

Teratology Primer, 3rd Edition

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## Teratology Communication: How Can I Provide Information in a Way That Supports Effective Decision Making?

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An estimated 9 out of 10 pregnant women use some type of medication during pregnancy. In many cases, women have serious medical conditions that necessitate treatment and avoiding or stopping medications presents a significant risk to the woman and/or her pregnancy. Children have enormous value and importance, and pregnant women feel tremendous responsibility for keeping their babies safe. Prior studies have suggested that pregnant women tend to overestimate the magnitude of risk from an exposure. Information on the safety of medications continues to improve each year but it is rarely sufficient to fully determine risk, and almost never guarantees safety. Even in situations where there is a great deal of reliable data, it takes a skilled provider to convey information in a way that can be understood and utilized for informed decision making.

### **Why is conveying teratology information so difficult?**

Probability and numbers are often used as a strategy to accurately convey teratogenic risk. *Health literacy* refers to an individual's ability to understand health information and use it to make decisions. *Numeracy* is the component of health literacy that involves understanding numbers such as ratios, fractions, and percentages. Many people, including some health care providers, have limited health literacy and numeracy. Perceptions of probability, risk, and benefit may be distorted by people who have lower health literacy. These individuals are more likely to be reliant on non-numeric sources of data such as emotions or trust/non-trust in the health care provider.

People with less health literacy are susceptible to framing and can be very sensitive to how the information is presented. *Framing* refers to the context or wording of information. When used consciously or inadvertently it can have a powerful effect on a patient's risk perception and decision making. For example, in a Motherisk study, women given negatively framed information ("your baby has a 5% risk for a birth defect") had a significantly higher perception of risk than those given positively framed information (you still have a 95% chance of having a healthy baby).

Probability of necessity includes uncertainty, but uncertainty is difficult for patients, especially in high stress situations. Most people, including health providers, view things in a black or white fashion (risk vs no risk) and have difficulty making decisions when the risks are uncertain. This difficulty can result in inflating risk, even if it is presented with data suggesting that the chance of an adverse outcome is small or, conversely, denying that the risk even exists.

### **What can I do to make my communication easier to understand?**

- Resist 'information dumping' (i.e., going into excruciating detail). Patients who are in a stressful situation often hear only your first couple of sentences, so weigh what you want to say carefully. You can always offer more if this is a patient who does want a lot of supporting information.
- When presenting probability information, frame it in a variety of ways (positive vs. negative) and compare it to the baseline risk. For example, a woman with an exposure that carries a 1/100 increase in chance for a malformation can be advised that even women who have not had any exposures during pregnancy have a 3/100 chance of giving birth to a child with a malformation, whereas she now has a risk of 4/100 because of her exposure. This can then be framed in a more positive light by pointing out that this means that despite her exposure she has 96/100 chance of having a normal, unaffected baby. Note the use of a consistent denominator! It is very difficult to do comparisons when the denominators are different (quick...which is bigger, 2/40 or 3/75?). Using natural numbers can also assist with understanding ("If there were 100 people in this room with the same chance that you have, 4 of them would have a baby with a birth defect").
- Use verbal expressions of probability cautiously. These are words like 'low risk', 'minimal risk', and 'high risk.' Studies have shown that people have various interpretations of the same expressions, and it is difficult to develop verbal probability expressions that all people interpret in the same way. Use numerical probabilities appropriately as a basis for providing information, but consider including verbal qualifiers to place the numerical risk in the context of other life events.
- Visual aids such as pie charts, graphs, pictograms, or risk ladders may enhance understanding of probability information. For example, bar graphs can be useful in comparing chances of various events. Be careful that visual aids do not introduce another form of bias, however. For example, graphs tend to draw people's attention to harm.
- Consider using the words 'chance' or 'probability' in place of 'risk' when discussing possibilities. Risk is a form of negative framing, because it implies a negative outcome. However, note how difficult this advice is to implement, since it has been difficult to eradicate 'risk' from this paper despite knowledge that the word is prejudicial!

### **What about doing teratology counseling on the telephone, or by email or texting? Will the patient understand the information as well as when it is presented in person?**

Teratology counseling is often done over the phone, and recently by other modalities including email, chats, and texting. These newer formats are an effective strategy for serving a broader group of clients including teenagers, non-English speakers, rural, and other medically underserved populations. Studies done on telephone genetic counseling suggest that patients appreciate the accessibility, privacy, and anonymity. While effective in expanding the reach of teratology information services, there are some down-sides including barriers to rapport and difficulty using communications strategies such as visual aids.

Many of the issues with regard to conveying teratology information are present with telephone, email, and internet-based counseling, and in some cases are enhanced by not providing information in-person. Thus, teratology counselors need to be especially cognizant of biases, framing of risk, and numeracy issues when utilizing these modes of communication. There are currently no studies comparing patient satisfaction with the various modalities, and few data on comprehension of information. In an effort to examine this issue, the Organization of Teratology Information Services (OTIS) is investigating these factors in phone vs text teratology counseling.

## **Conclusion**

It can be difficult to weigh the advantages and disadvantages of a particular medication and even more difficult to effectively convey the information needed for an informed decision. Nonetheless, it is worth making the effort to develop and practice strategies that improve communication. People tend to comprehend more and make better informed decisions when the presentation format makes

the most important information easier to evaluate and when less cognitive effort is required. Remember that this decision is an intensely personal one for each woman – she is the person who will benefit from the treatment but who will also have to cope with any possible adverse outcomes. Despite the temptation to provide huge amounts of information, remember that it is your responsibility to emphasize what is truly important so that the patient can put it into context and is not cognitively overwhelmed. What is important may vary from patient to patient, but selecting what is important is part of the art of effective communication.

***What we say:** “It is impossible to guarantee safety, and I cannot be absolutely certain about whether this medication will hurt your baby. However, the available animal and human data suggest low risk.*

*In addition, this medication is important for your health and the well-being of your pregnancy.”*

***What pregnant women hear:** “...this medication might hurt your baby, blah, blah...”*

## Suggested Reading

[https://www.cdc.gov/pregnancy/mets/treating\\_for\\_two/facts.html](https://www.cdc.gov/pregnancy/mets/treating_for_two/facts.html)

Austin JC. 2010 Re-conceptualizing risk in genetic counseling: Implications for clinical practice. *J Genet Counseling* 19:228-234.

Conover EA, Polifka JE. 2011. The art and science of teratogen risk communication. *Am J Med Genet Part C Semin Med Genet* 157:227–233.

Jasper JD, Goel R, Einarson A, Gallo M, Koren G. 2001. Effects of framing on teratogenic risk perception in pregnant women. *Lancet* 358:1237-1109.

Koren G. The way women perceive teratogenic risk. *Can J Clin Pharmacol* 2007; 14(1):e10-e16.

Mitchell AA, Gilboa SM, Werler MM, Kelley KE, Louik C, Hernandez-Diaz S, National Birth Defects Prevention Study. Medication use during pregnancy, with particular focus on prescription drugs: 1976-2008. *Am J Obstet Gynecol*. 2011; 205(1):51.e1-8.

Ormond KE, Haun J, Cook L, Duquette D, Ludowese C, Matthews SL. 2000. Recommendations for telephone counseling. *J of Genet Counseling* 9(1):63-71.

Paling J. 2003. Strategies to help patients understand risks. *BMJ* 327:745-748.

Visschers VHM, Meertens RM, Passchier WWF, de Vries NNK. 2000. Probability information in risk communication: A review of the research literature. *Risk Analysis* 29(2):267-287.