

respect for professionals, not diminish it.<sup>14</sup> In this way a balance may be struck between the “high touch” and the “high tech” approaches.<sup>14</sup>

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## The role of risk communication in shared decision making

*First let's get to choices*

I want to feel like a rational and autonomous person, even when I'm ill. Doctors ought to use their power (legal and knowledge) not only to relieve suffering but to enhance patients' autonomy.<sup>1</sup> A prescription for this is shared decision making, a middle ground between “nanny knows best” paternalism and rampant consumerism—an ideal that aims to reconcile the fact of professional power with the ethic of informed choice.

Laws are leaning towards informed choice. For example, the supreme court of Canada in 1980 ruled that doctors have a legal obligation to disclose, unasked, whatever a reasonable person in that patient's particular position would want to know before making a decision. The ethical positions of medical guilds have more or less followed suit: “Duties of a doctor [are to] give patients information in a way they can understand; respect the rights of patients to be fully involved in decisions about their care.”<sup>2</sup> Informing patients and involving them in decisions therefore seem to be a doctor's duty.

It is within the “black box” of the medical encounter that patients most value information and the doctor's help in interpreting it. A consistent theme in studies is that patients want more information than they get. How often they mean risk information is less clear.

Risk communication is risky. We are predictably fallible and prone to biases in our judgments of risks and our use of information.<sup>3</sup> There are relatively few medical problems for which good risk information is available. Uncertainty changes (as women taking hormone replacement therapy will have noticed recently). Risk evidence rarely includes psychosocial outcomes, although these are important to individual patients. The autonomous patient may not make a “better” medical decision, nor will better decisions guarantee better outcomes for the individual.

Informed and shared decision making has been called the crux of patient centred care<sup>4</sup>—an interesting

choice of words. On a rock climb, another high risk activity, the crux is the hardest move, the one on which the whole enterprise depends. Shared decision making, of the informed sort, is difficult, and evidence shows that it rarely happens. For example, options and patients' understanding of information and role are rarely explored.<sup>5-7</sup>

This deficiency is often attributed to attitude: “Doctors ... provide patients with too little information about the side effects of prescribed medicine ... Shortfalls could be corrected by a change in attitudes, rather than a change in structures.”<sup>8</sup> But the time available in the consultation and the training of doctors (for example) are functions of structure.<sup>9</sup>

Formative medical training, when students are “professionalised,” tends to be in acute care. They are taught to be responsible in settings where choices are few and patients' autonomy is limited. They are rewarded for being confident and getting the “correct” answer. This is unlikely to foster a predisposition to, or practice of, offering choices or enhancing patients' autonomy. They are taught interviewing and history taking but not much about giving patients information or risk communication. Most of our communications skills are habitual and learnt from role models—hard to change even when we wish. Are the most influential role models and opinion leaders also competent at shared decision making?

The things a doctor ought to be able to do to engage in shared decision making have been proposed.<sup>10</sup> The story begins after the problem is identified. It includes explicit clarification of roles; information preferences; discussion of options with reference to the patient's characteristics and the evidence; response to the patient's ideas, concerns, and expectations; and partnership building. A statement of options seems to be a good starting point that may lead to the other elements.

Interventions that stimulate patient questions result in more involvement.<sup>11</sup> Patients have difficulty asking questions—and they attribute this mostly to doctors' traits. They feel intimidated, are concerned about using the doctor's time, and fear that assertiveness will jeopardise rapport.<sup>12</sup> A patient's question is a teachable moment. A testable hypothesis is that a doctor's conscientious and judicious search for and offering of choices will stimulate questions from the patient and lead to better information exchange and more involvement, perhaps even a role for risk communication.

What would happen if "We have some choices and they are ..." was in the doctor's habitual script, and "What's the evidence for that, doctor?" in the patient's?

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## Patients' understanding of risk

### *Enabling understanding must not lead to manipulation*

Who would disagree that understanding risks in order to trade them off against potential benefits is a prerequisite for citizens or patients who need to make health decisions? But rational consideration of risk, even if graphically explained<sup>1</sup> and understood, is neither straightforward nor sufficient. Rationality is not the only component in decision making.

Apparently irrational influences and considerations exert strong pressures. Individuals' perceptions of risk, and attitudes to it, may lead them to choices that seem irrational to the health professional. Perceptions are built up over time, informed by personal experiences and social networks, and shaped by behavioural norms and media reporting. Fear of a disease, trust in technology, and the desire to take responsibility for health also contribute to decisions people make.<sup>2</sup>

Research shows that avoidance of regret (that an intervention was freely available but was not taken up), a perceived right to access, and pursuit of equitability are reasons given by men for accepting and recommending prostate specific antigen (PSA) testing for prostate cancer.<sup>3</sup> Prejudices and preconceived judgments, culture, and the social context of a disease are powerful motivators, as are belief and tradition.<sup>4</sup> American women's predilection for risk averse tactics in their choice of treatment for breast cancer can result in drastic therapeutic decisions (such as extremely toxic chemotherapy treatments) with only 1-2% possibility of effectiveness, in the name of their right to individual control.<sup>4</sup>

The framing of risks, both numerically and linguistically, and the value individuals place on the various gains and losses perceived, have an effect on the choices that they make.<sup>5</sup> This has considerable ethical

implications for information providers if manipulation of individuals and populations is to be avoided.<sup>6</sup>

Gain in the short term is often an attractive choice, even if it comes with later loss.<sup>7</sup> For example, many women use hormone replacement because they believe that the relief from debilitating and persistent daily menopausal symptoms now is worth the increased risk of breast cancer later. Many have stayed with their decision, even after recent headline news in the media reporting new evidence that heightens the risk.<sup>8</sup> This is in spite of the fact that women generally grossly overestimate their risk of getting breast cancer and of dying of it.<sup>9</sup>

Good quality information and graphics are needed to explain risks associated with medical conditions and options—for patients in consultation with their doctors, but increasingly also for members of the public attempting to take responsibility for their own health.<sup>1</sup> Pressures from many sources advise individuals to strive for health and prevent disease by various stratagems, from supplements to screening. Sometimes a series of risks, contingent on possible different courses of action, has to be considered and traded off against likelihood of possible benefits, both near term and long term. Each possible course of action will contain its own trade-off of harms and benefits. Research has shown that consultations in which doctors have been trained in the use of decision aids sharpened the focus of the consultation, changed the content, and resulted in greater perception of decisions actually being made.<sup>10</sup>

Even if patients have received the benefit of a clear explanation about a particular risk, their expectations and attitude to that risk will affect their perception of it: what one patient will deem acceptable, another will not. Patients may alter their opinion at different stages