Infected With Hepatitis C: Words Matter, So Does Compassion

June 24, 2019 By Lucinda K. Porter RN

I try not to wade in to controversy, but sometimes it finds me and I can't turn my back on it. So, here goes.

All the publications under the Smart and Strong umbrella (Hep, POZ, Real Health, Tu Salud, Cancer Health, etc) make a conscious effort to provide accurate, sensitive and useful information for their readers. Additionally, these publications produce supportive, stigma-free content.

If you think this is easy, let me assure you it is not. First, what offends or stigmatizes one person may not bother another. Second, culture and our sensitivity to it are always changing. There are many words from my childhood that were perfectly acceptable, but were wildly insensitive. They weren't just insensitive because of the meaning, but because we would use them derogatorily. (My apologies to everyone with Trisomy 21 (aka Down Syndrome) for calling Ralphie Formica the 'R' word when I was 9 years old. Apologies to Ralph too, plus for hitting him on the head with a hammer when he invaded our fort. Although I think all was forgiven when we went on a date when I was 14. Or, he had a concussion and didn't remember the incident.)

Back to words that stigmatize. Take the word 'leprosy' for example. This condition is now being replaced by its proper label, Hansen's Disease. The problem with the word 'leper,' is it is associated with being cast out from society. Look for synonyms for 'leper' and you find a list of really horrible, stigmatizing words, such as untouchable, pariah, outcast, and castaway. These are words that shun; words with no hint of compassion.

For many years, I felt comfortable with the word 'infection,' as in, I had hepatitis C infection. I started to rethink this when the wise voices of people living with HIV started to challenge the use of the word 'infect.' It is a loaded word, perhaps not medically, put to people who feel stigmatized by their diagnosis.

Context is everything. If my doctor told me I had a sinus infection, I wouldn't feel a blush of shame about it. But herpes and hepatitis C were harder to live with, and the word 'infection' had an element of stigma to it beyond the actual diagnosis. I felt like a 'carrier,' another word that makes me queasy.

Words matter. Words show love and support. Words bring us in to the fold, rather than cast us out.

Now, before I hear from critics, let me assure you that I am not going to start policing anyone else's language. Although words matter, so does compassion. Attacking someone for using a word that may have been used out of innocence, ignorance, or occasional habit, makes no sense to me. (Although there are a few words I draw the line at; words that are never OK to use unless they are reclaimed and self-referential. As a woman, I can call myself certain things that I never want anyone else to call me.) There are a number of words I have used in my lifetime that I learned to replace with more sensitive words. I learned these through education and gentle suggestion, rather than public attack.

Before you say, not yet another word I have to be careful about, let me say that it is totally your choice. I won't judge you. However, isn't fighting over what word to use a waste of time? If we can make a point without using stigmatizing language, shouldn't we? If we want to create a kinder, gentler world, don't we need to use kinder, gentler words?

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