

Miscommunication and Risky Communication

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Miscommunication

This edition of *SMA News* carries a letter from Prof Lee Hin Peng in response to the article “The Unknown Chinese Female” by medical student Warren Ong (*SMA News*, November 2012). Prof Lee rightly says that “In the conduct of medical practice, there is no limit to what we can do to ‘go the extra mile’ so long as it is practical, doable and within the limits of our jurisdiction.”

While I am not suggesting that Mr Ong may have misheard or misunderstood what the doctor told him, we do have to keep in mind that the latter may have been quoted out of context or wrongly quoted. Whatever the case, I am sure that Mr Ong will remain true to the dictum of doing no harm, and to work in the best interests of the patient.

I teach medical students, two courses on forensic science to non-medical students, and also courses to the police. I have had several experiences of students, both undergraduate and postgraduate, misunderstanding me or misquoting me. I always hope that students will contact me first to clear up any issues.

For example, after lecturing on the examination of victims of sexual assault, I try to make some light-hearted comments (not about victims or the seriousness of the crimes). My experience has been that the topic of sexual assault is very heavy going emotionally. I have had students cry on me after a lecture because of the emotional aspects of rape. One student accused me of being cavalier. Another accused me of promoting pornography (obviously when you lecture about sexual assault, you have to show examples of normal sexual anatomy and sexual assault). Yet another student accused me of promoting deviant behaviours when I spoke about auto-erotic injuries, sexual asphyxias, and male-male sex assault. I tell students not to judge patients, both victims and alleged perpetrators, but just do what is required of them from a forensic viewpoint.

In another case, after lecturing on disaster victim identification (DVI) processes, I emphasised (as always) that DVI responders who are called to

other countries do so at the request of the relevant authorities of those countries. DVI teams are trained to be cognisant of the fact that they are working under the jurisdiction of a foreign authority, and should never overstep this boundary. One student asked me why teams doing relief work (which was wrong, because DVI is not relief work) imposed themselves on other people’s misfortunes, and accused relief teams of being ethnocentric, causing people grief and anger. This was a total misunderstanding of the message that I had been emphasising.

Sometimes, students feel the need to teach their lecturers life lessons. What I would say to such students, where appropriate, is to ask them to examine their own lives, and not to be so self-righteous and arrogant. I put it down to their inexperience and youth. In one new class on fingerprinting, I had bought 100 ink pads for a class of 400. The inkpads were to be reused from year to year. A group of students from a green group wrote to me, to “explain” what would happen to the Earth if we used 100 ink pads. I encouraged them to put their money where their mouths were, by asking them to man a booth outside a lecture theatre on two afternoons with two inkpads, so that students taking the fingerprinting class could go to them instead, and save 98 inkpads. They declined, saying that they were too busy. I offered some gentle criticism to them that it was all very well to tell people how to go green, but when actions were needed, they themselves were passive, and not willing to put actions to their convictions.

The risks of communication

So we all know that communication can be risky. This brings me to a related topic – the communication of risks. In October 2012, it was reported that six scientists and a government official were indicted for manslaughter for underestimating the risk of an earthquake that occurred on 6 April 2009 in the Italian town of L’Aquila, and sentenced to six years’ jail.¹ In reality, the prosecutors and families of victims did know

that it was impossible to predict when an earthquake would strike. So the scientists were accused of failing to properly assess and communicate the risks, telling people that they were safe when there was no scientific basis for saying so.

In the healthcare sector, healthcare authorities are always communicating risks to the public, while medical professionals are always communicating risks of treatment and non-treatment to patients and their families. But as humans, we are predictably prone to errors, and our own biases about what is risky and what the impact of those risks are. People tend to overestimate the risks of being harmed in low probability events with high consequence (for example, a building collapse), compared to common events or conditions (for example, diabetes). People also tend to be more sensitive to a risk if it is involuntary, if it is virtually going to happen, if it is not well understood, or if there are many contrary views.

For medical professionals, another problem with communicating risks is that medical training in medical school is skewed to acute care, where often treatment choices are few, and the role of patients in making decisions (patient autonomy) is limited. Students take exams, and are rewarded with high marks and good grades by being confident in giving a right answer (diagnosis) and then taking a course of action (investigation and treatment). This type of teaching does not actively encourage doctors to enhance patient autonomy. Medical students are hardly taught, if at all, about how to give information and how to communicate risks to patients and their families. Many students learn how to communicate information from their seniors who are supposed to be “role models”, but how competent are our role models at teaching how to share information and communicate risks?

Communicating public risks

Many commercial companies, interest groups and non-governmental organisations employ trained public relations people to disseminate information. Public health risks have a very large impact on policy and regulation. Many health authorities know this, and have corporate communication departments. Yet, how many hospitals have trained public relations people? If public concern about public health risks is not handled correctly, it can create great distrust, for example, the MMR vaccine and autism risk controversy, or radiation risks from mobile phones.

Generally speaking, the appropriate approach to communicating public risks depends quite a lot on the situation and how it is developing. Sometimes, public health risks communication involves giving information to alert the public about risks (for example, about

the effects of a novel virus causing an epidemic). Sometimes, it involves raising awareness (for example, the risks related to smoking or unsafe sexual practices). Sometimes, it involves reducing anxiety (for example, concerns about product safety). Communicating public risks are usually and ideally proactive (for example, the risks of severe obesity), but sometimes it is reactive where circumstances and knowledge change very rapidly (for example, during the SARS epidemic).

Whatever type it is, there are some key things to keep in mind when communicating public risks. These are:

1. Assembling the evidence and remaining credible (for example, using experts to articulate the risks);
2. Understanding what the public's perspective of the risks is, so as to know how to address public concerns (for example, if public concern is inappropriately low to a low probability, high consequence event);
3. Considering broad response options (and demonstrating that these options have been considered, and explaining the costs and benefits related to each option);
4. Defining the nature of the organisation's involvement in communicating the risks (which includes knowing when to involve other organisations – this is not “tai chi”); and
5. Knowing who you want to reach and how to do it (for example, the use of statistics may benefit one group of people, but may confuse another group).

Communicating personal risks

In the examples of miscommunication above that I encountered while teaching, the consequences are usually trivial or mild, and can be easily dealt with. However, in clinical Medicine, miscommunication of risks can lead to harm, anger, and lawsuits.

Medical professionals can communicate risks to patients either by a rational approach, or by an often more difficult and time-consuming patient-centred approach. Most medical professionals are relatively good at the former, but not so good at the latter.

The rational approach is relatively easier for medical professionals because this fits the context of evidence-based Medicine (EBM) and scientific research. Doctors, particularly specialists and experts, for example, can identify an illness, and have some knowledge of the outcomes of non-treatment and treatment, and the consequences and risks of different types of treatment. Doctors transfer this knowledge to patients, in the hope (sometimes wrongly placed) that patients will make an informed decision. If doctors think that patients are making irrational decisions (for example, a patient with chronic obstructive airway disease

continuing to smoke), they can respond by working harder to convince patients of the risks, or by telling the patients about more risks associated with the apparent irrational decision.

The rational approach can become a form of “paternalism” where doctors emphasise the risks of all other forms of treatment, other than the one they choose. It can also become very radical, where doctors simply inform patients of the various treatment options and their risks, and leave patients to choose without the doctors making any recommendations. The latter format often arises out of doctors’ fears of being sued and perhaps a truly genuine wish to ensure patient autonomy, but these should not deprive patients of doctors’ appropriate recommendation of a treatment option.

However, in real life, communicating risks to patients is not so simple. Sometimes, there is conflicting information. This can come from trusted friends, relatives, the Internet, or medical databases, like the Cochrane database (if the patients have the knowledge and money to access these databases).

Another problem about risk communication is that the risks that doctors convey to their patients are obtained from retrospective epidemiological and clinical studies about the probability of harmful events if a certain course of action is taken or not taken. It can be very difficult or impossible to establish prospectively

the probability of a risk. These studies of the probability of something harmful happening measure past events that contribute to the probability of the risks, and may also throw up more uncertainties which need further research and clinical trials. Such studies also do not take into consideration stochastic risks due to randomness of biological processes.

Risk communication using retrospective probability estimates also does not take into account patients’ unique personal risks, and their family history, except in a few situations like prediction of cardiovascular risks or the risks of developing breast cancer. When using EBM, while a clinical question about a particular disease and its answer may be known, what is not taken into account in the EBM question is the patients’ values and beliefs.

Another problem with a probability of risks based on retrospective studies is that medical technology is improving so quickly, and so many new discoveries are being made at a rapid pace. New technology and new discoveries may not only decrease risks, but more importantly, we may be unable to use past experience and events to predict future risks. New technology and discoveries also create new risks for which there is no evidence, or for which only a very limited number of experts have knowledge of.

In addition to all the above, how patients interpret risks depends on how timely and relevant the



information provided is, on their personal experiences, and on their own values. Patients and doctors may also have different views on risks, and how the risks impact them. Patients may want to hear all the risks, but may not be able to understand the risks and or recall them in certain circumstances. Thus, a patient's main concern about learning that he has advanced cancer may not be its medical management, but how to die with dignity.

So instead of a pure rational approach, medical professionals also need to use a person-centred approach when communicating risks to patients, because communication is a two-way process.

The fact that patients often rely on trusted friends and relatives for information, and how they accept the information and interpret it suggests that patients are more likely to accept information from medical professionals who they have a relationship with and who they trust.

Therefore, for medical professionals to communicate risks effectively, they need to add on a person-centred approach, where communication becomes part of a process to build up the doctor-patient relationship, which in turn builds up trust and mutual respect. This type of communication might include talking (and more importantly, listening) to patients to identify issues which they are concerned with, and not just providing information about the risks. This allows doctors and patients to negotiate treatment to seek a mutually

agreed course, and to adjust expectations. This person-centred approach includes doctors learning more about patients' situations and knowledge levels, what risks patients are concerned about, and the patients' belief about such risks. It also includes patients learning what the views of doctors regarding how to manage the former's concern about risks are. If doctors ignore or fail to acknowledge patients' concerns, and expect patients to passively agree to a course of treatment, then there is a risk that the patients may also ignore their advice and later blame them when harm occurs.

A simple example of the use of both a person-centred and rational approach is as follows:

Doctor: If you continue taking medication, you will be less likely to have a relapse.

Patient: I hate taking medicines.

Doctor: Why do you hate taking medicines?

Patient: I may become addicted to it.

Doctor: Taking this medicine for the long term does not mean you will be addicted to it.

Patient: Well then, what is the chance of my condition relapsing if I do not take this medication?

The doctor can now go into a rational approach.

With multiple discussions like this, the information about risks that doctors communicate may need to become more precise, as patients ask more questions.



But in some cases, doctors may not need to become more precise, for example: “You have had one recent heart attack, and you have a strong family history of heart attacks and sudden deaths. Your risks of getting another heart attack and death are very high compared to the general population, and you will benefit from taking this medication long term.” In such cases, it may be more efficient for doctors with limited time to tell the patient of the diagnosis, treatment and risks, and answers to anticipated questions.

Once doctors and patients have agreed on expectations, and the patients’ concerns have been acknowledged and addressed, then the usual way of communicating the consequences of non-treatment versus treatment, and the risks associated with particular treatments can be discussed. At this stage, doctors assume the role of an expert again, talking more and providing information.

To put in another way, doctors should make clinical decisions using the best available clinical evidence, taking into account the patients’ (and their families’) values, goals and capabilities. Arguably, the most important thing that needs to be present for good and effective risk communication is that doctors are competent, caring and compassionate.

How to communicate risks

“We are drowning in information while starving for wisdom.”

– Edward Osborne Wilson, American biologist and myrmecologist

So, even if medical professionals know that good communication of risks to patients is essential, they may not know how to communicate these risks. I am talking about the nuts and bolts, the actual process of communication of risks. Time constraints will remain a problem at the start, but an investment of time for discussions at the start will often save time in future.

There are no hard and fast rules, but there are basic principles that medical professionals can keep in mind, assuming that the doctor has the necessary technical knowledge.

One obvious principle is that medical professionals need to learn effective communication skills when communicating risks, which include active listening, using non-technical jargon as far as possible, pacing the time and amount of information provided to the patients according to the patients’ needs and preferences, giving information in digestible bits, delaying discussion if patients are distressed, knowing how to encourage patients to talk, knowing how to explain complex probabilities, and checking for understanding. In some situations, doctors may be able to give patients more time after a discussion

to consider the information, for example, in uncomplicated mild hypertension with no end organ damage, where starting medication is not urgent.

Generally speaking, risk evidence can be communicated in a number of ways:

1. Giving a general concept of the specific benefit or harm (for example, “if you continue taking this medication, your condition is not likely to relapse”);
2. Using numbers;
3. Using graphs, pie charts, and the like; and
4. Using decision aid programmes.

How doctors present risks depends on the characteristics of the evidence (for example, effect magnitude), of the patients (for example, cognitive capacity), of the families (for example, whether they are influential or not involved), and of course, of the doctors (for example, their communication styles).

When using numbers, it is important to use outcome numbers that are appropriate and that patients can understand. For example, citing the “response rate” of a particular treatment for advanced cancer, instead of morbidity and mortality rates, may make patients believe that they will live longer, when actually they do not live longer significantly. Another example of using an inappropriate outcome might be telling patients only about the “relative risk reduction (RRR)”, because the RRR tends to make a positive benefit look very good, when actually, the absolute benefit is very small or can only be seen in the far future. Many patients (and possibly some doctors) do not know how to interpret “number needed to treat”. Even doctors can be swayed by how evidence is presented, for example, doctors are more likely to prescribe a cardiac drug if the result of a clinical trial is expressed in RRR rather than absolute risk reduction.²

There is not much research on the value of these statistical terms to patients. It would seem that using a combination of them might be appropriate, although there is a risk that patients may find different combinations of outcomes confusing – so take care not to overload them with too much information.

There are problems with using numbers. The numbers describe a fictitious “average patient”. Another problem with numbers is that they do not take into consideration the burden that the condition and the risks impose on patients.

Doctors can also use visual representations of risks, like graphs, stick figures and crowd figures. Graphical representation of information is particularly useful for common clinical conditions for which a great deal of data is available. But doctors have to be aware that there may be factors which may influence patients’

decision making when they are presented with graphs, for example, the order in which graphs (say of survival and of mortality) are presented.

Decision aid programmes are commonly used to compare various treatments for the same condition, which have different risks of different value to the patient.

The language used can be important in how patients interpret the risk information. Saying "eight in ten diabetics will get retinopathy in ten years or more" (the actual figure may not be the example used) instead of "you have an 80% chance of getting retinopathy if you have been a diabetic for more than ten years" may lead patients to attribute the risk to others. But be aware that whether it can be generalised which outcome is better to use for patient understanding is not yet clear, partly because there has been little research on this.

Part of the language issue is how the information is framed (framing effect). Telling patients that "there is an 80% chance that this medicine will not help you" may lead to a different decision than if they were told that "there is a 20% chance that this medicine will help you". Therefore, doctors should not present information only in a negative frame, but in both positive and negative frames.

Another language problem is the variation in understanding of terms like *rare* or *frequent*. Misunderstandings of the meaning of the terms used are more likely if patients and doctors are not of the same ethnicity or socio-economic status. The same person can also interpret a term, such as *rare*, differently in different contexts, for example, in genetic counselling versus an antibiotic drug reaction.

There are various recommendations on how to standardise the language of risks. Calman has suggested a scale with standardised terms for specified frequencies (for example, high risks for one in less than 100, moderate risks for between one in 100 and one in 1,000).³ Paling has also made a similar suggestion, with added pictorial representations.⁴

We have to be aware that there is no particular approach that will work with each and every patient, even with patients who have the same condition. It depends quite a lot on what you have found out, about how much the patient wants to know, and how the patient wants to receive the information. Therefore, doctors must be flexible in communication, and know a variety of techniques on how to present information on risks and how to test patient understanding.

In our culture, many patients trust and entrust their family members with some aspects of their care. If patients so desire (and sometimes the desire may not be explicit), doctors should thus engage family input. But they should keep in mind that there may be

value conflicts among family members, and ensure that ultimately, the patients' decision is the most important.

Conclusion

In summary, in the context of clinical care, risk communication should be defined as a two-way exchange of information and opinions regarding the risks, with the goal that patients can better understand the risks and make better informed decisions.

Information is not the same as data. Information is data that is presented in context so that the data becomes meaningful to the patient. After or while information is being presented to patients, discussions with patients firstly recognise that decision making is often not rational, and secondly, discussions build mutual trust, confidence and respect. Doctors should, where possible, be receptive to reconsider other treatment options in response to patients' needs.

Communicating clinical evidence to patients has practical and ethical components. Practically, good communication is more likely to result in patients agreeing to a particular course of treatment and participating in it. Ethically, good communication rightly allows patients to understand their condition, treatment and prognosis, and as importantly, allows patients to make informed decisions, even if this decision is to opt for non-treatment. Good communication ensures that the "art" is put back into the "science of Medicine", and that "high tech" Medicine also becomes "high touch". **SMA**

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Dr Cuthbert Teo is trained as a forensic pathologist. The views expressed in the above article are his personal opinions, and do not represent those of his employer.