

## Patients at the center: in our practice, and in our use of language

In their editorial about patients sharing decision-making responsibilities with physicians, Guyatt and colleagues (1) review some of the evidence that patients favor involvement in their own care. They neglect a more complex body of evidence, however, that suggests that while patients like the idea of greater choice, they often find it to be less satisfying in practice (2). Just as the authors suggest that physicians incorrectly “assume that physiologic outcomes will lead to improvements in mortality and quality of life,” they themselves assume that more choice will lead to greater patient satisfaction.

As suggested by Barry Schwartz, a psychologist at Swarthmore College, the opposite may be true (3). Schwartz has identified a number of problems that arise as choices proliferate (4, 5). First, reliable information is difficult to obtain. The advent of the Internet has increased access to information, as Guyatt and colleagues contend, but the information being accessed may be unreliable or untrustworthy. Obtaining additional opinions and performing research are potentially costly and time-consuming.

Another problem is that as options multiply, patients’ standards for what is an acceptable outcome rise, with a loss of perspective of what may reasonably be achieved. Schwartz also notes that people may fear making the wrong choice and allow that fear to guide their choices. Or, post hoc, they may come to believe that an unacceptable result is their fault, and that their choice of therapy was mistaken. As the saying goes, good judgment is the result of experience, and experience is the result of bad judgment.

In one example of a study that stands in contradistinction to those cited by Guyatt and colleagues, people were asked to describe the role they would select in choosing their treatment plan if they had cancer (6). 150 women, newly diagnosed with breast cancer, were compared with 200 women with benign breast disease. Most of the women with breast cancer preferred a passive role, leaving the decision-making responsibility to their physicians; the benign disease control group preferred a collaborative role with decisions made jointly between the patient and the physician.

Schwartz has written that “Indeed, there may be a point when choice tyrannizes people more than it liberates them” (7). Like the patients in the study cited above, my own mother, an intelligent, strong-willed professional, was faced with the choice between lumpectomy and mastectomy for breast cancer. She sought opinions from 2 oncologists, an internist, a gynecologist, and her son, a nephrologist. I thoroughly reviewed with her the medical literature of the day. Finally, after many weeks, her unwavering decision was a nondecision: to let me make the choice, without her offering any real guidance. For the rest of her life, she was grateful to me for having “saved her breast”.

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### References

1. Guyatt G, Montori V, Devereaux PJ, Schünemann H, Bhandari M. Patients at the center: in our practice, and in our use of language [Editorial]. *ACP J Club*. 2004 Jan-Feb;140:A-11-2.
2. Schneider CE. *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*. Oxford: Oxford University Press; 1999.
3. Schwartz B. *The Paradox of Choice: Why More is Less*. New York: Ecco; 2004.
4. Schwartz B. Self determination. The tyranny of freedom. *Am Psychol*. 2000;55:79-88.
5. Schwartz B, Ward A, Monterosso J, et al. Maximizing versus satisficing: happiness is a matter of choice. *J Pers Soc Psychol*. 2002;83:1178-97.
6. Beaver K, Luker KA, Owens RG, et al. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nurs*. 1996;19:8-19.
7. Schwartz B. Nation of second guesses. *New York Times*. 2004 January 22. [www.nytimes.com/2004/01/22/opinion/22SCHW.html](http://www.nytimes.com/2004/01/22/opinion/22SCHW.html).

### In response:

Dr. Goldfarb is correct that patients may legitimately choose not to participate in decision-making. Indeed, at the outset of our editorial, we described how in the past it may well be that most patients preferred to leave decisions to their clinician.

We argue for the importance of patient autonomy. That autonomy begins with a preference, on the patient’s part, about the extent to which the patient wants information, wants to participate in deliberations, and wants to take responsibility for the decision. We believe, as does Dr. Goldfarb, that clinicians can harm patients by forcing them into a decision-making role that they do not want. Some patients, however, may choose not to participate in the decision-making process because they believe physicians will not present relevant information in a manner the patients can easily understand.

Dr. Goldfarb seems to believe that a study in which the degree of enthusiasm for active participation in decision-making varied with the underlying condition somehow undercuts our point. Preferences will vary between patients, and between contexts. Our contention is that evidence suggests that patients today are more inclined toward active participation in decision-making than were the patients of several decades ago.

Will patients be better off if they choose to participate more actively in decision-making? This is an empirical question best answered by randomized trials of alternative decision-making approaches. A systematic review of 34 randomized trials of use of decision aids, a process that promotes active patient participation, showed that in general these approaches reduce decisional conflict (weighted mean difference 19 on a 100-point scale, 95% CI 13 to 24) (1). Furthermore, results of randomized trials have shown that coaching patients to become more involved in making decisions can improve patient well-being and some disease-specific outcomes (2, 3).

In our editorial, we stated that “Shared decision-making—like evidence-based medicine in its initial phases and perhaps even today—also faces risks for misunderstanding.” Dr. Goldfarb’s letter vividly illustrates our point. In his final paragraph, Dr. Goldfarb

tells the story of his mother's choice between lumpectomy or mastectomy for breast cancer. The patient sought opinions from 5 physicians and ultimately reviewed the evidence with her son. Having heard multiple opinions and with an understanding of the evidence, she chose to leave the decision to her son. It appears that Dr. Goldfarb's mother was interested in obtaining the best understanding she could of the tradeoffs around her decision. Presumably, had there been a clear choice, she would have made it herself. In the end, it appears she concluded that the decision was closely balanced. Thus, she was most comfortable leaving the final choice to someone whom she trusted would have an in-depth knowledge of the benefits and risks of the alternatives, and an equally deep understanding of her values and preferences.

To the extent that this chronicle of events is accurate, Dr. Goldfarb's story is completely consistent with the shared decision-making that our article advocates.

Dr. Goldfarb's mother's choice to have him make the decision proved to be the right one because he understood her values and preferences—this is no doubt why she chose him, rather than the other 4 physicians she consulted, as the final decision-maker. Outcomes might be less positive if decision-makers do not have a deep understanding of patients' values and preferences—for instance, if Dr. Goldfarb's mother relied on a physician who selected mastectomy as the best option for her cancer.

Among the skills required by clinicians aspiring to evidence-based decision-making are an appraisal of the complexity of the decision, the informational needs and the decision style of the patient, and the likelihood that patients with different values and preferences will make different choices after receiving the same information. In preparing information, clinicians must avoid framing bias and attend to uncertainty in knowledge about likely outcomes. Ultimately, whatever the degree of involvement the patient chooses, the clinician must focus not on clinically relevant, but rather patient-important, outcomes.

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#### References

1. O'Connor AM, Stacey D, Entwistle V, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2003;(2):CD001431.
2. van Dam HA, van der Horst F, van den Borne B, Ryckman R, Crebolder H. Provider-patient interaction in diabetes care: effects on patient self-care and outcomes. A systematic review. *Patient Educ Couns.* 2003;51:17-28.
3. Michie S, Miles J, Weinman J. Patient-centredness in chronic illness: what is it and does it matter? *Patient Educ Couns.* 2003;51:197-206.

## In Memoriam – Hui Lee

### FAREWELL TO HUI LEE

The editors and staff of *ACP Journal Club* mourn the tragic death of Hui Lee, one of our associate editors. Hui was a 39-year-old general internist working in Sault Ste Marie, a community of about 80 000 people on the Canadian shores of Lake Superior and over 400 miles away from the nearest medical school. One could imagine a busy and fulfilling clinical practice in such a setting, and Hui certainly had that. But he had much more. He completed a Master's degree in the Health Research Methodology program at McMaster University and took his research skills with him, designing and leading many projects in health services research and clinical trials, and collaborating in many others. He caught the evidence-based medicine bug while at McMaster and carried this

with him everywhere—in his own practice, in his local teaching, through the Canadian Society for Internal Medicine (where he seemed destined to become president), and in his travels. He was awarded the College of Physicians and Surgeons of Ontario 2002 Council Award, recognizing physicians who come closest to meeting the society's vision of an "ideal" physician.

Hui was a dedicated family man, husband to Anne and father to Brian, Steven, and Erin. Hui was also an outstanding athlete. He died after the Ontario Provincial Masters Swimming Championship, where he came second to a competitor who set a new record. He burned brightly and we all celebrate his remarkable life, while regretting that it ended so quickly. Farewell to Hui Lee.

*The Editors*