Health Literacy & Hepatitis C

September 1, 2016 By Matthew Zielske

Health literacy (HL) is the ability to understand and use written, spoken and numerical information to make better decisions about their health. The ability to read a prescription bottle and understand how often to take medicine, what it may interact with and whether or not to eat a meal (and how much) when taking it are some examples of numeric HL. The readability of a brochure given to a patient by a doctor, or information found online, is an example of written HL, and lastly, the words used when having a conversation about an illness, or during a medical appointment is an example of oral HL.

In 2003 the National Assessment of Adult Literacy (NAAL) found that roughly one third of Americans had low HL. In the 13 years since the NAAL study was published more focus has been placed on the improvement of health literacy through creating materials that are easy to understand. To help with this the U.S. Government released the Federal Plain Language Guidelines as a resource for individuals and organizations.

People with low levels of HL are more likely to avoid health care, have lower levels of formal education, and have worse overall health outcomes than those with average or above average HL. Meaningful delivery of health information has the best chance of success when we are present in the relationships with our clients and the populations we are trying to educate.

We need to have conversations with people who use health information on a daily basis so they can give input on ways to make it more user friendly. Having low HL can result in shame and avoidance, especially if people are spoken to by others in a condescending tone. This means talking about HL concerns requires the health care worker and patient to be on equal footing.

I think all of us have experienced situations where health information was difficult to understand or not completely clear. This common shared experience can be used to dispel the myth that low HL is a problem exclusive to people who lack higher education. The truth is, HL like all literacy, isn't fixed. If I wake up tomorrow and am diagnosed with an unfamiliar chronic illness, my HL in relation to it would likely be low. I might be able to learn information about it quickly, but I wouldn't be inherently better off at the start than anyone else who is also new to it.

Health literacy plays an important role in the hepatitis C treatment cascade. The information currently available on topics such as the liver, long term progression, diagnosis, treatment and prevention is complex, conflicting and sometimes not even made readily available. A real world example I encounter is the difference of acute and chronic hepatitis C. When I first started my job I

used to explain there differences in group sessions by going through the clinical definitions, but overtime I've found I have more success by saying sudden or short term and long term or lasting. This isn't a big change, but it is one my clients led me to that has helped.

The difference between hepatitis C antibodies and hepatitis C RNA is also an area where HL and simple language can play a role. When we talk about the fact that people will always carry hepatitis C antibodies if they are cured how well we explain it will either reduce anxiety or increase it. If we combine this with other conversations like, "your liver isn't bad enough yet, come back in 2 months," or "eat well, drink alcohol moderately & maintain a good weight," then you can begin to see that improvement of HL is more than making written information simple. It's also being more specific with suggestions and less condescending with the assumption that a person should know the meaning of a vague statement. If that sounds like something I've said before it's because I covered it extensively in a recent article on unique hurdles to health care, and it's also a point that can't be stressed enough.

I've learned from my clients that the information given to them by health care workers isn't always easy to understand or comprehensive. At times they have to ask, which can be embarrassing because hepatitis C is associated with a certain type of person (e.g. people who inject drugs), and if information is offered to them, it often comes with a judgmental tone. Their conversations with providers are often short, dismissive and end in anxiety instead of feeling better about their health and future.

Health literacy is a constantly changing field, and still in its infancy. There are debates over how to best measure it and even over how to best define it. These conversations are important to have, but until we can reach an agreement on the ways to find and address low HL, it can be difficult to know where to begin.

I think an easy place to start is by making a conscious effort to write and deliver health information less like we are trying to remind people we are experts, and more like we are having a friendly chat over dinner. We need to always be improving how we deliver health information by working together with the people who we want to access it.

We are not here to impress with how much we know. We are here to empower with what we can give. Information isn't a privilege, but sometimes we make it seem that way.

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