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Decision aids – ideals and dilemmas of user involvement

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At present, user involvement permeates health care policy in many Western countries. An outgrowth of user involvement is shared decision-making, which is characterized by the mutual sharing of information and values, as well as the pursuit of agreed upon decisions within the patient-physician relationship. Patient decision aids are tools developed to support shared decision-making. The tools are developed to increase the patient's knowledge and elucidate values that are relevant to his or her decision. Despite their increasing use and evidence base, decision aids demonstrate a number of unsolved paradoxes inherent in shared decision-making. The volatility of the core concepts underlying decision aids and shared decision-making is a considerable challenge for their future role in health care.

Many medical decisions are straightforward. Few doctors would think too long before administering antibiotics to a child with life-threatening bacterial meningitis, and not completely removing a melanoma is hardly an option. However, between the extremes of the clearly beneficial and the clearly non-beneficial interventions reside the grey zone treatments, a domain in which the right decisions are not always clear-cut. Nearly half of all treatments have unknown effectiveness, and 7% of treatments are trade-offs between benefits and harm (1).

When there is uncertainty, or a trade-off between benefits and harm, the weight the individual patient places on the probable outcomes of the options can be decisive. The decision will depend on the patient's values and preferences, and the decision can be labeled preference-sensitive.

To be able to assign values to the outcomes, the patient has to possess enough knowledge about their options and their outcomes, and be aware of his or her values. Moreover, if the values are to exert any influence on the decision, the physician needs to know about, and recognize, the patient's values. Finally, an informed consensus can only be reached if both parties engage in a discussion about the best choice, though to create such a reciprocal process can be difficult. *Decision aids* are tools that help patients and health care personnel share knowledge, elicit values and participate in shared decision-making.

These tools are presently pinnacles in the social movement of patient participation, or more specifically, *shared decision-making*. Concrete and tangible by nature, they exemplify many of the aspirations, accomplishments, shortcomings and dilemmas within the movement. This article will describe some of their most prominent facets.

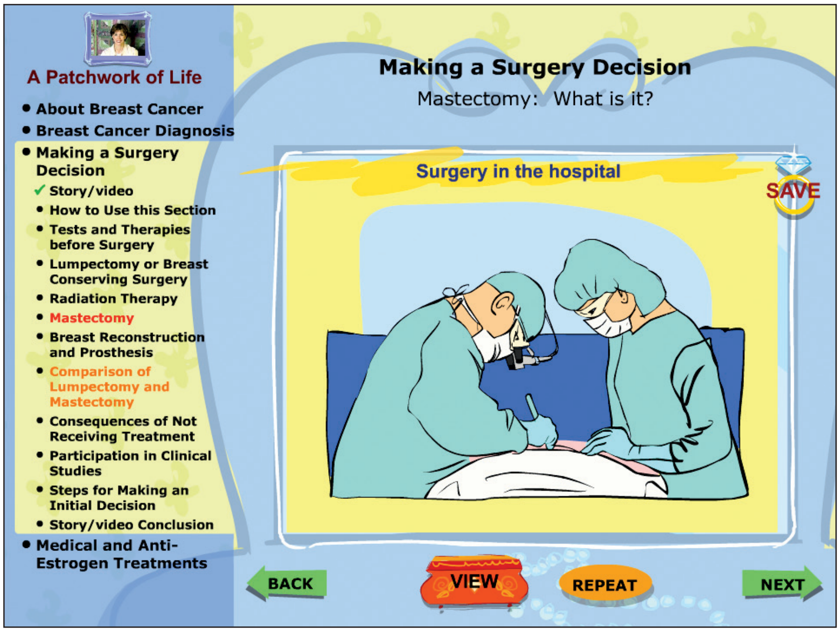
Definition of a decision aid and an introductory example

Decision aids are tools designed to support patients in making an informed and value-congruent choice in situations in which no single therapeutic action is appropriate for all patients. Patient decision aids are commonly defined as «evidence-based tools designed to prepare clients to participate in making specific and deliberated choices among health care options in ways they prefer» (2). The media type in which the decision aid is cast can be a book, a video, a pdf file or an interactive website. Decision aids should bring personalized, evidence-based information about the relevant health condition and options at hand. The knowledge conveyed should enable the patient to choose between the preference-sensitive options in the decision problem. In general, this specific, problem-solving purpose makes them different from educational materials. For the most part, their purpose is not only to solve a problem, but to further patient participation. Most decision aids are created to enhance and support a patient-clinician relationship, as opposed to being used independently by patients, e.g. browsing for information on the web. Patients can be presented with a decision aid before, during or after a clinical encounter.

Examples of decision problems

The inducement for all decision aids is a distinct and explicit decision problem. Decision aids have been developed for a long list of decision problems such as:

- The choice of antithrombotic therapy (e.g. aspirin and warfarin) for a patient with atrial fibrillation;
- Risk reduction choices (e.g. statins) for a patient with an increased risk of a cardiovascular event;
- The choice of disease modifying drugs for a patient with multiple sclerosis;



Ill. 1. Screenshot of a web-based decision aid for patients diagnosed with early breast cancer who are about to decide their treatment. The benefits and disadvantages associated with the various options are given. Ill. A Patchwork of Life: One Womans Story.

- Whether or not to take an antidepressant for a patient with depression;
- Treatment choices for abnormal uterine bleeding;
- To try to get pregnant or not for women with diabetes who are considering pregnancy;
- To start, continue or not to have a mammogram for women 40 years and over;
- When surgery should be performed for a patient with an abdominal aortic aneurysm;
- To be screened for prostate cancer: now, never or later;
- To screen or not to screen for colorectal cancer for people between the age of 50 and 80.

This selection only represents a small proportion of the clinical circumstances in which a decision aid has been developed. A total of 246 decision aids for more than 100 conditions can be found in the Ottawa Inventory (3). The quality of each decision aid is rated according to a standardized set of quality criteria called IPDAS. The assessment is published on a website in conjunction with the hyperlink to the decision aid. Decision aids were accessed over eight million times in 2006, primarily via the web, and their use appears to be increasing (4).

Evidence of effects

Decision aids fared reasonably well in the most recent Cochrane review evaluating their efficacy (2). According to the review, which includes 55 randomized and controlled trials, decision aids were found to be beneficial in three domains. First, patients who have worked their way through a decision aid know more than those who have not. They know more about their options and relevant outcomes, and they have more accurate perceptions of the probabilities of the individual outcomes. Many patients participating in the included studies changed their preferred choice once their knowledge improved, which suggests that increased levels of knowledge do matter. Second, compared to patients who received usual care, the decision aid users felt more informed about options and clearer regarding their personal values. Third, patients who have utilized decision aids were more involved in decision-making. The authors of the review suggest that patients who initially prefer to be passive might do so because they mistakenly believe that the best choice depends on the experts. This group of patients could change their strategy in favour of a more active one when they acquire more knowledge and realize that the best choice should instead be anchored to what matters most to them. Decision aids have been shown to reduce the uptake of medications and invasive surgical procedures in favour of more conservative options (5). The effects of decision aids on other outcomes such as satisfaction with the decision-making process and adherence are variable, limited or unknown (2).

Shared decision-making

The tradition of decision aids finds it roots in an ideal model of treatment decision-making labeled *shared decision-making.* The most commonly cited conceptualization defines the approach as an «involvement of both the patient and the doctor, a sharing of information by both parties, both parties taking steps to build a consensus about the preferred treatment, and reaching an agreement about which treatment to implement» (6). A doctor who participates in shared decision-making with a patient avoids the paternalistic role of «the doctor knows best», nor does the physician let the patient choose alone, like a customer picking from a menu. Shared decision-making occupies a middle ground, which should be characterized by mutuality and sharing. The model gained momentum in the 1990s, and is closely associated with other health policies such as patient-centred care, patient autonomy, informed consent and empowerment. In sum, shared decision-making can be regarded as the patient version of evidence-based health care.

Decision aids: The ideal

The IPDAS collaboration

As the number of decision aids in different countries increased during the 1990s and early 2000s, many of the main proponents of decision aids felt that a common quality framework was needed. With the aim of achieving international quality criteria for decision aids, the International Patient Decision Aids Standards (IPDAS) Collaboration was established in 2003. To establish the quality criteria, a multi-step consensus process was employed, involving patients, researchers, developers of decision aids and policymakers (7). The resulting checklist describes the current consensus on how a decision aid should be developed, and what it ideally should contain and achieve.

Options

There is no choice without options, and according to the IPDAS criteria the options for the health condition at stake should be listed, including the alternative of doing nothing. For every choice, the decision aid should describe the benefits and disadvantages such as any potential side effects. An ideal decision aid describes the procedures that a choice entails such as a surgical procedure. The patient should also be informed about what would happen were the disease allowed to take its natural course, without any options at hand (8).

This model for information about the decision problem («formalization») echoes classic, rational decision theory: A *state of the world* (health condition) prompts a *decision maker* (patient) to make a *choice* between different *acts*. The acts will have different *outcomes*, both good and bad.

A ruptured Achilles tendon can be used as an example. The health condition is the sad fact that the tendon is ruptured, and the patient has a limited number of options: undergoing surgery or treatment with a cast only (the patient could also choose to do nothing, but such an act would not be reasonable). If the patient chooses surgery, the risk of a re-rupture will be diminished, compared to treatment without an operation. On the other hand, surgery comes with a risk of a wound infection. Treatment with a cast will not engender any risk associated with surgery, although the patient will have to endure more weeks in the cast, and the risk of re-rupture will be permanently elevated.

Probabilities

The world is only partially controllable by humans. A patient experiencing a ruptured Achilles tendon can choose whether to have surgery or not, but whether he or she will have a re-rupture or a wound infection is by and large a matter of chance. In an ideal decision aid, the probabilities for positive and negative outcomes should not only be included, but be presented in a number of ways. Visual diagrams should be used in the decision aid, in addition to words and numbers. Moreover, the patient him- or herself should be allowed to select the way of viewing the probabilities, ideally based on their own situation. In the Achilles example, age and level of physical activity would theoretically give different probabilities for different patients. Uncertainty around the probabilities should also be described in the decision aid.

Effectiveness

An ideal decision aid ensures all aspects of informed and value-based decision-making: Decision aids should help patients make decisions that are informed and based on their personal values. An informed decision is possible when patients know their options and the features of the various options. Patients that make decisions based on values understand that their values affect their decision. Decision aids should also make it easier for patients to discuss their values with health care practitioners and to be clearer about which option features matter the most to them. Returning to the example, a patient with a ruptured Achilles tendon would gain knowledge and determination through the use of a decision aid. He/she would, for example, find that he/she is averse to the risks associated with surgery and does not value physical activity much, so therefore prefers a cast. When the surgeon enters the room, the patient feels empowered to discuss the options, and finally both agree that a cast is the best solution in this case.

Decision aids: The dilemmas

Limitations of the quality criteria

Many researchers and developers of decision aids have criticized the IPDAS quality criteria and a revision is being planned. There is a concern that the uncritical use of the criteria could stifle reasoning about the intervention among developers, and it is still unknown whether utilizing the criteria results in more effective decision aids. In the following, we will elaborate on some fundamental criticisms of decision aids and shared decision-making.

Shared decision-making and patients

Patients are generally favourable to being involved in decisions, and patient participation is an important feature of most definitions of health care quality (9), though how to proceed from this general starting point is far from clear. To begin with, no definitive consensus on shared decision-making exists (10). A systematic review identified 161 definitions, of which only the concepts of «patients values/preferences» and «options» appeared in more than half the definitions. The effectiveness of shared decision-making, defined in several ways, is also undetermined. Research is scarce and inconclusive (11), and no benefits of the approach are revealed in the context of single, acute decisions. The lack of evidence of effect might partly explain why shared decision-making is not a mainstay in clinical encounters. Research has also been conducted on how to increase the adoption of shared decision-making among health care practitioners, although no firm conclusions can be drawn (12). Supposing for a moment that effective implementation strategies will be found, applying shared decision-making indiscriminately is problematic. A significant proportion of patients prefer the paternalistic approach, and many others do not necessarily demand to feel involved. In a Swedish study about non-participation, not being provided with appropriate information during the clinical encounter was a significant aspect of non-participation. Not being listened to and a lack of recognition as individuals with individual needs and concerns were also characteristics of non-participation (13). Many patients may feel sufficiently involved when met by a respectful, interested and listening physician who welcomes the patient's contributions to the discussion.

Decision quality

By chance, bad outcomes can follow good decisions. It is therefore commonly agreed that the quality of a decision should not be assessed based on the outcome of the decision. Another increasingly problematic quality measure is patient satisfaction. For example, a patient who has low expectations can be quite readily satisfied. So what is a good decision? The IPDAS collaboration currently defines the quality of a decision as «the extent to which patients' decisions are consistent with their informed values.» Good decisions are «those that result in individuals choosing and/or receiving the health care interventions that are most consistent with their informed and considered values.» In both instances, there are two dimensions in a good decision: The patient is informed, and the choice of treatment reflects what is important to the patient. Both the knowledge and value aspect of the definition have been questioned. What kind of knowledge should the patient have, and when is it sufficient? What are «values», and how stable are they? The current drift in the understanding of these terms makes it problematic to operationalize a measure of decision quality. Glyn Elwyn, one of the founding fathers of shared decision-making, has proposed that the critique of the existing definitions of decision quality could be met by defining decision quality as the quality of the deliberation process. According to his proposal, the availability of information and clarification of patients´ values in the decision-making process could be operationalized and measured (14). Some authors claim that values and information, whether part of a process or the result, are not sufficient dimensions of quality: A decision has to be implemented to be good.

Values

Two people facing a decision on how to treat their Achilles rupture might value the possible outcomes of the options differently. To one person, the risks associated with surgery are perceived as acceptable, whereas to another risk-averse person surgery is a hazardous gamble. Different values and preferences could explain why the same illness, treatment or outcome may have a very different meaning in different peoples´ lives. Values are central in the prevailing definitions of both decision aids and decision quality, although the concept appears to be increasingly problematic. To start, there is no consensus on the definition. In the literature on shared decision-making, values are sometimes defined broadly as existential values or deeply held general goals. Other authors assert that values should be defined narrowly as «the patients´ attitudes about the relative desirability of each therapeutic option» (15). An even more fine-grained definition is «the relative desirability of each of the possible benefits and harms.» Second, the validity of values is no more agreed upon than their definition. There is a long-standing tradition within the shared decision-making movement that patients´ values and their value judgments are valid and should not be questioned. However, values are not stable and may change over time. Values and preferences are easily influenced by the framing of information and by external circumstances (16). Additionally, peoples´ stated values and what they actually choose are often inconsistent. The fluidity and malleability of human values has led some authors to argue that internal preferences should be discarded altogether in the decision-making process. One author suggests that eliciting patients´ values should be replaced by economic considerations in health care situations in which there is more than one option (17). Less radically, the idea of stable values could be replaced by the assumption that values do not exist in advance, but instead are constructed. Disturbingly, it is disputed whether patients value the offering of choices in current health care practice in the first place (18). Finally, there is little evidence that the use of decision aids and deliberating the options at hand increase the value consistency of decisions.

Personalization

Personalization includes using technology to accommodate differences between individuals and could, for example, imply an adjustment of the content and presentation of knowledge to the literacy level of the patient. The concept of personalization is often included in the definitions and descriptions of patient decision aids. Paradoxically, most decision aids are one-size-fits-all and do not include personalization features, nor the possibility for interaction whatsoever. Current web-based decision aids do not offer adaptations tailoring the content to the patients´ biological and psychological idiosyncrasies: data about the individual patient on everything from blood pressure measurements to literacy level. The rapid development in information and communication technology could alter the situation, offering new opportunities for web personalization, customization and tailoring in decision aids. Adaptive hypermedia could facilitate interaction between patient decision aids, online electronic medical records and other resources. Web personalization could customize the delivery of content based on the user´s knowledge level, goals and the technical platform (19). The effects of personalization techniques on patient knowledge levels, decision quality, cognitive bias and treatment adherence remain largely unexplored.

Uncertainty

Uncertainty is commonplace in medicine, and learning to manage personal and collective uncertainty is an inherent part of medical education and training. With a twist of irony, evidence-based health care has drawn attention to the considerable uncertainty that pertains to many health care interventions. Decision aids communicate the often shaky knowledge base to the patient, including both the lack of research and the role of chance. Shared decision-making therefore involves sharing uncertainty with patients who do not have any formal training in how to cope with it. Moreover, the risks and voids are presented to them in a situation in which they are personally affected and invited to participate. Potentially, the result is a considerable amount of uncertainty perceived by the patient. It might be correct that true decisions can only be made under uncertainty, though people often abhor uncertainty (16), which means that the decisions may come at a price – a suffering and distressed patient. A reduction in uncertainty might not be achieved until patients interact with health care personnel. The scarcity of evidence and the role of chance also challenge the physician, who has to manage uncertainty, while simultaneously engendering the patient's trust and confidence (20).

Theoretical framework

Key concepts on how individuals should or actually do make decisions could potentially drive or at least guide the development of decision aids. Scientific theories about decision-making could improve the understanding of their use, as well as their reliability, uptake and effectiveness. At present, decision-making theories are most often not applied in the development of decision aids. A recent review demonstrates that 33 out of 50 decision aids do not rely on any conceptual framework, and could be considered atheoretical. Half of the remaining 17 make poor or partial use of the cited theory (21). The most frequently applied theory has been classical decision theory, which has had a strong influence on the conceptualization of medical decision-making in general. Classical theory contains a mathematical foundation for rational decisions, and takes as its basic premise that people act rationally and wish to maximize utility or value. Practical utilization of the theory is labeled decision analysis. This idealized approach to decision aids has been of limited value in the development of decision aids, and there is considerable doubt about its future usefulness (22). A number of alternative theoretical approaches have been explored, both descriptive – how people think in the real world – and prescriptive –how people should think to make the best decision. Generally speaking, the theories give an imperfect foundation for the development of better decision tools. The frameworks also pay relatively little attention to patients´ emotional needs for support and collaboration with others in the decision-making process, both of which are core characteristics of real-world decision processes. In conclusion, a large theory–practice gap exists.

Bias

There is broad agreement that information provided to patients in decision aids should be as unbiased as possible. Whether bias can be avoided altogether is doubtful because of framing and ordering effects – all information has to be presented in some order, and the order might exert an influence on the decision. Even if bias in the decision aids is minimalized, cognitive factors such as memory and emotions have the potential to affect the decision in a plethora of ways (23). The belief in unbiased information and the processing of knowledge could be regarded as a powerful persuasion technique in itself. Decision aids can result in a significant change in patients´ choices; one example is the substantial reduction of major elective surgical procedures in 9 of 11 trials on the effect of decision aids (5). The use of narratives – patients' stories – in decision aids is particularly debated because they are likely to be biased and could have a powerful, persuasive effect. Nevertheless, quality criteria concerning patient stories are included in IPDAS, thereby encouraging the use of narratives.

Conclusion

Within the paradigm of shared decision-making, physicians should actively solicit the patient's preference when the proper medical decision is not apparent, such as when the choice involves a trade-off between benefits and harms, or when the outcomes of the treatment alternatives are uncertain. Decision aids have been developed to help patients aqcuire sufficient knowledge, clarify their values and communicate with health care personnel in such a way that a shared decision can be made. There is considerable evidence to suggest that the tools increase patients´ knowledge, help clarify personal values and facilitate involvement in decision-making. Even so, considerable confusion still exists core concepts such as values, patient involvement and decision quality. Basic assumptions such as the indisputability of personal values, and the imperative communication of uncertainty to patients, are challenged. How decision aids could be personalized to fit individual patients better, and what constitutes sufficient knowledge, are other unsolved questions. The atheoretical foundation of the tools is another example of their precarious base. The utility of future empirical research on shared decision-making and patient decision aids depends on presently unaccomplished theoretical clarifications.

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