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Consumer/Patient Decision Support in the New Millennium: Where Should Our Research Take Us?

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> [W]hile Canada has a lot of health-related information, much of this information is neither accessible nor usable.... How can we develop methods and incentives which encourage providers, administrators, and policy makers to adopt best evidence into practices, programs and policies to support decisions related to...health care...what can be put in place to make it easier for the public to become more involved in the decision making process surrounding...health care and their personal health?
>
> — National Forum on Health Key Strategic Direction:
> Using Better Evidence for Better Decisions

There is a growing interest in the area of decision making and the contributions of nurses to the science of decision support for patients. Several factors have contributed to this interest. The rise of consumerism and patient empowerment has shifted the emphasis from the more passive informed consent to informed choice. Health-services research in practice variations and the movement for evidence-based practice have stimulated the dissemination of clinical guidelines not only to practitioners but also to patients, particularly when the best course of treatment is uncertain; when the decision involves making value trade-offs among risks and benefits; or when patients can play a role in reducing inappropriate use of health services. The increase in technology assessments of current interventions using decision analysis has led to increased identification of treatment decisions that are "utility"- or "value"-sensitive — that is, dependent on the importance that patients place on the risks relative to the benefits. Large outcomes studies and overviews have provided stable estimates of benefits and risks among patient subgroups, which permits tailoring of decision aids. There is also considerable interest in the cost-effectiveness of adopting a more selective, patient preference-oriented approach and reserving interventions for those patients who consider the treatment

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benefits to outweigh the risks (for example, reserving palliative surgery for those patients who consider alleviation of their symptoms to be worth the surgical risks, rather than basing a surgical policy on the utilities of the average patient).

The role of practitioners in helping patients to make decisions varies according to the nature of the decisions, the preferences for control in decision making, and the expertise of clinicians and patients. Several practice guidelines advocate a shared decision-making approach, and Marilyn Rothert of the Faculty of Nursing at Michigan State University has described the various roles as follows: Practitioners provide information about the options available, the risks and benefits, and the health-care resources that are required and available; patients convey their value for the risks and benefits and the personal, financial, and instrumental resources that are available to help them make and implement the decision. Both Degner (Degner, Sloan, & Venkatesh, 1997) and Llewellyn-Thomas (1997) have contributed tools to facilitate this process.

Degner's tool (Degner et al., 1997) helps us to assess the role that patients want to play in decision making so that we can tailor our support to their needs. Her work raises as many questions as it answers. How do preferences vary among cultural groups? Which decisions are associated with stronger preferences for decision participation and which decisions are associated with weaker ones? How do preferences change over time? Should we tailor our counselling to decision-participation preferences or should we try to change them? If the former approach is advocated, which strategies work best with patients who have different participation profiles?

Llewellyn-Thomas (1997) has developed a strategy for helping patients to consider and communicate their values. How does this strategy improve the quality of patient-practitioner communication, the quality of the decision, and the outcomes of the decision? Are patients more likely, if this strategy is used, to choose alternatives consistent with their personal values? Will they be more satisfied with their decisions and more likely to stay with their decisions? What is the efficacy of this approach to values clarification relative to other approaches?

My colleagues and I highlighted the early phase of development for this field of inquiry in an annotated bibliography on decision-support interventions (O'Connor et al., 1997). Why only the early phase, when patient-education research has existed for well over 30 years? Decision support can be distinguished from general patient education by virtue of its: focus on alternatives, benefits, and risks; tailoring of information to a patient's clinical risk profile; provision of detailed descriptions of the benefits and risks in functional terms; use of probabilities, when these are available, to describe the likelihood of benefits and risks; asking patients to consider their values either implicitly or explicitly during deliberation; and emphasis on choice and shared decision making. Decision support evolved from the general field of patient education through a fusion, in the late 1980s and the 1990s, of consumer and health-services research influences.

To date, most decision-support applications have been developed for patients with chronic or life-threatening diseases, particularly cancer. The focus has been on decisions about surgical or medical therapies, although a few studies have considered preventive, early-detection, end-of-life, and clinical-trial participation issues. The decisions are characterized by the need for careful deliberation about alternatives due to the risk or uncertainty of the outcomes or the value-laden nature of the decision where benefits need to be balanced against risks.

The approaches used to provide decision support vary widely, from personal counselling to the use of structured aids as adjuncts to counselling. Some include formal decision analytic methods in which the patient's utilities are elicited and incorporated into a decision tree. Others use a decision analytic perspective to structure the aid, but rely on the patient's intuitive choice, rather than a mathematical combination of probabilities and utilities, to guide action. Research over the past 15 years has demonstrated the poor correspondence between intuitive choices and those derived from expected-utility decision analysis. Advocates of the intuitive-choice approach maintain that decision analysis should not be used in prescribing choice because it is poor in describing actual decision behaviour. Proponents of decision analysis argue that individuals are incapable of processing complex information and therefore should be guided by logical mathematical models. This debate will probably continue as both approaches are applied and evaluated in clinical practice.

The decision aids vary in the ways in which the probability of benefits and risks are described (numerical, non-numerical) and illustrated (pie charts, bar charts, 100 figures). The approach to values clarification also varies (implicit, or explicit using tradeoff tasks, relevance charts, weigh scales, or utility assessments). The provision of normative information describing the opinions of experts and patients also differs. The impact of these variations on actual decisions has yet to be established.

The decision aids vary widely in mode and cost of delivery. They are presented via decision boards, interactive video discs, personal computers, audiotapes, booklets, pamphlets, and group presentations. Their relative effectiveness, efficiency, and acceptability need to be evaluated.

The published studies evaluating decision aids are few in number and often have several methodological limitations. For example, only 14 of the 31 published studies used a randomized trial design and only five of these had a usual-care control arm. Even in these five studies, it was not always clear what the decision was and whether all patients were actively considering the decision. Moreover, most of the studies were limited in generalizability because of the small and non-random sampling. Therefore it is difficult to make any conclusive statements regarding the efficacy of decision support relative to usual care for a broad range of patients facing actual decisions.

Despite these limitations, the following trends have been noted. Decision-support strategies have received generally consistent positive ratings by patients in terms of feasibility, acceptability, length, balance, clarity, amount of information, and usefulness in decision making. Yet to be determined is the generalizability of these results to different groups who vary by age, education, ethnicity, and preferences for control in decision making and the comparative advantage of different approaches. Utilization of decision aids in general-education programs such as CHESS is fairly limited, because many users are not actually at that point in decision making.

Before/after studies have found that decision aids usually increase patients' general knowledge of alternatives, risks, and benefits after they are administered. However, there do not appear to be any gains in general knowledge when information about alternatives, benefits, and risks is presented via different delivery methods (e.g., video, brochure/pamphlet, group, audiotape, computer) or intensities of decision support. The lack of difference is presumably due to the considerable overlap in content provided in the different interventions.

Tailored decision aids have the potential to create realistic expectations (due to the tailored probabilistic information) and to clarify values (due to detailed information about outcomes from which value judgements can be formed and the explicit values-clarification exercises). There have been few studies to examine impact on expectations. In terms of clarifying values, three studies have shown that decision aids promote value congruence with decisions. More investigation is needed using these important endpoints, which tap two key differences between decision-aid interventions and usual-care approaches.

Both before/after and comparative studies have found the impact of decision aids on decisions to be quite variable. This variability may be the result of the nature of the decision, the strength of the baseline predispositions toward the issue, the degree to which the decision was hypothetical, or methodological limitations. Four of the five stronger randomized trials with patients at the point of decision making found no differences in decisions. The one exception was a study comparing information presentations on prostate screening (single sentence versus detailed information on benefits and risks). This is an area that clearly needs more investigation. Optimal study designs should have baseline predispositions, be randomized, have a control group, clearly define the decision, and recruit patients at the point of decision making.

Even less is known about the impact of decision aids on patients' satisfaction with the decision and with decision support. Practitioners' reactions to using decision aids are under-explored. Evaluations are also needed to determine the impact on long-term decision persistence, health outcomes, health-care utilization, and costs.

In conclusion, the National Forum on Health has challenged us to find ways of involving consumers/patients in decisions about their personal health. Many tools and approaches have been developed to assist us in helping our clients to make difficult decisions. However, the jury is still out regarding their effectiveness, efficiency, and suitability with different groups under different circumstances. We have our work cut out for us until well past the year 2000!

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