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Effective Communication: Improving Patient's Understanding of Cancer Risk

Announcer:

Welcome to CME on ReachMD. The following CME activity is provided by TOPEC and the Roswell Park Comprehensive Cancer Center through the generous support of BlueCross BlueShield of Western New York.

Dr. Reid:

Hello, my name is Dr. Mary Reid. I'm Professor of Oncology and Director of Cancer Screening and Survivorship at Roswell Park. I'm also a cancer epidemiologist, and I'll be talking to you today about how to communicate risk to patients diagnosed with disease. I have no disclosures.

The objectives of this talk are just to provide some initial introduction on the ways to communicate risk, and we know that how this is communicated can affect the patient's perception of their risk of the disease or risk of survival. We'll talk about a few different ways that you can do this effectively to

improve a patient's understanding of risk.

So risk is defined as danger, and it's important that we remember this when we're talking about risk because this is really how individual patients perceive it. It's the danger of having their disease. It's the danger of their disease coming back. It's the danger of their dying from this disease. So there are some basic terms that we use in epidemiology that you'll find in the literature, particularly odds, meaning the probability that an event occurs divided by the probability of it not occurring. We have another term, absolute risk reduction, which is really the difference between two groups, one subtracted from the other. And when you're discussing with patients, you can use this term to say, "There's a risk reduction if you have one characteristic over another. After surgery we'll talk about what the characteristics of your tumor are and how this may reduce or increase your risk." There is relative risk, which is really a ratio of risk of a given event or outcome, and this ratio includes the disease rate of an exposed group and the disease rate of a nonexposed group. And then there are hazard ratios, and this is a really commonly used calculation and risk. It's related to survival curves. It's used as kind of a graphical way of describing the risk or the hazard of a certain condition. Most of the time this is around survival, but it's also around recurrence. It can be used in patients who are exposed to one component or another and their risk of disease. When you have patients looking up in the literature or going online, frequently they're going to come to you with survival curves, and it's important that you understand how to explain it to them.

There are also some epidemiologic and risk management definitions. From an epidemiologic standpoint, we want to look at the probability that an event will occur, that an individual will become ill or they'll die within a certain period of time or age. Formally defined, this is the proportion of initially disease-free people who go on to develop a disease over a certain period of time. And then there's the risk management definition, which is the probability of an adverse event will occur, such as an exposure from a chemical incident, and what are likely to be the outcomes for patients.

Now, this is an example of a survival curve looking at the HIPEC, which is heated intraperitoneal chemotherapy, and a prediction model, and it's using a certain score, the Peritoneal Cancer Index. And what you see here is that when you look at survival probability by years, that the patients with the lowest score actually survive better, significantly better, than patients with the worst score, which is the highest score. If you're presented with this or you want to discuss this with a patient, you can go year to year, and you can see that over 5-year time, still patients even with the best score do die from the disease. And this difference of the high score versus low is immediate, and really, it leads you to put a patient into one category or another and allows you to give them some idea is their risk of survival better than if they had a higher score. It's complicated with patients because what we know from the literature is often times they don't really want to know their exact risk. They don't want you to

necessarily give them a time that you think they're going to survive. But on the contrast, other patients will interrogate you about a survival curve.

There are different ways of describing it, especially when you have people with maybe less inquisitive nature on the internet and maybe a slightly lower medical literacy, but these are some really great tools, I think, in describing risk. So if you want to say that a disease is very common, it may be as common as someone else in their family has the disease, or 1:10, versus common, which is someone on their street, and it gives them some kind of geographical or population reference, versus very rare disease, which there may only be one other case of this particular tumor in a whole town or whole city. These are kind of good references for patients because they do actually understand more about population groups as opposed to ratios.

The other part of describing risk—and this is very common in the literature of a risk communication—is how they feel about you as a provider. The level of trust they have for you is whether they sense that you really care for them and that you're highly competent, and that's when they trust you the most, and that's when the message that you're trying to give to them about risk is the best received. They can have a provider who's highly caring and maybe not as competent, and while they have affection for that provider, the message that you communicate on risk may not be as well-received, and respect and distrust. And so as you communicate with a patient, you have to sort of put yourself in one bucket or the other, because if a patient respects you and may not have full trust in you, how you communicate risk to them will be really important. You need to be careful that you're addressing their level of what they want to know, what their family wants to know. And again, a lot of this is tempered on the severity of the disease.

Just a graphical presentation of different perceptions, how experts perceive risk is really about hazard, by exposure, by susceptibility, by other covariates—such as age, the size of the tumor—all of those things that we plug into models, whereas with patients, they see them as hazards, plus how fearful they are about their disease, how angry they are about the disease, how it's going to affect their family. And so when you're dealing with patients, you need to plug this in and temper how detailed or what information you give based on where that patient is, where their family is, and modify your message accordingly.

So in summary, risk can really communicate... it affects how a patient perceives their future and how they perceive their likelihood of living through this episode. Often times numerical data can supplement the explanation, but again, you have to gauge the patient's medical literacy and how much they really want to know about their odds of surviving. You can use absolute numbers again looking at a 1:1000 or 1:10000, and you can also apply it to these geographical references like cities or towns. You can

state the odds from a positive or negative perspective, things that may give them some advantage in the length of their survival or some of the characteristics of their tumor that really negatively affect their risk, and it will negatively affect their perspective on how they receive that risk information. Definitely, use visual aids, and make sure the patient's consent is informed by the data. So you can develop strategies that individualize to the patient, either using data if you think that they can handle it, or not using data. Again, it's really dictated by your relationship with the patient and what kind of information you think they can handle.

Thank you very much. Please feel free to contact me at Roswell Park if you have any questions. Thank you.

Announcer:

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