When Hepatitis C Treatment is Hard and Scary

June 22, 2015 By Lucinda K. Porter RN

Hepatitis C treatment is curing a higher percentage of people than ever. The side effects are milder, and people are on the drugs for a shorter length of time, which lowers exposure to adverse effects. Compared to the older days of triple therapy using peginterferon, ribavirin, and a protease inhibitor, the new treatment is relatively easy. Those who went through 72 weeks of daily interferon, may look at 8 to 12 weeks of Harvoni, and think, "This is a cakewalk."

However, what if hepatitis C treatment isn't a cakewalk for you? And while I am asking questions, isn't a cakewalk a weird metaphor?

Recently I was following a conversation on the Hep Forums regarding side effects that some people are experiencing. Some people are having a hard time. Here are some observations (code for here is my opinion):

- Some people have a harder time with treatment than others do.
- Although some have more side effects than are typical, if they are supported with good medical intervention and community help, they will tend to have an easier experience.
- Minimizing someone's hepatitis C treatment experience is careless at best; cruel at its worst. Treatment is hard enough, and if ours is atypical, it makes us susceptible to isolation.
- Those of us who have endured really long, hard hepatitis C treatment may be tempted to say, "You think you have it bad, let me tell you about the old days, when I was on five years of interferon and had to walk ten miles to school every day, uphill in the snow." We don't have to wear our prior treatment experience as a badge. It is best worn as a symbol to encourage others.
- Even if you went through treatment before with the older hepatitis C drugs, these newer medications might still present some challenges. Just being a few years older may make us a bit more vulnerable to side effect.
- If we are on hepatitis C treatment and have a side effect that is not reported in the drug's

literature, that occurrence may or may not be related. Coincidence happens but we are also still in the early days of these new treatments. Both scenarios are possible.

- The more we report our side effects to the FDA, the better off we all will be.

Now, a word about the FDA. Someone sent me info about the adverse events by patients taking Harvoni reported to the FDA from Oct 10, 2014 through March 15, 2015. The person who sent it was concerned that the public wasn't getting accurate information about the risks of Harvoni. (Thank goodness for advocates like this one, who aren't afraid to challenge the system, ask hard questions, and try to get the facts.)

The data were raw, and there was no way that I could infer anything from it. In five months, there were 759 reports. (There may have been less, since some appeared to be duplicates.) In that time, there were 20 or 21 deaths (I think one was clearly a duplicate, which is why I think there were 20). One was related to taking Harvoni and amiodarone together. So far, the other deaths have not been connected to Harvoni.

Still, that sounds like a lot of deaths. However, most of the reports were of patients with very complicated medical histories. I suspect that many of the patients on treatment began with very advanced disease. One of the huge problems we are facing is that insurance is denying treatment to many except to those with cirrhosis or comorbidities. Death and severe symptoms are routine in this population. Nurses and physicians I know are scrambling to get treatment for their sickest patients first, so they can prevent death, which happens a lot in these patients.

When I was a clinical trial nurse, I had a patient who was in a car accident while on treatment, and another who suffered a chainsaw accident. I had to report these incidents. It could be argued that these patients were more likely to have accidents since hepatitis C drugs can mess with your concentration. On the other hand, people who aren't on medications have accidents every day. Just because someone is on a medication and has an adverse event, doesn't mean that the drug caused it.

On the other hand, drugs can, and do cause adverse events and we should report them.

Side effects are scary, and it is always best to go in to treatment knowing the risks. However, keep in mind that about 53 people die from hepatitis C every day. If we count premature death from heart attack, stroke, and cancer, than the figure is four times that amount.

Sometimes we need to take some risks in order to get great benefits.

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