A Close Look at Hepatitis C Research

October 23, 2014 By Lucinda K. Porter RN

Hepatitis C recently claimed the life of a close relative of a Hep Forum member. Death from hepatitis C doesn't just ripple like a tide--it comes in like a tsunami, and affects us all. We are on the Internet trying to avoid premature death, and then here it is, close to us, happening to someone we have come to care about.

Approximately two people die from hepatitis C every hour in the U.S., most of them ranging from 45 to 65 years old. Another 10 people with hepatitis C will die each hour because hepatitis C increases the risk of premature death from other diseases, such as stroke, heart attack, or cancer. Although dying is the worst possible outcome of hepatitis C, living with it can also be its own nightmare. Cirrhosis is a miserable condition to have.

The potential outcome of hepatitis C is what drove me to try treatment three times. I did not want to die from this virus, not if I could do something about it. I reviewed data, talked to people, joined Internet and community hepatitis C groups, and talked to experts. In the end, I was cured. But my research had another benefit - I became a better critical thinker and learned how to look at data and apply it to me.

Here are some tips I've picked up along the way:

Look at the source. If statistics are used for commercial or political purposes, the numbers may have been spun. If the numbers come from a reliable medical journal, such as *Hepatology*, *New England Journal of Medicine*, or *Lancet*, it is likely that these have stood up to scrutiny.

Use data from big studies. Data from small studies are less reliable. To illustrate this, let's look at the COSMOS study, which investigated simeprevir (Olysio) and sofosbuvir (Sovaldi). On the forum, we call it S+O. If you have cirrhosis, and wonder if you should take S+O with ribavirin or without, you'd look at the COSMOS study. You might think you are better off without ribavirin because 93% of the subjects with fibrosis stage of 3 or 4 on 12 weeks of S+O+ribavirin had an SVR4, compared to 100% of those on the ribavirin-free arm.

However, there were only 7 people in the ribavirin-free arm and 15 people in the S+O+ribavirin arm. One of the people dropped out of the S+O+ribavirin arm, so it makes it look like 93% had an SVR. Small numbers make big differences in the data.

Granted, both numbers are close enough that one could argue, "With 100% of those in the ribavirin-free S+O arm, that is an obvious choice. But, if two people had dropped out, then it would have appeared the cure rate was only 73%. The bottom line is small numbers are not reliable.

Look at final numbers. In the COSMOS study I quoted above, preliminary data was reported. SVR4 is

not final data.

Compare apples-to-apples. Again, looking at the COSMOS study, it appears there are a lot of side effects. Be careful, since side effects from all the arms are often lumped together. Ribavirin has many side effects, so if you aren't taking ribavirin, look for data that applies precisely to your case.

Then there is the BIG issue of death. When reading study results, it isn't enough to read that someone died; read why they died. Example: The one death among all of the sofosbuvir treatment groups was determined to be caused by heroin and cocaine overdose on the first day of treatment. This can hardly be attributed to sofosbuvir.

Again, compare apples-to-apples. S+O is nearly always used for pre-transplant (and some post) patients, so we are looking at those who are at risk for serious medical problems. There is a big difference between someone who has stage 3 fibrosis and someone with cirrhosis who is on the liver transplant list.

Finally, never let research tell you how you feel. If in a survey, half of the people with hepatitis C patients reported feeling fatigued, that does not mean you should or will feel fatigue. No lab test or research should ever tell you how you feel. Data may be reassuring, but it is not a substitute for your opinion about your own health.

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