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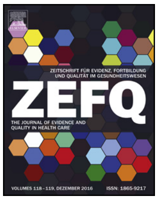

Beteiligung von Patientinnen und Patienten / Patient Participation

How contextual issues can distort shared decision making

Verhindern oder verzerren Kontextbedingungen partizipative Entscheidungen?

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A B S T R A C T

Shared decision making in medicine has become a widely promoted approach. The goal is for patients and physicians to reach a mutual, informed decision by taking into consideration scientific evidence, clinical experience, and the patient's personal values or preferences. Shared decision making, however, is not a straightforward process. In practice, it might fall short of what it promises and might even be misused to whitewash monetary motives. In this article, which summarizes a presentation given at the 17th Annual Conference of the German Network Evidence-based Medicine on March 4th, 2016 in Cologne, Germany, we discuss three contextual factors that in our opinion can have a tremendous impact on any informed decision making: 1) opinions and convictions of physicians or other clinicians; 2) uncertainty of the evidence regarding benefits and harms; 3) uncertainty of patients about their own values and preferences. But despite barriers and shortcomings, modern medicine currently does not have an alternative to shared decision making. Shared decision making has become a central theme in good quality health care because it has a strong ethical component. Advocates of shared decision making, however, must realize that not all patients prefer to participate in decision making. For those who do, however, we must ensure that shared decisions can be made in a neutral environment as free of biases and conflicts of interest as possible.

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Z U S A M M E N F A S S U N G

Partizipative Entscheidungsfindung ist zu einem weit verbreiteten Ansatz in der Medizin geworden. Ziel für PatienInnen und ÄrztInnen ist es, unter Berücksichtigung von wissenschaftlicher Evidenz, klinischer Erfahrung und persönlichen Werten und Präferenzen des Patienten/der Patientin, eine gemeinsame, informierte Entscheidung zu treffen.

Allerdings ist die partizipative Entscheidungsfindung kein einfacher Prozess. In der Praxis, entspricht sie oft nicht den Erwartungen und wird mitunter stark von Marketing-Strategien der medizinischen Industrie beeinflusst. In diesem Artikel, welcher einen Vortrag bei der 17. Jahrestagung des Deutschen Netzwerks Evidenzbasierter Medizin am 4. März 2016 in Köln, Deutschland zusammenfasst, erörtern wir drei kontextbezogene Faktoren, die unserer Meinung nach einen erheblichen Einfluss auf jede informierte Entscheidungsfindung haben und diese verzerren können: 1.) Meinungen und Überzeugungen der ÄrztInnen; 2.) Unsicherheiten bei der Evidenz hinsichtlich Nutzen und Risiken 3.) Unsicherheit der PatientInnen über ihre eigenen Werte und Präferenzen.

Trotz Hindernissen und Defiziten gibt es jedoch in der modernen Medizin keine Alternative zur partizipativen Entscheidungsfindung. Partizipative Entscheidungsfindung ist zu einem zentralen Gegenstand einer hochwertigen Gesundheitsversorgung geworden, da sie eine starke ethische Komponente aufweist. Partizipative Entscheidungen unterstützen die Autonomie von PatientInnen, wenn sie in einem neutralen Umfeld möglichst frei von Bias und Interessenskonflikten getroffen werden können. Partizipative Entscheidungen und objektive Information sind jedenfalls immer ein wichtiger Gegenpol zu Informationsquellen, die wirtschaftliche Interessen verfolgen.

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Background

Patient involvement and patient preferences have become central components of high quality medical care and are often summarized under the term shared decision making. In 1982, in the United States, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, proposed shared decision making as a new approach for better patient-care provider relationships [1]. In 2015, in a landmark ruling, the United Kingdom Supreme Court decided that the standard of patient information must be determined by what a reasonable patient deems important, not what a responsible body of physicians deems important [2].

The concept encourages patients to actively participate in medical decisions on health and disease. The goal is for patients and physicians to reach a mutual, informed decision by taking into consideration scientific evidence, clinical experience, and personal values or preferences of the patient. Ideally, in shared decision making, the patient and physician form a partnership and undergo the decision-making process together, weighing the pros and cons of different management options [3–6].

Shared decision making breaks from the traditional role of the paternalistic physician-patient relationship. A systematic review of studies on patient-physician relationships showed that before 2000, about 50 percent of patients preferred to participate in medical decision making [7] Studies conducted since 2000 report that, on average, 71 percent of patients wanted to be actively involved in the decision making process concerning their treatment [7]. With the advent of new information technologies, patients are now able to access medical information easier and faster. This in turn, has led to better informed, more emancipated patients who increasingly expect self-determination in health and disease [8].

Shared decision making, however, is not a straightforward process. Elwyn and colleagues developed a conceptual framework that outlines shared decision making in daily clinical practice [9]. The framework describes three distinct steps which are depicted in Figure 1. After identifying and diagnosing a patient's health problem, the first step is a "choice talk" [9]. In this initial step, the care provider presents different management options to the patient. Based on existing knowledge or experiences, a patient might develop initial preferences for any of the available options. The second step is an "option talk", a more detailed, mutual analysis of the different possibilities. The care-provider presents benefits and harms of each option and determines whether the patient fully understands positive and negative consequences of different treatment options. During the second step the clinician could also offer decision support tools. During this step, talks concerning initial preferences lead to informed preferences. Nevertheless, psychological, social, and emotional factors will have an impact on the process. The third step, the final "decision talk" supports the patient in making a decision [9].

While in theory shared decision making is clearly the best approach to making optimal decisions, in practice it might be hampered by a multitude of factors that are outside the realm of shared decision making models as the following example illustrates.

Susan Gubar, an emerita professor of English at the Indiana University writes in a New York Times blog about her life with cancer (http://well.blogs.nytimes.com/category/live/voices-2/living-with-cancer/) In her blog entry on January 15, 2016 she describes her decision making process to participate in a Phase I trial testing a new experimental cancer drug. "*When before the start of my trial I read the 20 or 30 pages of boilerplate, I signed on the dotted line, even though the document informed me that the drug might kill me and that its administrators would not be held accountable. I signed because I wanted to see if a new approach might save me from the miseries of standard treatments that had proven inefficacious. I also signed because I wanted to help other people with cancer.*" [10]

Given 20 or 30 pages of information material, her background as a university professor, and a likely discussion of benefits and harms with her clinicians, Susan Gubar probably made an informed and shared decision to participate in the clinical trial. Nevertheless, her words reveal that the decision was not based exclusively on a rational weighing of benefits against harms but also on other more powerful forces namely fear, despair, and the hope that a new, untested drug could provide the key to heal her cancer.

Although this example might not be representative of most healthcare decisions, informed decisions in health and disease are rarely exclusively rational and reasonable. Emotional factors such as fear, despair, hope, psychological strain, and many others are commonly involved when people make medical decisions about diagnosis, treatment, or prevention. In addition, social expectations, opinions of clinicians, marketing of the industry, stigma, uncertainty about benefits and harms, or uncertainty about values and preferences can distort any well-intended informed decision making.

In the following sections, we will argue that shared decision making is a noble idea but in practice it might fall short of what it promises and might even be misused to whitewash monetary motives. We will discuss three contextual factors that in our opinion can have a tremendous impact on any informed decision making: 1) opinions and convictions of physicians or other clinicians; 2) uncertainty of the evidence regarding benefits and harms; 3) uncertainty of patients about their own values and preferences.

Opinions and convictions of physicians and other care-providers

In any shared decision making process, physicians naturally play a fundamental role. For most patients, their physicians' judgment about the best management strategy is important and affects their decisions. In a survey of adult German citizens, about 70 percent stated that their general physicians are the most important source of information regarding issues of health and disease [11]. Only 30 percent viewed printed information material as an important source of information. In a study involving more than 900 citizens in the United States, the majority of participants believed that physicians have a responsibility to discuss evidence with their patients but that they should be arbiters whether to adhere to evidence-based practice in the case of an individual patient [12].

The remarkable trust that the general public has in physicians begs the question how trustworthy physicians actually are because they are clearly not free of their own biases and convictions.

A publication in the prestigious journal *Health Affairs* already answers this question in its title: "*Survey shows that at least some physicians are not always open and honest with their patients*" [13]. The survey, conducted among almost 2000 physicians in the United States, reports that 55 percent of physicians admit to having been too positive to patients within the past year about a prognosis. Furthermore, 33 percent of physicians thought that medical mistakes do not always have to be admitted openly and 35 percent stated that conflicts of interest do not have to be made transparent.

Although these positions clearly violate the Charter on Medical Professionalism, such findings do not mean that physicians, on average, are more dishonest than other people [14]. Most likely physicians are just as honest or dishonest as everyone else. In an international landmark study called the *Dishonesty Project*, Daniel Ariely and colleagues explored the "dishonesty of honest people". A film documentary of this project called *(Dis)honesty-The Truth about Lies* was released in 2015 in the United States [15]. Results of this research provides a revealing insight of honest and dishonest