



Shift in Doctor Patient Relationship- Supplement to 2013 North American Education Program

Marie Namey: I think now because the decision making process is more complex, because there are more medications that we can use to treat multiple sclerosis, and there are certainly concerns about the risk benefit ratio, there, there needs to be more communication between patients and their healthcare providers. There really needs to be more of this dialog. You know patients ask questions, clinicians answer, clinicians say, do you feel comfortable with this? What are your thoughts about this? And that in turn makes for a better partnership and then hopefully yield better adherence over time in taking some of these disease modifying therapies.

Dr. Fox: Years ago decisions about therapies were mostly deferred to the physician. One would go to the doctor's office and say what do I do? The doctor says do this. You take your prescription, you go get it filled and you do it and you do it dutifully. We are now in the information age. And there is lots of information available to patients. The physician is still an important component and indeed studies have found that in terms of guiding decisions,

physicians are still very, very important and nurse practitioners and all of the care providers on the team, but the source of information about therapies has broadened out. And now the internet and uh published uh papers and magazines and there, there's a lot more sources of information and where before the decisions and the information all came from the care provider, now it's much more split and splintered as to where the information is coming from for guiding what to know about therapies.

Dr. Bar-Or: There's been an interesting and from my point of view a welcome shift in the doctor/patient relationship over the years in the context of MS in particular. And this has to do with the huge amount of information that is now available at the fingertips of patients and their families often coming to us with already decisions about their views of what they might prefer in terms of treatments, questions that they ask about information that is out there on the web or through the popular media. This is a very, very helpful source of information for them to have.

One of the things that we try as a team to do is to make sure that they can distinguish between information that is high quality and that has perhaps been somehow vetted, and information that may be out there but won't necessarily or shouldn't necessarily carry the same weight. The change in the way that people now make decisions has invoked much more participation by the patients themselves and often by their family and caregivers and this is something that contributes importantly to a treatment

decision that is more likely to stand the test of time. If people come in and feel that there's a back and forth discussion about their treatment preferences as well as the care team preferences, at the end of the day a decision is made that is much more likely to work well for that individual and for them to be able to stick with and possibly feedback more likely and more reliably to the team in terms of their experience, even if they're not happy with it.

Deborah Miller: I find the trend, trend towards shared decision making between uh, patients and physicians to be a very healthy um, move forward. It really leads to greater adherence to treatment decisions. It makes um, people aware and thinking aloud about what it is that they do when they do not want out of their care. Our physicians are very um, open and prefer this approach to care because they know that if they have this openness, they're more likely to hear from patients what's really going on in their lives and what may be influencing their ability to stick with the treatment or not. Um, there are some patients who had MS for a very long time who prefer to have a more paternal or maternal doctor in um, involved in their care. And it's important to be respectful of that. But to the extent that we can, we actively encourage patient involvement in most aspects, in all aspects of care.

Dr. Fox: There has been a shift over time, not a large shift but a, a moderate shift in how decisions are made. Perhaps the biggest

shift in decision making is information source. So it used to be that the doctor's office, the nurse's office was the major source of decision about medicines, about treatments, and now that has broadened into a much larger area. And so now the internet, chat rooms, publications, uh talking to your cousins and your neighbors, that has become a much more important facet of gaining information about disease, about symptoms, about treatment options.

However, I've come to find that when it comes down to well what should I do, Doc, what should I do, nurse, about my, my disease, patients are much more likely to defer to the clinical team about what they should do. And there is some data that's emerged about that from the NARCOMS MS patient registry where patients were surveyed about their source of information and their source of decision making, and the information source was very, very broad, but the decision making still had the clinical team as the main drivers regarding their decisions.

Patty Marmaduke: As I've stayed with the same doctor now for over 7 years, um, 6 years, 6 or 7 years that I've grown to a close relationship and he knows my goals in life and are taking those into account as we decide on therapies and treatments for um, spasticity.

Aaron Hawkins: From a healthcare standpoint he has become a, we, I, I gave him blind trust in the beginning, um, but over the years he, I

gave him that at the beginning. He has earned it uh over the last 10 years. Uh because when I do have questions he asks, he answers me very, very succinctly. He answers me very, very truthfully and I believe what he has to say. Um, so that goes a very long way from me giving it at the beginning to him early and over the last 10 years.

Jennifer Whelan: In the 10 years that I have been diagnosed with multiple sclerosis, my healthcare team has changed but just as importantly or maybe even more importantly I have changed. Because I think it's important to work collaboratively with them to make sure that you're set up for success. If you as a patient don't share information about what's actually happening with you, they don't have complete information to take the right step that they believe should be taken and just as important if they don't listen and understand who you are as a person, as well as what your situations are, they can't make the right decisions or um, they can't make the right recommendations on what the next step should be.

I'm a firm believer that the person who is ultimately responsible for my medical care is me. It's my job to make sure that I share information, that I'm comfortable with the doctors that I have, the team that I have and that if I'm not comfortable, I keep asking questions until I am comfortable or I find the people who can answer the questions. So my team has grown and changed over time.