

Bridging The Patient-Doctor Communication Gap (Part 2 of 3)

The Importance Of Patient Education

Last month, in the first part of this series, we examined why patient-doctor communication is often difficult and frustrating for both sides. Systemic issues such as language differences, combine with outside pressures, such as the ever present risk of litigation, to create what is sometimes a volatile situation and often a less than optimal environment for success. This month we will look at half of the solution to this vexing problem.

As with any communication issue, or any relationship for that matter, true communication can only occur when both sides understand each other and are speaking - and more importantly listening - from common ground. In other words, in order to effectively communicate, even though they may start at different places and approach things in different ways, both patients and doctors must understand each other at a fundamental level and meet in the middle to succeed. And the path to the middle ground for patients lies through education.

I believe the importance of patient education can not be overstated. There are numerous reasons for this, following are just a few:

- **Effective communication requires a common language** - Everyone has experienced the pain of being lost in medical jargon, but as with any language, knowing the basics can go a long way. A patient who takes the time learn the anatomy that is basic to their condition (terms like posterior fossa, dura, foramen magnum) will greatly improve their comprehension of what is being said to them. In addition, by making an effort to understand the basics, a patient can then ask a doctor a single clarifying question (or even better ask them to use English for non-anatomical/disease terms such as location and direction) instead of taking up hours of their time.
- **Knowing the basics allows you to focus on the key issues** - By understanding the basics of your disease and treatment options, the short time you have to spend with your doctor can be spent on the most important issues. Instead of asking if this or that symptom is related to Chiari, you can ask your surgeon why he chooses the type of dural patch he uses and when and how he decides to open the arachnoid. The surgeon is trained and paid to be a surgeon, not a medical educator. In addition, just like in any business or professional situation, if you do homework, you will be taken much more seriously and your questions will not be dismissed out of hand.
- **Doctors are not perfect** - Although highly trained and specialized, above all, doctors are human. This means they make mistakes, have opinions and biases, and are subject to the pressures of their work environment. This fact combined with the lack of clarity on so many issues surrounding Chiari and syringomyelia means that patients must take on the burden of finding quality care they are comfortable with. And the only real way to select a doctor is to know enough about the conditions and treatments to be able to evaluate them intelligently. Patient's must educate themselves about the issues that exist in deciding whether to have surgery, the surgery itself, and effective recovery. In other words, a patient must know enough to ask the right questions and evaluate the responses. As a side note, I prefer to steer clear of doctors who are not willing to engage in intelligent discussions, answer questions, and/or are offended or put off by a patient educating themselves. One of the reasons I felt comfortable with my surgeon was because in talking about Chiari, he mentioned how treating it had evolved since he started practicing and predicted that by the time he retired we would have a completely different understanding of the disease. I took this a sign that he understood the current limitations of knowledge and was aware of what he didn't know. Maybe some people are willing to put their fate blindly in the hands of someone they have just met, but I'm not one of them.
- **Education is psychologically empowering** - Although I don't have scientific evidence to back it up, I believe that patient education improves both the patient experience and clinical outcomes. Being diagnosed with a disease like Chiari and/or syringomyelia is a devastating psychological blow. Events can start to spin quickly out of control and feelings of being overwhelmed are extremely common. Educating yourself about the conditions is a way to bring some level of sanity and control back into the picture. Having the disease is outside of your control, but responding to it is within your control. When telling me their stories, many people characterize Chiari as an enemy and use the language of battle and conflict. Well in this battle, knowledge is the ultimate weapon and can give people a real emotional boost. Understanding is the first step towards conquering.

It is also important to realize that CM/SM can be chronic diseases, and there is substantial evidence that patient education can significantly benefit how well people manage chronic diseases. That is why there are so many education programs for diseases like diabetes.

Finally - in regards to psychological empowerment - education brings awareness of what to expect and leads to realistic expectations. Having realistic expectations as to how long recovery will take, whether symptoms will persist, etc. can improve the patient experience overall. I - quite naively - thought that the whole experience would be like recovering from a sports injury. My unrealistic expectations led to a lot of frustration in the time just after surgery.

- **By educating yourself, you are in a position to educate others** - I am convinced that one of the most effective ways to improve the clinical outcome for CM/SM is for people to be diagnosed as early as possible. By educating yourself, you are in a position to raise awareness among the medical community and the general public. If you know what you are talking about, nurses, dentists, general practitioners, and others will listen. As awareness grows, the number of people who go years without a proper diagnosis will hopefully drop proportionately.

- **It's the right thing to do** - This is not a logical reason, it is a philosophical one. Patient education is important because it's the right thing to do. It's better to be active than passive. It's better to stand up for yourself than throw yourself at the mercy of the medical system. The best defense is a good offense. There are a hundred ways to say it, but they all mean the same thing: As much as possible, take charge of your own fate.

I could probably write a thousand more words on why patient education is so critically important, but hopefully these reasons are enough.

For those who are convinced, you don't have to read every journal article to be educated. Learn the basics first. Learn the anatomy terms, learn the basics of the disease and treatment options, and understand what issues are generally agreed upon, and which are controversial. Learn enough to ask intelligent questions and find a doctor you are comfortable with. Knowledge is power; and in this case, a little knowledge can go a long way.

Next month, the third and final part of the series, focusing on what doctors can - and should - do to bridge the communication gap.

- Rick Labuda

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