

# Patient perspectives

## Exploring patient values and preferences

Cathy Telfer MED

I was born in a time when families had one doctor who served all their health care needs from birth to the grave. The doctor was one step above the head of the household and was almost always male and definitely always right. We did not question his advice or directives. As the delivery of family medicine evolved toward the patient-centred approach, patients took on roles as partners with physicians, bringing meaningful experiences, values, preferences, and expectations. Patients became more adept at advocating for their health care and that of their families.

As a retired educator and a cancer survivor with additional chronic conditions, I am not an expert in any medical field, but have personal knowledge of many areas of health care. I am so grateful for the professionals who treated my basal cell carcinoma and malignant melanoma, cured my husband of bladder cancer, helped my parents stay healthy enough to live independently into their 90s, allowed my sister to survive more than 50 years with type 1 diabetes, and helped me thrive in spite of 2 autoimmune diseases and related issues. All of this has encouraged me to become an advocate for myself and others.

### Pressure on patients to decide

The medical profession has become much more technologically advanced and aware of the importance of prevention and detection of disease before symptoms appear and before treatment becomes imperative. Screening for relevant age groups is available at no or low cost to the patient and has proven to be very effective for certain diseases. For example, we believe that early detection can reduce the effects of breast cancer and colon cancer, and screening for at-risk populations is available for other diseases such as type 2 diabetes. We know a great deal more about how to prevent heart attacks and strokes, how diet and exercise affect health, and how our emotional state affects our physical well-being. If information is power, why would we not want to screen? Why would we not want to know how to make changes to our habits to live well?

For patients, it is disconcerting to be offered choice in screening decisions or treatment options. Doctors might say “These are the possibilities—which would you prefer?” As a patient, you do not know what you do not know. How does one choose without knowing what the doctor knows? The patient often feels a time pressure to decide and that, too, is an issue, especially if you have already waited months for other diagnostic tests or appointments and are fearful of waiting any longer for treatment to begin. Further, when presented with both the benefits and harms of screening, it is often

difficult to understand the numbers and how you might feel about a health decision 10 or 15 years from now.

### Choice and information

Making a choice without information is very difficult. How do I know the benefits and the harms of a screening test or treatment, the side effects, or the potential outcomes of decisions? I want guidance from those who do know but unfortunately there rarely seems to be enough time in an office visit to discuss pros and cons, risks, and short-term and long-term results. If given a choice of next steps and time to make a decision I, like most patients, would search for information. There is so much available on the Internet and it is difficult to be sure the sources are reputable. Guidance from physicians or health care teams is essential to determine the credibility of the data and to sift through conflicting details.

Information without choice is no better. Unlike years ago, most people no longer want doctors to give them quick details and single solutions without allowing them to explore options. Many patients want to know that they have their doctors’ support to investigate the melding of medicine with complementary or alternative approaches. Some patients find relief with complementary therapies and want their doctors to work with them as partners to learn what might supplement rather than interfere with what is known to be effective.

Research has given us so much more information than in the days when there was one doctor for each lifetime. For example, we now know that many types of cancer can be prevented by changes in lifestyle—lung and other cancers related to smoking, and, in my case, skin cancer resulting from long-ago sun damage. We know so much more about environmental carcinogens and the effects of external factors on our health. We know that lifestyle decisions made now might substantially affect our heart health in the future. With this knowledge comes choice about how to adjust habits to increase well-being. We have the power to change outcomes for ourselves and our loved ones.

### Expanding the patient’s role

The role of patients has expanded to that of active participants in not only their own care but in that of others with similar conditions or diagnoses. There are increasing opportunities for patients to help others by enrolling in clinical trials, to contribute to increased medical knowledge through genetic testing for diseases such as hemochromatosis or some types of cancer, and to perform altruistic service in the health care field through volunteering. This meaningful shift in thinking and the inclusion of

empowered patients opens exciting opportunities for further involvement in medical research and health care.

Not everyone wants to become an integral member of their own “health care team,” however. Some still want to be told what to do and will willingly follow the doctor’s advice without question. How is anyone in the medical profession able to determine what type of patient they are dealing with, what their preferences are, what they value? Is this a patient who wants choices and to be involved in decision making or one who wants to be directed to a single action? Is this patient one who wants quick and aggressive action or one who prefers to take time to consider alternatives?

Not everyone is able to clearly articulate their questions, fears, or values. It takes a skilled physician to determine if what is being said is what is meant. It also takes time, often more time than busy doctors have to devote to individual patients, but it is time well spent.

Everyone is different. Every disease takes a different path. Everyone has emotions and values and preferences. So—how to help?

### How can doctors help?

Here are my suggestions for doctors on how to explore patient values and preferences. The Prevention in Practice article in this issue on **page 28** also discusses how to elicit this information.<sup>1</sup>

- Move away from your computer and look me in the eye.
- For the brief period of time we are together, make me feel that I am your only patient and my health is your only priority.
- Take a few minutes to explore my values and preferences before we develop a plan of action.
- If I am a candidate for a screening test, help me understand pros and cons, and benefits and harms, then give me time to process the information before I decide. Allow me to “sleep on” decisions, even those that might seem straightforward to you.
- Hone the skills needed to “read people”—to determine who is the information seeker, who is the emotional responder, and who is too worried to hear anything you are saying.
- Be patient when I am confused, unaware of preventive health screening, or anxious about unfamiliar symptoms or asymptomatic presentations.
- Help me understand the terminology, especially the acronyms and short forms that are familiar to you but like a foreign language to me.
- Give me the most common and important side effects of a test, treatment, or medication, but do not overwhelm me with all possible negative outcomes.
- Give me “take-aways”—printed information, summaries, or references to reputable sources of information (such as those created by the Canadian Task Force on Preventive Health Care) so I can come to the next appointment more prepared.
- Clarify the process of communicating screening or testing results; reinforce that no news is good news.

- Explain next steps: what is going to happen from this point, when I need to see you again, what I should watch for, who I should contact if I run into problems.
- Encourage me to take advantage of opportunities to prevent or improve health issues for myself and loved ones.

### What can patients do?

Patients can maximize the benefit they get from a doctor’s appointment by being prepared. Here are my suggestions:

- Go to your appointment prepared to share your values and preferences while you and your health care team develop a plan together. Reflect on what is important to you and what options you might prefer.
- Bring someone with you as a second set of ears to help with questions and to take notes for later reference.
- Come with a few general questions and later, as you process the information, record additional questions to ask at a follow-up visit; ask about screening benefits and harms.
- For testing situations, when symptoms are present, document any physical or emotional changes and their frequency and duration.
- Seek information and support from your full health care team, such as a registered dietitian who can help you learn to read nutrition labels or a pharmacist to assist you with understanding medications.
- Check with your doctor before accessing alternative treatments.
- Do not assume that action is always better than no action; based on your values and preferences, it might be better for you not to have a screening test or undergo a particular treatment. Discuss this fully with your doctor before making a decision.
- Take a proactive approach; be willing to accept and implement screening and preventive strategies to avoid more serious health issues. Be open to making lifestyle changes to prevent or improve health issues.

### Conclusion

Asking not only what a patient wants or needs but also what they value results in more meaningful decision making for both preventive and responsive health care. By blending current information and appropriate choices, there is an increased commitment by physicians and patients to preventive care, which leads to healthy Canadians. We are so fortunate to live in a time when there is the willingness and expertise to make this happen.

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#### Competing interests

*Mrs Telfer* was reimbursed for her time and efforts by the Canadian Task Force on Preventive Health Care.

The opinions expressed in commentaries are those of the authors. Publication does not imply endorsement by the College of Family Physicians of Canada.

#### Reference

1. Lang E, Bell NR, Dickinson JA, Grad R, Kasperavicius D, Moore AE, et al. Eliciting patient values and preferences to inform shared decision making in preventive screening. *Can Fam Physician* 2018;64:28-31 (Eng), e13-6 (Fr).

Cet article se trouve aussi en français à la **page 13**.