On Risk and Harm

January 11, 2010 By Paul Dalton

I am part way through the book, 'Denialism: How Irrational Thinking Hinders Scientific Progress, Harms the Planet, and Threatens Our Lives,' by Michael Specter. I will review the book properly when I am done reading it. Right now though, I want to talk about one of the important concepts he talks about- one that is of vital importance to people living with HIV/AIDS. The concept is how harm and risk are understood and misunderstood in our society.

It is my experience that people with HIV/AIDS, and those who work with us think about risk and harm quite a bit. We think of it in terms of our meds, of our sex lives and increasingly of things like heat disease, cognitive decline and other consequences of aging. It is also my experience that we often talk about risk and harm in ways that are both inaccurate and unhelpful. While some of this can be chalked up to inadequate math and science education, the important concepts involved are neither highly technical nor particularly complicated.

Most importantly: all risk is relative. In other words if you want to understand how risky something is, you have to compare it to something else. So to say something is 'safer' means nothing if you don't say what it is safer than. For example if you want to understand how risky it is to fly on an airplane you can't just look the likelihood of perishing in a plane crash (the number of plane crash fatalities divided by the number of people taking flights during a defined time), you need to compare it to something appropriate- like driving a car, taking the train, or

not traveling at all.

Relative risk is what we need to understand to make good healthcare decisions. As a person living with HIV I have to weigh the risk of taking an HIV drug. I can do this in a few ways. I can look up the list of possible side effects and leave it at that. This will give me important, but incomplete information. It will tell me what to look for, and that is all. A better way to look at the same thing would be to look at how likely any possible side effect is- what percentage of people got the side effect- is it 5% or 25%? This way gives me a better, but still incomplete basis to make a decision. I now know how likely a side effect is, but I need to know one more thing- what is my risk of not taking the drug? This should be though of in two ways- both by comparing that risk to other drugs I might take, and to the risk of not taking any drugs at all?

The foundation of medicine is the concept of ’do no harm.’ Sometimes the most harmful thing to do is nothing at all. An easy example would be whether or not to take something like Septra or Bactrim to prevent PCP (*pneumocystis jerovici pneumonia)* if your CD4 count is below 200. There are known risks to taking these drugs, including the risk of death. If the question is posed as ’is taking Septra more risky than not taking it?’ the answer may be different if you only look the risk of a fatal drug reaction than if you compare that risk to the risk of getting PCP if you don’t take it. While there is a small risk of a fatal drug reaction from taking Septra, there is a bigger risk of getting PCP if you don’t take it.

This is made more difficult because of the power of the anecdote. To most anyone who isn’t a

statistician or scientist, anecdotal evidence (otherwise known as our real life experience) is much more powerful and compelling than an incidence calculation or risk ratio. Back to flying as an example- as Specter says in the book- we are bound to remember dramatic and compelling events like a plane crash, and just as likely to forget all of the planes that didn't crash. But the risk of flying is demonstrably lower than the risk of driving. Plane crashes are more dramatic and much less common that car accidents- this leads many of us us to be more fearful of flying than driving, even though our chance of dying in a plane crash is a tiny fraction of our risk of dying in a car crash.

I had a discussion about this with a friend recently as I was starting a non-HIV related meds. She was telling me of some online forums she had used when taking the same drug, and warning me of the horror stories people posted. I thanked her for the resource and told her that because of my work in HIV treatment activism, I had a pretty good lens to view those kinds of things.

Whenever I talk about HIV drugs and side effects, I start off by stating that I think that almost everyone with HIV or any close connection to people with HIV is highly likely to have an exaggerated sense of both the frequency (how often) and the severity (how bad) of side effects from any HIV drug. The reason for this is simple- we notice when people have side effects, especially the more severe ones. We don't notice when people don't have them, just like we don't really notice when planes don't crash.

This is not to discount the reality of side effects- they happen and should be paid attention to. It is

simply to remember that most every medical decision we make entails risk and the only way to really understand that risk to compare the risk of the alternatives, including the risk of doing nothing at all.

I am not a math person. Numbers make me cranky. I take comfort however in the realization that I make relative risk calculations for myself every day, the same way anyone reading this does. If I get in a car, I know there is some risk in doing that. I try to minimize the risk by wearing seat belts, and not texting while I drive. The risk is never going to be zero, but neither is the risk of not getting in a car. So, if you need to drive to your job every day you accept the risks of driving because they are more tolerable than the risks of not driving (losing your job for example).

AIDS activism grew out of this understanding- people were willing to fight for the right to take very real risks with their lives by taking drugs that were not well understood or even known to work, because the risk of not trying them was understood to mean almost certain death. A drug like Hivid (ddc) would never stand a chance of being approved (or probably even getting in to human studied) today, because it caused too many side effects and there are safer alternatives. When the drug was approved the risk of side effects was pretty much (but incompletely) understood- but there weren't really safer alternatives. Therefore it made sense for the drug to be approved at that time. It equally makes sense for the drug not to be used now- the relative risk has changed.

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