

10 ways to make better decisions about cancer care

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ANN ARBOR, Michigan - Talking with doctors about cancer and cancer treatments can feel like learning a new language, and people facing cancer diagnoses often need help to understand their treatment options, and the risks and benefits of each choice.

"People are making life and death decisions that may affect their survival and they need to know what they're getting themselves into. Cancer treatments and tests can be serious. Patients need to know what kind of side effects they might experience as a result of the treatment they undergo," says Angela Fagerlin, Ph.D, associate professor of internal medicine at the University of Michigan Medical School and a U-M Comprehensive Cancer Center researcher (see also University of Michigan Health System).

Fagerlin and colleagues have published a commentary in the Journal of the National Cancer Institute that outlines 10 things health care professionals can do to improve the way they communicate information about treatment risks to patients. Here, they explain how patients can tap into these same best practices to become fluent in the language of cancer care and better understand their options.

- 1. Insist on plain language. If you don't understand something your doctor says, ask him or her to explain it better. "Doctors don't know when patients don't understand them. They want patients to stop them and ask questions," says Fagerlin, who is also a research scientist at the VA Ann Arbor Healthcare Center.
- 2. Focus on the absolute risk. The most important statistic to consider is the chance that something will happen to you. "It's important that patients and doctors know how to communicate these numbers, and patients need to have the courage to ask their doctor to present it so they can understand," Fagerlin says.

Sometimes, the effect of cancer treatments is described using language like, "This drug will cut your risk in half." But, such relative risk statements don't tell you anything about how likely this is. Research has shown that using relative risk makes both patients and doctors more likely to favor a treatment, because they believe it to be more beneficial than it actually may be.

- If, instead, your doctor told you that, "The drug will lower your risk of cancer from 4 percent to 2 percent," now you know that most people won't get cancer regardless. And it will give you the exact benefit you would get from taking the drug. Fagerlin suggests asking doctors for this absolute risk information for a truer picture.
- 3. Visualize your risk. Instead of just thinking about risk numbers, try drawing out 100 boxes and coloring in one box for each percentage point of risk. So, if your risk of a side effect is 10 percent, you would color in 10 boxes. This kind of visual representation, called a pictograph, can help people understand the meaning behind the numbers. Ask your doctor to draw it out for you, or do it yourself.
- 4. Consider risk as a frequency rather than as percentages. What does it mean to say 60 percent of men who have a radical prostatectomy will experience impotence? Imagine a roomful of 100 people: 60 of them will have this side effect and 40 will not. Thinking of risk in terms of groups of people can help make statistics easier to understand.
- 5. Focus on the additional risk. You may be told the risk of a certain side effect occurring is 7 percent. But if you didn't take the drug, is there a chance you'd still experience that? Ask what the additional or incremental risk of a treatment is. "You want to make sure the risk number you're being presented is the risk due to the treatment and not a risk you would face no matter what," Fagerlin says.
- 6. The order of information matters. Studies have shown that the last thing you hear is most likely to stick. When making a

treatment decision, don't forget to consider all of the information and statistics you've learned.

- 7. Write it down. You may be presented with a lot of information. At the end of the discussion, ask your doctor if a written summary of the risks and benefits is available. Or ask your doctor to help you summarize all the information in writing.
- 8. Don't get hung up on averages. Some studies have found that learning the average risk of a disease does not help patients make good decisions about what's best for them. Your risk is what matters not anyone else's. Focus on the information that applies specifically to you.
- 9. Less may be more. Don't get overwhelmed by too much information. In some cases, there may be many different treatment options but only a few may be relevant to you. Ask your doctor to narrow it down and only discuss with you the options and facts most relevant for you.
- 10. Consider your risk over time. Your risk may change over time. "What seems like a small risk over the next year or two may look a lot larger when considered over your lifetime," says study author Brian Zikmund-Fisher, Ph.D, assistant professor of health behavior and health education at the U-M School of Public Health.

If you're told the five-year risk of your cancer returning after a certain treatment, ask what the 10-year or 20-year risk is. In some cases, this data might not be available, but always be aware of the timeframe involved.

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