

## Bridging The Patient-Doctor Communication Gap (Part 1 of 3)

Just about everyone that goes to a doctor on a regular basis has experienced frustration with a visit at some point in time. Whether you leave the room wondering what the doctor said or found the bedside manner to be lacking, communication between doctors and patients is not always easy. In fact, research has shown that complaints about doctors usually center on communication rather than competency. Research has also shown how important doctor-patient communication is. Effective communication is not only critical to patient satisfaction, but research has shown that effective communication can actually improve patient health outcomes.

While communication is important in every doctor-patient interaction, it becomes critical when dealing with conditions like Chiari and syringomyelia. These complex diseases come with a variety of symptoms, can affect people for the rest of their lives, and there are many controversies surrounding their treatment. As Editor of this publication, I have heard numerous stories from people expressing frustration with their doctors. This is not to say that the problem lies only with doctors; it takes two for miscommunication to occur and it will take two to correct the problem.

So why is patient-doctor communication such a big problem? In this, the first of three parts on this subject, we take a look at the ingredients that go into this combustible situation.

I believe patient-doctor communication is sometimes difficult for three reasons:

1. Patients and doctors speak different languages
2. Patients and doctors enter the exam room with drastically different perspectives
3. 21st century culture, and the Internet in particular, has fundamentally changed the relationship between doctors and patients

### Patients And Doctors Speak Different Languages

Doctors and patients speak different languages, literally. Sometimes when dealing with medical conditions it is necessary to use medical terms. When dealing with Chiari and SM there are a host of technical terms for anatomy, medical procedures, and even symptoms. Doctors spend years learning this language and even specialize in certain dialects. They are immersed in it everyday and like any other language it becomes second nature to them. Because of this, doctors not only use technical terms for things like anatomy, but they tend to use technical terms instead of plain English. For direction they use words like caudal, distal, superior, and anterior. For some doctors, most every sentence will be infused with this type of med-speak, making them very difficult to understand and creating a language barrier that at times can seem as imposing as the Great Wall of China.

This puts patients at an extreme disadvantage and undermines the entire communication process. Common language is fundamental to true communication and understanding. Adding to the language problem is that patients and doctors may have a different understanding of even plain English words, such as success. How does a doctor define a successful surgery? Guaranteed it is probably different than a patient would. This last language barrier is a result of patients and doctors entering the room with entirely different perspectives.

### Patients And Doctors Enter The Exam Room With Drastically Different Perspectives

To truly understand someone, you must understand where they are coming from and what their perspective is. As human beings, we can not escape the fact that our background, experiences, and emotions will influence how we interpret what is being said to us. The same words spoken by someone to two different people may have entirely different meanings to each of them. Similarly, one person may interpret the same words spoken by two different people differently. Many communication problems can be traced to not understanding someone else's perspective and in the case of patients and doctors, the difference in perspectives is large and varied.

By definition, patients are holistic in how they think about their health and problems with their health. If someone has a chronic condition, like Chiari, it is natural for them to try to trace every little problem back to that condition. Why? Because there is a problem with their body, not their nervous system or their brain. It is also natural for a patient to want or expect a doctor to think about them as a whole and listen as they describe all their symptoms.

The problem is that doctors are trained to be reductionist in their thinking. They are very specialized in their practice and this translates in to the way they think about problems and symptoms. Symptoms are neurological, or orthopedic or some other specialty.

This clash in perspectives can cause problems. A patient may raise a symptom that he feels is connected to Chiari. The doctor may think it isn't and dismiss it out of hand. This strain in communication is amplified by a second difference in perspective.

For patients, a doctor's visit is an emotionally charged event, but doctors approach the situation as caring, but dispassionate and objective professionals. How can a doctor's visit not be emotional for someone with Chiari/SM? These are serious diseases with serious consequences and limited treatment options. Patients have days to think about a doctor's visit and the anticipation of learning test results can be agonizing. On the flip-side, a doctor, even a very caring one, has to remain somewhat dispassionate. Not only to effectively treat a patient (emotion could cloud their judgment), but to protect themselves emotionally. If a doctor truly got caught up in the intense emotions of every case, they probably wouldn't last too long.

As if that weren't enough, there is a third difference in perspectives between patients and doctors, and that is how they view each other.

Unfortunately, if a Chiari patient has been bounced around the medical system, been misdiagnosed, and seen specialist after specialist, they may grow to distrust their doctors. They will go into the meeting guarded and with low expectations. Before you know it, low expectations lead to poor outcomes in a cycle of self-fulfilling prophecies.

Similarly, when some doctors are presented with a situation that is outside the norm (in their experience), they tend to distrust what the patient is telling them. As scientists, doctors are trained to rely on "objective" tests like MRI's and treat patient reports with skepticism. This is apparent in the language that doctors use in their medical records. "Patient complained of headaches. Loss of balance was denied." Words such as complain and deny are not very useful in building a trusting, communicative relationship.

Finally, while this seems strange, doctors and patients may have different goals. Yes, both people want the patient to get better, but there can be subtle differences in how patients and doctors define a successful outcome. For doctors, success in a Chiari surgery may mean that a cine-MRI shows adequate CSF flow or that a syrinx decreases in size. For a patient, that is all well and good, but success really means a return to full, normal function with no limitation. Granted that may not be realistic, but it is difficult for a patient to define anything less than that as a success.

It is easy to see how language differences and differences in perspective can put a strain on the patient-doctor relationship, but perhaps the biggest strain of all is the rise of the 21st century patient armed with the Net.

## **Twenty-first Century Culture - And The Internet In Particular - Has Fundamentally Changed The Relationship Between Doctors And Patients**

The 21st century patient: informed, demanding, and ready to take charge of their own healthcare. Gone are the days of the paternalistic doctor patting patients on the back and saying trust me; in are the days of internet research, shopping around for doctors, joint treatment decision making, and e-mails between doctors and patients. While I strongly believe that this is in general a good thing, I also think it will take a period of time for this new relationship between doctors and patients to find a natural balance.

First the good news. The 21st century patient is a good thing because patient's should take some level of responsibility for their own care. While we must keep in mind that doctors are highly trained specialists, we as patients should also rely on our own intelligence and feelings to find the doctors we trust and enact treatments we are comfortable with. Because in the end it is our bodies and we have to live with the results.

Now the bad news. Doctors will respond to this shift in different ways. Some will be more willing to accept an active patient who surfs the internet for information and some will be resentful. If a doctor is uncomfortable with a patient trying to exert more control, it will naturally lead to tension in the relationship and effect communication. However, doctors have a right to be suspicious of how patients use the internet and we would be wise to examine the issue objectively (yes, I'm aware of the irony of what I'm about to write).

Estimates place the number of health related web sites at more than 100,000 and growing exponentially. While this can be a treasure trove of information for patients, the quality of the information remains a concern. In addition to containing flat out incorrect information, given the rapid pace of research and medical advances, it can be difficult to keep sites updated with accurate information.

A second problem with many sites is that they offer only brief descriptions of diseases and conditions. In this case, a little knowledge can be a dangerous thing. If a patient thinks they know more than they do about a subject, their communications with their doctor will suffer.

A third problem is that - in my opinion - there is a generally pessimistic and worst case bias in medical information on the web. Just like the evening news, the worst outcomes tend to be reported more than the successes. Having experienced this myself a number of times, I know it is easy to get frightened when researching a new medical condition on-line. I also think that the message boards and chat rooms tend to attract people who are suffering more from their disease than average. Why is this? If someone is diagnosed with a disease and quickly recovers there isn't much incentive to participate in a chat room; chances are they want to forget about it and move on. This negative bias on the web can lead to heightened concerns for a patient which in turn leads to them being labeled an alarmist and again the communication breaks down.

Clearly, the Internet is here to stay, so both doctors and patients will have to find a way to adapt to the new reality it brings to their relationship.

### **What's The Solution?**

Given the profound difference in language and perspective that exists between patients and doctors and the disruptive force of the Internet, it is no wonder that communication is often frustrating and the patient experience less than ideal. The question is what to do about it? With the stakes as high as they are for Chiari and syringomyelia patients, doing nothing is not an option. Next month, I will talk about half of the solution: The Importance of Patient Education.

- Rick Labuda

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