necessary to get to this point?

Shared decision making as a model can be used to focus on problem areas that can influence the possibilities of patient involvement on treatment decisions. But it seems necessary to employ a broader understanding of how and when treatment decisions are made than the one inherent in the model.

For instance, in the model, shared decision making is not employed until a choice is imminent. But heart patients and the health care professionals in charge of their treatment are often unclear about when there is a choice. Thus, implementation of patient involvement in decision making in areas similar to the heart rehabilitation in this study requires attention to the period before a choice becomes imminent, and to the reflections and weightings which form the basis of the next step in treatment.

Arthritis patients and their health care professionals, on the other hand, would gain more from making the dialogue about valid decision making occasions - and the rationales behind them - more explicit than from a narrow focus on the choice

between alternative treatments. In other words, dialogue about the basis for the choices are at least as important as dialogue about the choices themselves.

The empirical study of this report demonstrates that some parts of the dialogue leading up to treatment decisions take place before the choices are expressed. Course of action and creating explicit dialogue thus seem to be more important areas for patient involvement than the decision making itself.

In line with this, we conclude that more information of a higher quality is not in itself a viable way to increase patient involvement. It is rather the way information is given in each separate unit that should be addressed.

Both patients and health care professionals spend a lot of energy interpreting each other and the situation they find themselves in, and much of that interpretation takes place in an implicit manner. The question is how much of this interpretation that must necessarily be silent. For instance, patients could be asked about their wishes for information, to stop health care professionals from adapting information to their subjective interpretation of the patients needs. Patients can also be supported in asking questions, so that they need not depend on having medically educated acquaintances in order to be able to engage in dialogue about their treatment.

If health care professionals are sometimes criticized for being incompetent when it comes to inter-human dialogue, the argument here is the complete opposite. Health care professionals are very competent with regards to empathic dialogue – and to interpret the patient and the situation in question – but sometimes they might be too competent, at least when the goal is to increase patient involvement in decision making.

In line with these results, the report concludes that there seems to be a potential in supporting explicit patient involving dialogue. Within research on patient involvement, a number of different tools for this kind of communication support have been developed. The report concludes with a proposal to work for an adaptation of these tools to the conditions of the Danish health care system and society.

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