

Chapter 2

Decision Aids

Decision aids are tools designed to enable effective shared decision-making (SDM). They are used to assist patients in considering options associated with medical intervention. They describe where choice exists and where there is an option of taking no action. They are used to improve the communication process between doctor and patient.

These aids or tools assist patients in considering alternatives regarding short, intermediate, and long-term outcomes which have relevant consequences. They support the SDM process of constructing preferences and eventual decision-making, suitable to their individual situation [1]. While these interventions have been available in a variety of forms for over 25 years, there is evidence that the use of decision aids has not become routine practice for most physicians [2].

Many of the groups and institutions supporting the use of decision support interventions are based in North America, including *The Informed Medical Decisions Foundation* and *Healthwise*. There are also many active research groups in the field, including the *University of Ottawa*, *Dartmouth College*, *Cardiff University*, and *Hamburg* (A comprehensive collection of decision aids can be found at www.Med-Decs.org) [3].

There are many ways in which decision aids can, and have been, be used [1]. Evidence from randomized trials has been summarized in a Cochrane Collaboration systematic review [4]. This review confirmed that decision aids, when used, performed better than usual care interventions in terms of: (1) higher level of patient understanding; (2) higher level of SDM; and (3) reduced conflict related to feeling unclear about personal values. More specifically, exposure to decision aids demonstrated reduced rates of elective invasive surgery in favor of more conservative options.

There has been an increase in use of decision support, and a global interest in developing these interventions exists among both for-profit and not-for-profit organizations [5]. There is also evidence that the number of patients using decision aids has steadily increased over the years, both in Europe and the US.

While decision aids are not common, they are considered to be a key component of SDM. However, a majority of patients have no knowledge of them. As a result, most patients facing important medical decisions continue to assent to the suggestions of their doctor without using a decision aid [3].

While the reasons for this situation are manifold and difficult to quantify, the current quality of decision aids and medical community resistance to their use are probably key factors. The development of decision aids can be characterized as a dynamic process, which has not come close to meeting its potential. Decision aids will not achieve their maximal value if the only thing they accomplish is to increase patient knowledge; information does not necessarily lead to triggering SDM.

Many of my patients do come in with information that they obtained from newspapers, the internet, or other doctors. That information alone is not sufficient to help them make an informed decision. One common example of this relates to Alzheimer's disease, a horrible form of dementia that people will do anything to treat.

Many family members of demented patients have read everything they can about the disease. They have visited neurologists and other experts and have pursued every treatment available. There are medicines for dementia that can, according to many experts, help mitigate the disease's symptoms.

When side effects cause patients to stop a dementia drug, or if a patient refuses to take it, the spouse, knowing how important the drug is from all that he/she read and was told, feels devastated. But such drugs are much more nuanced in their impact, as we will discuss, and often other more mundane interventions can have more profound effects on the progression of dementia. Simply having facts and an arbitrary base of knowledge regarding the disease and its treatment does not help such patients and families reach informed decisions with their doctors.

In order to remedy this situation, it will be necessary to develop a universally accepted paradigm for decision aids with internationally accepted standards. This will result in the larger medical community being on "the same page" and will provide patients with a consistent and objective approach for all health endpoints.

As was noted above, there is general agreement that positive benefits result from the use of decision aids. That having been said, it is also acknowledged that these tools require upgrading if they are to be accepted by large numbers of physicians and patients [6, 7]. One of the reasons this has become a glacial process may be related to financial incentives to perform unnecessary procedures. There is another more subtle, but very significant, issue. Before patient empowerment can be achieved, doctors need to accept the notion that it is the patient who makes the final decision.

To facilitate this transition, emphasis would need to be placed on the concepts of patient-preference and a patient's definition of acceptable risk. There appear to be encouraging signs lately as patients appear to be positively predisposed to SDM. A recent discussion paper released by the Institute of Medicine [8] states, "... people recognize the common-sense value of sharing information to improve health and health-care – and possibly that there is a thirst in the general population for care improvement through data sharing. Physicians also need to be open to modifying behavior regarding the adherence to following standard procedures."

A common example of this is the practice of ordering routine cardiac testing. In my practice, many of my patients see cardiologists regularly. Some of these patients had heart attacks in the distant past, have ongoing stable heart disease, or have no heart disease but want to be proactive. Very often they are told that they need to get periodic screenings with stress tests, echocardiograms, or Holter monitors. These tests are not based on new or changed symptoms, but rather are done fairly routinely as screening tests. Most of my patients accede to the tests without question; they assume that if the doctor wants the test, there is good reason for it. Many also believe that getting the test will help them avoid a heart attack.

Recently one of my patients asked me why he needed to get the stress test. I told him that I was unsure, but I did tell him that in the majority of people who die suddenly from a heart attack a stress test would have been normal and not predicted risk. I also told him that many abnormal stress tests in asymptomatic people are false positives; they pick up problems that are not clinically significant and that will not lead to heart attacks if left alone, but which can lead to unnecessary invasive tests and treatments when discovered. When the patient subsequently talked to his cardiologist about his concerns, both agreed to defer the test.

At a minimum, patient decision aids should:

- Provide information about options and their associated relevant outcomes;
- Help patients to personalize this information and understand that they can be involved in decision-making;
- Assist patients in understanding the scientific uncertainties inherent in most choices;
- Clearly present potential benefits relative to potential harms;
- Help patients gain skills in the steps of collaborative decision-making.

A pivotal question is how to prepare patients for taking an active role in determining what form of medical intervention, if any, is best for each individual. Once decision aids are successful in preparing patients for this role, they will play an essential part in empowering patients. Key to achieving this goal is overall agreement on criteria which would constitute a meaningful decision aid. While few disagree with this need, controversy associated with the definition of the term SDM and the inherent inertia in large public institutions may continue to slow down this process.

References

1. Elwyn, G., Frosch, D., Volandes, A., Edwards, A., & Montori, V. (2009). *Investing in deliberation: Defining and developing decision support interventions for people facing difficult health decisions*. White Paper Series. Gaithersburg, Maryland, USA: John M Eisenberg Center for Clinical Decisions and Communication.
2. Gravel, K., Légaré, F., & Graham, I. D. (2006). [Barriers and facilitators to implementing shared decision-making in clinical practice: A systematic review of health professionals' perceptions](#). *Implementation Science*, 1, 16. doi:10.1186/1748-5908-1-16. PMC 1586024. PMID 16899124.

3. Ubel, P. A. (2012). *Critical decisions: How you and your doctor can make the right medical choices together*. New York: HarperOne. 360 pp.
4. Stacey, D., Bennett, C. L., Barry, M. J. et al. (2011). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 3, CD001431. doi:10.1002/14651858.CD001431.pub3. PMID 19588325.
5. O'Connor, A. M., Wennberg, J. E., Legare, F. et al. (2007). Toward the 'tipping point': Decision aids and informed patient choice. *Health Aff (Millwood)* 26(3), 716–725. doi:10.1377/hlthaff.26.3.716. PMID 17485749.
6. Elwyn, G., O'Connor, A., Stacey, D. et al. (2006). Developing a quality criteria framework for patient decision aids: Online international Delphi consensus process. *British Medical Journal*, 333(7565), 417. doi:10.1136/bmj.38926.629329.AE. PMC 1553508. PMID 16908462.
7. Elwyn, G., O'Connor, A. M., Bennett, C. et al. (2009). Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). *PLoS One*, 4(3), e4705. doi:10.1371/journal.pone.0004705. PMC 2649534. PMID 19259269.
8. Alston, C., Paget, L., Halvorson, G., Novelli, B., Guest, J., McCabe, P., Hoffman, K., Koepke, C., Simon, M., Sutton, S., Okun, S., Wicks, P., Undem, T., Rohrbach, V., & Von Kohorn, I. (2012). *Communicating with patients on health care evidence*. Discussion Paper, Institute of Medicine, Washington, D.C. <http://www.iom.edu/evidence>.

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