

## CLINICAL RISK COMMUNICATION: EXPLAINING CAUSALITY TO GULF WAR VETERANS WITH CHRONIC MULTISYMPTOM ILLNESSES

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Nearly all Gulf War veterans recall a range of environmental and combat exposures during their Gulf War service. Frequently veterans have developed their own theories and ideas about the extent that these exposures represent threats to their current and future health, theories that are sometimes causally related to the subsequent onset of symptoms, though very often they are not. Frequently, the veteran seems to overestimate or overvalue the apparently low chance that a rare, improbable cause (e.g., in theater vaccinations or biological weapons exposure) is responsible for symptoms than more ordinary and likely causes (e.g., early degenerative joint disease in an airborne infantry soldier). Under these circumstances, the manner and message of the physician when communicating may well alter subsequent veteran:

- Acceptance of and adherence to the physician's medical advice and opinion regarding causation.
- Satisfaction with care.
- Confidence in the physician.
- Future level of functioning.
- Likelihood of returning successfully to various life roles.

Much has been written about the doctor-patient relationship. One of the more commonly addressed issues is the skill with which physicians communicate bad news to patients. Probably more common for most physicians, however, is the need to effectively convey reassuring information when the available medical evaluation suggests the absence of a catastrophic or rapidly progressive problem.

There are several barriers when attempting to offer reassurance to patients. These include the lack of physician time, patient mistrust of their physician, the limited ability of most patients and many clinicians to appreciate the impact of chance and probability on diagnosis and cause, the abstract or complex nature of many illnesses, and the deceptively difficult interpretation of most diagnostic testing. Indeed, there is a large literature suggesting that the diagnostic characteristics of various common clinical tests are even a source of confusion for most physicians, let alone for patients. Maybe the most important reason physicians have difficulty consoling many patients is the growing public mistrust of the medical profession. This mistrust is amplified in clinical situations wherein the physician is perceived as having to balance the interests of the patient with the interests of a third-party payer, an employer or a social program.

Risk communication is the science of communicating information about risk under circumstances involving some combination of low trust, high concern, perceived crisis, or differential interpersonal power. The National Research Council (NRC) Committee on Risk Perception and Communication defined risk communication more formally as, "An interactive process of exchange of information and opinion among individuals, groups and institutions. It involves multiple messages about the nature of risk and other messages, not strictly about risk, that express concerns, opinions, or reactions to risk messages or to legal and institutional arrangements for risk management." Risk communication as a social science has developed out of the need to enhance bilateral communications about risk that occur regularly between organizations, governmental agencies, businesses, or industries and the constituents, employees, or other stakeholders who fear that such groups may unreasonably or unfairly jeopardize their health.

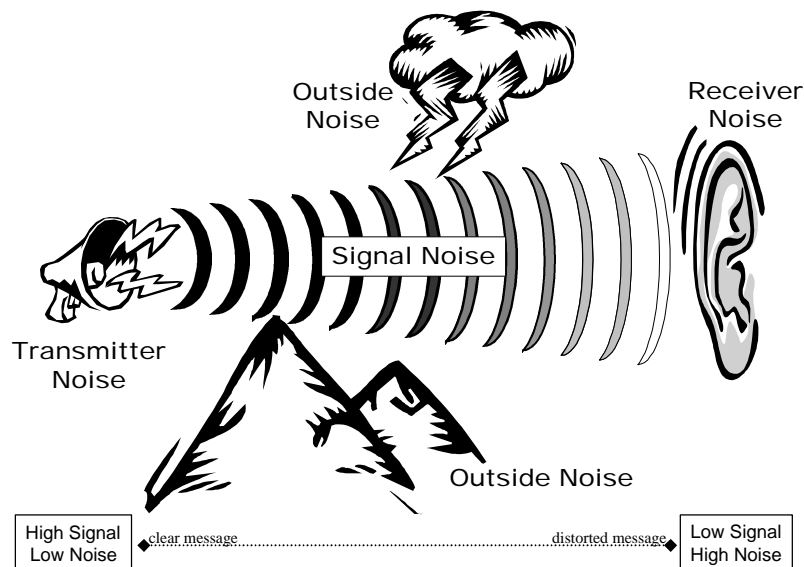
Nearly all clinicians regularly encounter patients under conditions of high concern, low

trust, perceived crisis or differential interpersonal power. Clinicians can learn to improve their capacity for effective doctor-patient communication about risk, disease, and prognosis from the burgeoning literature on risk communication. This brief overview, then, is an attempt to offer a risk communication perspective to inform and improve physicians' *clinical risk communication* skills. Improved clinical risk communication may alleviate unnecessary patient distress and physical health concern, reduce frustration and tension in the doctor-patient relationship. Most importantly it may help patients simplify the daunting task of coming to grips with relevant health risks and discarding irrelevant risks in the context of what is generally a hurried health care encounter. The remainder of this paper borrows some points from the risk communication literature in an effort to construct a model for thinking about clinical communication of risk to ailing Gulf War veterans concerned about war-related exposures.

### Modeling the Clinical Communication Encounter

Extensive cognitive psychology research literature shows beyond doubt that people (clinicians as well as patients) often misjudge causal mechanisms behind illnesses and events. In simple terms, the risks we worry about most are probably not the risks that evidence suggests are most important. To understand this observation further, it is useful to consider some ways that miscommunication of risk occurs. Signal theory is one way to model the communication of information between doctor and patient (see figure 1). A signal (the intended message regarding risk) emits from a transmitter (e.g., the doctor) to a receiver (e.g., the patient). Any number of influences creates "noise" (distortion) that hinders the accurate reception and processing of the signal. Noise can come from the transmitter (the talker), the signal (the message), the receiver (the listener), or the outside (the context or environment).

**Figure 1.** A simple-minded model of the types of "noise" (distortions) that can overwhelm providers' intended reassurances regarding potential health risks.

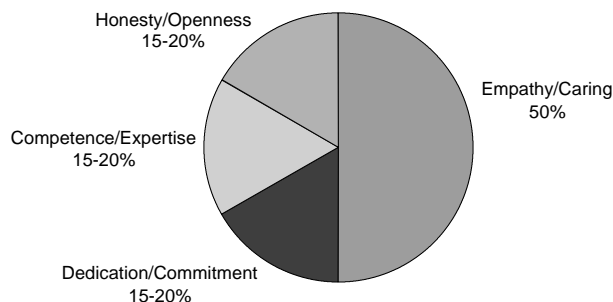


#### Transmitter Noise

Transmitter noise occurs when the person doing the speaking unwittingly clouds the verbal message with nonverbal and usually unintended messages that detract or distract from the verbal message. Commonly, the clinician is the transmitter, and there are many factors that

relate to the way the clinician is perceived that determine the amount of noise sent with the intended message. Research has explored the factors impacting perceived risk and suggests that the single largest determinant is the extent that the person doing the talking is perceived as trustworthy. The extent that the person talking is perceived as empathic and caring is in turn the single largest determinant of whether a communicator is viewed as trustworthy. In medicine, most of us value scientific and technical competence as perhaps the hallmark of an excellent clinician. Common sense might well suggest to us that perceived communicator competence and expertise would be a more important factor than research suggests it is (see figure 2).

Figure 2. Factors impacting on perceived trust and credibility.



The professionalization process in medicine sometimes promotes the image of physician as the detached and objective scientist over that of the warm and interpersonally connected confidante. In contrast, clinicians interested in improving their communication skills should develop the capacity to present themselves as caring, empathic, honest, and open.

### Signal Noise

Signal noise is increased when some aspect of the message (for example, its wording, order, or structure) creates misunderstanding. The structure of the message is particularly important. One simple method that has been suggested by risk communication experts is to use a structure that you can remember using the following mnemonic: “**C**ompassion & **C**aring **D**etermines **R**isk **A**ceptability.” First, begin your message with a statement of **COMPASSION**. Second, offer a brief ‘sound-bite’ **CONCLUSION**. Third, state no more than two pieces of supporting **DATA**. Fourth, **REPEAT** your conclusion. Last, describe the **ACTION** you intend to take in response to the situation. For example, suppose a patient is seeing you for fatigue, diffuse pain, and difficulty concentrating, and you have been unable to determine a clear medical etiology. During one visit, the patient finally says, “look doc, several men in my unit have died from symptoms like this – the way I look at it, this has got to be something chemical from the War.” One response might be “Mr. Smith, I have great respect for the way you are battling with your symptoms – I know it this must be a frustrating and frightening time for you (compassion statement). I am confident that you are not dying (conclusion statement). Studies show that Gulf War veterans have poorer health than expected though causes are often elusive. The good news is that death rates are not elevated in Gulf vets (data statements). I can assure you that you are not dying (repeat conclusion statement). So far we have not found anything on testing, and so I don’t recommend that we do more of it right now, but I’d like to schedule you to see me back in two weeks to see if things are better, worse, or the same (action statement).”

The first and last components essentially frame your message, so be sure to include them. The step that veterans’ are frequently most concerned about is *action*. Patients are

much less sensitive about clinicians' opinions if they feel reassured that they are not going to be used to justify clinical inaction or, worse yet, rejection.

### Receiver Noise

Receiver noise is the distortion introduced by factors related to or impacting on the listener. Risk communication experts emphasize that peoples' responses to risk are seldom predicated on technical data. Instead decisions about risk are value judgements. Just like informed consent, they are based upon highly personalized factors that may sometimes appear irrational to the clinician-observer. As clinicians, it is generally not our place to make decisions for our patients. However, it is crucial that we are aware of the issues that can adversely effect our patients' decisions (strong emotions, particularly mistrust, worry, fear, or outrage) so that we do not unnecessarily exacerbate them. Some of the most crucial factors that alter individuals' appraisal of risk are listed in table 1.

**Table 1.** Factors contributing to decreased acceptability of a given health risk. Risks are generally less acceptable if perceived as . . .

- **Involuntary** (e.g., pollution) rather than voluntary (e.g., smoking)
- Man-made or **Industrial** rather than natural
- **Unfamiliar** or novel rather than familiar
- **Dreadful** in their consequences
- **Catastrophic**, dramatic, or memorable
- **Unfair** (some people benefit while others suffer consequences)
- As subject to **contradictory statements** from responsible sources (worse yet, the same source).
- Dangerous to **children**, pregnant women, or future generations
- **Mysterious**, hidden, or poorly understood
- Uncontrollable or **inescapable**
- Harming **identifiable victims** (rather than anonymous ones)
- **Irreversible** or delayed harm
- **Mistrusted** party or source is responsible
- Involving a **passive response** from a responsible party or source

\*Bennett P. Understanding responses to risk: some basic findings. Risk Communication and Public Health. P. Bennett and K. Calman, Editors. Oxford University Press, New York; 1999

It should be clear from table 1 that sometimes what clinicians say or do can alter the extent that a patient's judgement about risk might become clouded. For example, it is almost always unwise to directly compare risks with patients. Comparing, say, the chance that a Gulf War veteran's ailments are due to an obscure Gulf War exposure (a mysterious, poorly understood, and involuntary risk) versus the chance they are due to a twenty pack-year smoking history (a well-known, well-understood, and voluntary risk) is likely to elicit patient outrage. This will diminish the chance that they will return to see you much less adhere to your medical recommendations.

### Outside Noise

Outside noise is produced by the peripheral or contextual issues that distort the risk message. For example, discussing chronic illness with a Gulf War veteran or a woman with silicone breast implants is a different matter from discussing it with the average patient. Of course, this is because the Gulf War and silicone implants have been the focus of intense scientific, governmental, and media scrutiny as potential sources of illness (see table 2). Clinicians who discount or overlook the context of the risk discussion do so at their own and, unfortunately, the patient's peril.

**Table 2.** Media triggers. A possible risk to public health is more likely to become a major media story if the following factors are (or can be made) prominent.

- Questions of **blame**.
- Alleged **secrets** and attempted **cover-ups**.
- **Human interest** through identifiable heroes, villains, dupes, victims, etc.
- Links with existing **high-profile** issues or personalities.
- **Conflict**.
- **Signal value**: the story as a portent of further ills ("What next?").
- **Many people exposed** to the risk, even if at low levels ("It could be you").
- Strong **visual impact** (pictures of suffering).
- Links to **sex** and/or **crime**.

\*Bennett P. Understanding responses to risk: some basic findings. Risk Communication and Public Health. P. Bennett and K. Calman, Editors. Oxford University Press, New York; 1999

### Conclusion

This presentation introduced the topic of clinical risk communication, using a basic illustrative model that borrows from signal theory. The goal is that this simple model will come into clinician's mind when he or she cares for patients. It is hoped that clinicians will find the approach helps them develop an increased sensitivity to the ways that patients decide about risk. Clinicians are well advised to adapt the elements of this approach in the interest of conveying accurate information to the Gulf War veterans who visit them to discuss issues of high concern in settings that all too often entail mutual mistrust, differential interpersonal power, or perceived crisis.

### REFERENCES.

1. National Research Council, Committee on Risk Perception and Communication. *Improving Risk Communication*. National Academy Press, WA, DC; 1989
2. Bennet P, Calman K (Editors). *Risk Communication and Public Health*. Oxford University Press, New York, NY; 1999