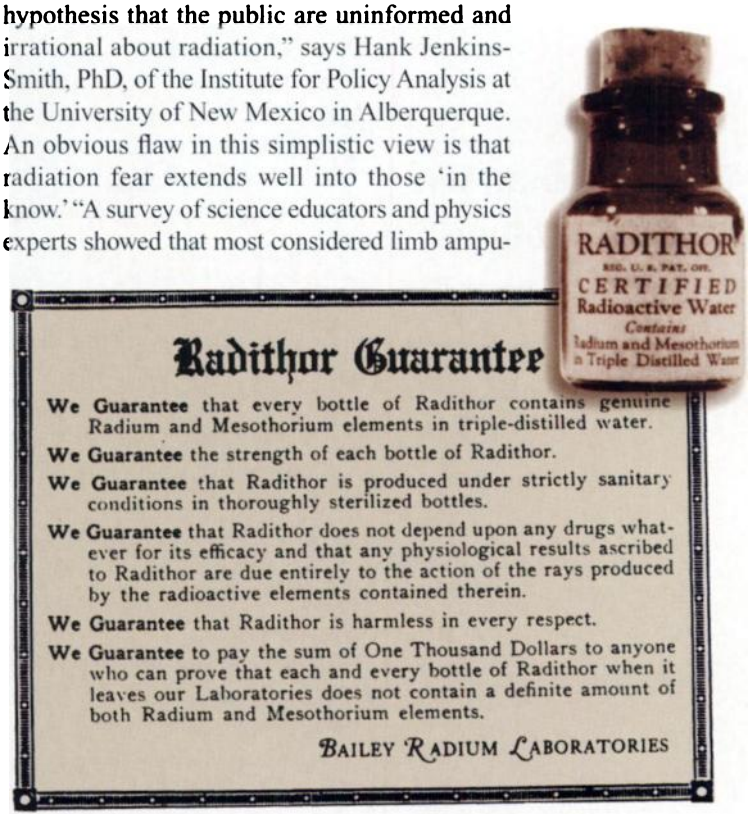
Communicating Risk: Nuclear Physicians as Patient Advocate

From demonstrations in Washington at the 50th anniversary of Hiroshima-Nagasaki to the latest hype over cellular phones and irradiated milk, radiation phobia continues. Although it has not been the public's intent, fear-driven policy has harmed radiation medicine in very tangible ways—from surging regulatory costs to a growing waste disposal crisis. Very recently, economic pressure has opened the door to serious questions about the regulatory costs versus the questionable benefits of the regulation. This "movement" has, in turn, caused a gradual shift in scientists' role toward comparing the unproven risks of low-level radiation to the proven benefits. "Scientists adopted the linear no-threshold paradigm for political reasons, and we may now be forced to abandon it for political reasons," explains Leonard A. Sagan, formerly with the Electric Power Research Institute in Palo Alto, CA, and now a consulting professor at Stanford University. Opinion leaders in science and policy are now searching for ways to communicate the 'rational cost-effectiveness' approach to radiation risk in ways that will benefit.

Nuclear physicians have a unique place in this effort as patient advocates in communicating potential radiation risk, both in terms of their knowledge of and experience with radiation doses and effects and their unique position of first hand observation of patient benefits. As experts, however, it is important to recognize that radiation fear is real and legitimate. We should work to assume an active role as a communicator and patient advocate. It is necessary to realize that radiation often frightens the public, and physicians must help patients understand their choices. "Physicians are used to communicating large numbers—such as that a patient has a 50% chance of remission. But it's much harder for people to convey an intuitive feeling for very small risks, such as 1/10,000 or 1/1,000,000," explains Baruch Fischhoff, PhD, professor of social and decision sciences and professor of engineering and public policy at Carnegie-Mellon University.

To address radiation fear, it is important to understand the complex social context in which people evaluate radiation risk—the distinct realm of value judgements in which people define the risk as "safe" or "unsafe." Contrary to traditional scientific opinion, radiation fear is not simply a matter of ignorance. "It's a popular, but wrong, hypothesis that the public are uninformed and irrational about radiation," says Hank Jenkins-Smith, PhD, of the Institute for Policy Analysis at the University of New Mexico in Alberquerque. An obvious flaw in this simplistic view is that radiation fear extends well into those 'in the know.' "A survey of science educators and physics experts showed that most considered limb amputation to be preferable to various levels of radiation exposure," says Fred A. Mettler, Jr, MD, professor and chairman of the Department of Radiology at the New Mexico School of Medicine, Alberquerque.



Radiothor, a radium tonic from the 1920's which contained more that 2 μCi (74 kBq) of radium in each bottle. The guarantee was a reminder that customers were getting the "real" product (reprinted by permission from *Radiographics*).

Paul Slovic, PhD, director of Decision Research in Eugene, OR, and a leader in risk-perception theory has identified two interrelated thought processes by which people perceive radiation risk. The first process is characterization of the risk. Radiation as a general concept scores high on all of Slovic's "unacceptable" characteristics: It is seen to be involuntary, uncontrollable, potentially catastrophic, carcinogenic and evocative of dread. Specific radiation risks are perceived according to the degree to which these characteristics are reinforced or offset and the degree to which the responsible parties are trusted. This explains why nuclear power and nuclear waste push all our hot buttons, while radiation medicine and nuclear medicine are generally considered to be acceptable risks.

Public concern over the recently declassified human radiation experiment data (*Newsline*, July 1994, pg 13N) symbolized the country's feeling that

ing that we have involuntarily accepted the risks of radiation for the sake of industry and scientific agendas, explains Kenneth Mossman, PhD, of Arizona State University. "The fact that none of the subjects was harmed was not the point." While scientists might have recognized that the studies were conducted before informed consent reforms, the public inferred that scenarios like the plutonium-injection trials, in which the word "plutonium" was classified, could happen again. "In general, risks seen to have high personal benefit are automatically perceived as low, while risks with no obvious personal benefit are automatically perceived as high," Slovic explains. While scientists may know that a source of radiation is not highly carcinogenic or new, they still weigh the voluntariness of personally accepting even what they know to be a small risk.

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The second thought process is evaluating the trustworthiness of the groups regulating the risk. Our society suffers from a rampant trust deficit, says Chris Whipple, PhD, of ICF Kaiser in Oakland, CA. Well-reasoned expert decisions are not necessarily accepted by a public determined to take charge of its own risk exposures. Nowhere has this been more obvious than in the case of radiation safety. "Trust is determined by the perceived competency, credibility, and objectives of groups making claims of safety about radiation," explains Jenkins-Smith.

From x-ray boxes in shoe stores to "impossible" power-plant accidents, the regulators have eroded trust by failing to protect and/or failing to understand that people expect protection and to have their legitimate concerns addressed. "As a result, many of the public are convinced that we're not safe, and that the scientific evidence on radiation risk is used to champion predetermined outcomes in regulator and regulated self-interests."

Jenkins-Smith's work shows that public responses to radiation risk information derive from filtering incoming "signals" (claims about radiation safety) through prior beliefs about radiation. "Since the public sees the radiation industry and regulators as biased and self-serving, signals from those groups can heighten perceived risk but can't depress perceived risk," says Jenkins-Smith. In many cases, the media heighten people's sense of risk by simply describing the presence of radiation. "Most people have no concept that radiation is a natural phenomenon and that we're exposed to it all the time," says Letty G. Lutzker, MD, chief of nuclear medicine in the Department of Radiology at St. Barnabas Medical Center in Livingston, NJ. "They don't understand how weak a carcinogen radiation is." In other cases, the media maintain credibility by intentionally affirming negative signals.

"Within six months after the Three-Mile-Island accident, the newspapers featured front-page articles on a study claiming that the incidence of childhood leukemia had increased tenfold among families living downwind from TMI," says Francis X. Masse, director of Radiation Protection Programs at MIT and radiation safety officer at Tufts University in Boston. "The one problem with the study was that the researchers got their wind directions backward and actually ended up disproving their own theory. Of course, corrections were buried in the back pages."

The technical community is partially to blame in the cycle of distrust in that it has focused on satisfying itself with risk assessment science without considering how use of the science affects public perception, adds Jenkins-Smith. "We've long realized that we're creating public policies in an atmosphere of trust deficit, and yet no effort has been made to characterize public distrust or create organizational relationships that promote trust of the radiation regulators. Trust is a hard to renew resource, and we impose great costs on the future every time we erode trust away." One important casualty of public distrust has been significant delay in opening low-level radioactive waste disposal projects.

Eight Tips for Communicating Risk to Patients

In an atmosphere of distrust and fear of radiation, even a positive message is received with suspicion. Communicating radiation risk to patients is unique, however, in that the physician-patient relationship is a status relationship. "Many physicians can talk a patient into anything, but what is relatively innocuous to you isn't necessarily viewed in the same way by the patient," explains A. Bertrand Brill, MD, PhD, professor of nuclear medicine at the University of Massachussets Medical Center and chairman of the SNM Radiation Effects Committee. "It's important to communicate what you believe the patient needs to know and understand—why you want to do a procedure—while responding to the patient's needs and concerns." For each situation, the context varies and it is important to clarify roles: **with the patient as the final decision maker and the doctor as the information resource.**

1. Understand the responsibilities of the patient in making an informed decision. Responsibility for accepting a radiation risk differs greatly for an adult patient than for the parents of a small child. "Tell the responsible party what they must bring to the problem to make their own decision—this legitimizes and delineates your role as

a risk communicator," says Petcovic. To this end, it is important to have a clear communication objective, or set of points that you want to get across, before your meeting.

2. Recognize that no one is ever impartial about radiation risk.

"It's crucial to find out what's already written on the slate, what the patient's fears and concerns are," says Edward B. Silberstein, MD, professor of radiology and internal medicine at the University of Cincinatti Medical Center. Effective communication should elicit: (a) what the patient knows about their disease and (b) what they know about radiation, recommends James Conway, MD, chief, division of nuclear medicine at Children's Memorial Hospital and professor of radiology at Northwestern Medical School in Chicago. "Most people know a fair amount of relevant information about radiation risk but are missing critical bits, undermining the value of what they know," adds Fischhoff. Recognize, for example, that it is not generally obvious that radiation is well understood compared to other environmental hazards. A savvy communicator reinforces correct conceptions while respectfully addressing misperceptions.

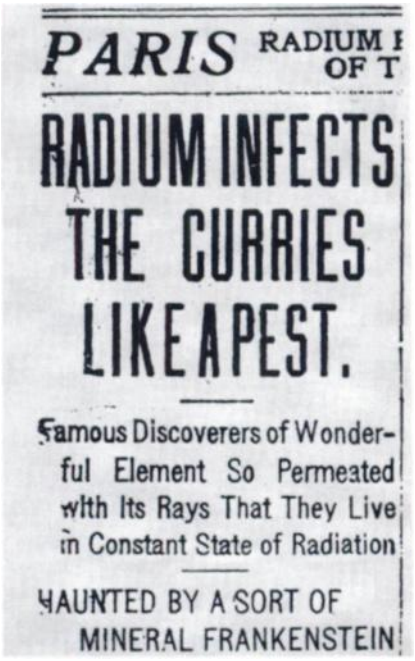
3. Make the decision process personal. Once you've determined what the patient knows, make sure the patient understands the benefits of the procedure before attempting to explain the risks. In describing risks, emphasize "feeling" rather than "thinking" aspects of the risk—a 99% chance that a procedure will help rather than a 1% chance that it will do harm. "It's important to clarify the distinction between the real risk of false or inadequate information about the patient's illness and the small theoretical risk of radiation," says Conway. A practical method to tailor your message, says Fischhoff, is to draw a decision tree from the patient's perspective, then work backward to determine information they will need in interpreting the outcomes of the alternatives. "For example, a patient may need to know how to recognize a treatment side effect." It is also important to communicate how you would handle a decision process for yourself or for a family member.

4. Avoid making comparisons that mix risks. "It may be simple to say that the risk of a nuclear medicine procedure is comparable to smoking one cigarette every ten years, but you can be sure many patients don't smoke at all," explains Neil Weinstein. Moreover, avoid explaining risks in the long-term; a message that a dose of radiation today will not affect your cancer risk but exposure to that dose over 30 years could be harmful will tend to confuse rather than clarify.

5. Give personal opinions to value-loaded questions. Technical or judgmental responses to questions that ask for your opinion—such as 'We really don't know, we need to study that more' or 'I can't imagine why you're worried about such a trivial risk'—are not helpful to the patient. "Acknowledge that it's normal to worry," says Conway—"but that yes, I'd expose myself or my family to this radiation risk because the exposure levels are low and the benefits are high."

6. Be upfront about the limits of your knowledge and the limits of the science in terms of your part in the patient's decision. Never fudge—data or statements known or sensed to be uncertain or incorrect will instantly discredit anything else you say.

7. Anticipate post-test questions. Don't assume that discourse breaks off after a patient opts to have a procedure. "The need for risk communication is usually after the fact, when a test shows up normal or needs to be repeated because it was not done properly the first time," says Conway. "That's when patients start to worry about the risk of the procedure itself." Moreover, keep in mind that it is often hard for patients to keep track of what you say, says Neil Weinstein, PhD, professor and chair, department of human ecology at Rutgers University Cook College. "A patient is more likely to recall a diagnosis than treatment information—my wife and I once discussed a test with a doctor and we both came away with completely different information."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HAUNTED BY A SORT OF MINERAL FRANKENSTEIN

Newspaper clippings such as this one have only heightened public radiation fears (reprinted by permission from *Radiographics*).

8. Evaluate and reinforce your message. Ask the patient to tell you what comes to mind after reading risk information aloud or listening to your statement; afterward, ask them to make inferences and summarize the message. Provide an audiotape of your conversation. While repetition is important, remember to always be flexible in your approach—be prepared to explain something in more than one way. Repeating a pat statement that was rejected the first time will not clarify it the second time.

—Jill Steuer