

A Patient's Perspective for Researchers and Disseminators: Facilitating Patient Engagement

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This is a very timely conversation that we're having not only in bringing forward evidence but as leaders in academic centers, collaborators, and AHRQ to pull together the pearls of wisdom because patients are clamoring for help.

I represent that aspect of the patient population, patient research partners, patient engagers, by reason of a disease diagnosis. It probably helped that I could speak English. It helped that I have a graduate degree from Purdue University. It helped that I have three physicians and six pharmacists and two engineers and an attorney in my family. I am an Asian-American, fourth generation Californian. All of the things that you would think would make for better success with a chronic condition called inflammatory arthritis or rheumatoid arthritis. I was diagnosed at age eighteen. Within a few short years after diagnosis I ended up in a wheelchair. The first medications were 26 aspirin a day. I had no say so over that. But there's nothing like five years in a wheelchair to help a person understand what the person needs to bring to the paradigm of personal medical care.

No one trains us as human beings to deal with a health crisis. You rely on what you can. I was fortunate enough to have that kind of family support but being Asian, it worked against me. Everybody kept their mouth shut. It was not American; it was more Chinese to not talk about those things and that was not good. So I suffered silently for those five years. In fact, when I could not use my arms and legs and had to eat like a dog, bringing my head to the table to eat food, I realized that something had to change. I hit bottom. At some point when you are faced with a crisis, you hit bottom, whatever your bottom is. My bottom was being embarrassed in front of my family because I was eating like a dog. I needed to do something.

The trips to the physician were grueling because it was a two hour trip every two weeks for 5 years. One of my parents would have to take the day off from work. This was not just an individual crisis, it was a family crisis. Going through the physiotherapy, the only choice I made was to answer the question, "Where would you like to go for lunch Amye?" And, there is nothing like being at home by yourself for eight hours a day to realize that you've got to do something.

I realized that I had not been asking the right kinds of questions. The first time I began to ask questions was to my rheumatologist, "How come you never ask me if I want to get out of this wheelchair?" It was simple. It wasn't about disease. It wasn't about my condition. It was about something very tangible and real for me. I expected me to get out of a wheelchair. I expected the doctors to know what it would take to get me out of a wheelchair. The visits every two weeks never addressed that. No one ever asked me what I would like; what my preferences, needs were, and what I wanted to know more about in order to better handle this. It was truly top down as it is and continues to be in an Asian family. I was shocked that his response was that he opened eyes and took a step back. I realized by his response that he had no idea what my goals were. So, realizing that it was time to speak up I asked, "Well, that's my goal. Now, what will it take to get me out of a wheelchair?" And he replied, "It's going to take a lot of joint replacements." Not knowing what that meant, I said, "Sure, where do I start?" And he replied, "Well, I'm going to put you in touch with someone." Thus began the rebuilding of Amye. Twenty-six surgeries, sixteen joint replacements later, and possibly two on the way.

Objectives

Participants will be able to identify:

- Revolution or Evolution: the road of a patient
- Nexus: crossroads benefitting patient-centered care & research
- Patient Voice in development of research/dissemination/outcome measures tools/clinical care relevancy: how far we've come
- Facilitators to patient engagement
- Challenges
- Opportunities



I share that part of the story with you because it has been evolutionary for me. In many other patients' case it's absolutely revolutionary. This slide is my perspective that I'm giving you informed by deep health crisis, informed by five years in a wheelchair and 297 days in hospitals, and on Social Security Disability for years. I had the gumption to write to Social Security Disability to I think you should stop paying me that little stipend you give me because I think I can do this on my own now which meant create a life for myself, create a productive life, become a taxpaying citizen again.

Joint replacement surgeries help. Unfortunately, the medications were ineffective and then I lost my hair and my sense of taste. There were all kinds of side effects and adverse reactions that happened along the way. When it became revolutionary for me was when I realized that the medical people I had entrusted my life too were not listening to me. Absolutely not listening to me. It's true across all therapeutic areas because unfortunately our healthcare professionals as much as we patients love them because our life is dependent upon them, don't ask us the right questions. Now, if one could say to me, "I want you to tell me what the ten most questions are that I ought to be asking you in the next visit, or over the course of the next month. Do you think you could do that for me?" It took me a long time to learn that. Would an evolving engaged patient want to do this? Probably with help, with help of another peer to better understand the implications.

We do not have this disease alone. We have our families, our friends who help us out and give us feedback. We have the Internet. We have our health professionals and our health professional friends. And we have whatever we can glean from TV, radio and other media. We're all talking about the kinds of common things we should know, just like washing our hands; simple things like the basic care of our body. Yet it's not taught anywhere.

I had the great opportunity of working with Dr. C. Everett Koop when he was Surgeon General. That was at a time when the concept of self-help was not even a category on bookshelves. Dr. Koop held a national forum on self-help and public health and brought in stakeholder leaders from many different areas, including the American Hospital Association, American Medical Association, funders, foundations, self-helpers themselves, organizations, and payers to come up with very specific recommendations that he and his office could use. The recommendations were prioritized using the Delphi process over the two-and-a-half day forum. I had the good fortune to be selected as the self-helper and sat with Dr. Koop on the media panel. From that forum he and I got to know one another very well. I was invited, because of my background in organizational development, to help develop an advisory council on self-help and public health to the Surgeon General's office. And after doing our review of what was going on politically and every other way, we suggested that Dr. Koop do a public service announcement, to begin to get information to the public about self-help and that there was place to go to get help, no matter your condition. In those days the Federal government was funding self-help clearing houses. Patient advocacy groups had huge reservoirs of information but no one really knew where to go for a variety of different things. So we crafted a 30-second public service announcement for him to utilize and put up. It got wide publicity. There was an 800-number that anybody could call to get information about the place that was closest to them. And it began to galvanize the American public's understanding about the simple concept of self-help. I've been fortunate enough to be a part of that policymaking and implementation of the role of leaders, thought leaders, recognizable personalities, recognizable experts in that field. So I do believe we are at a bigger crossroads benefitting patient-centered care and the disseminators and the originators of research in the area of patient-centered care.

We were talking about technology. Many of you have been on NIH study sections, I don't know about you but every clinical trial grant review that we've had to look at has been about the development of an app. We're talking about biomedical research which is amazing to me. Researchers want to go to where the people are. People are on their smartphones. How can we use that to take blood pressures, to monitor your A1c, how to monitor all different kinds of aspects for me as a flare, how do I know when I've just done too much. Did I take my medications? I can't remember. I take so many of them. When am I next due to get a refill on that? I'd like to be reminded as we talked about earlier. But I'd like me to remind me or I'd like someone to prompt me and then I can put it in my own device so that I'm the manager of my care. Our technology companies are chomping at the bit. Google has just partnered with Cisco, I believe, in developing those kinds of things. So you're going to see big name companies merging technology with science and medical tools. In addition, patients are saying "I've got a voice. I can have a louder voice. You mean, I can talk to you about research?" I've been involved with a group at the international level called OMERACT, "Outcomes Measures in Rheumatology," since 2002. We patients meet with researchers from around the world. Forget the cultural part of just one country over another; we're talking about multinational countries! We're also talking multinational musculoskeletal projects that are multidisciplinary – the rheumatologist, orthopedic surgeon, occupational therapists, physical therapists, nurse practitioners, nutritionists – the whole group. It's a beautiful nexus.

There are facilitators to patient engagement and those facilitators are the advocacy groups. But there does not exist at this point in time a way to train a patient to become an advocate, an advocate to become an advocate leader, or an advocate leader to become an engaged research partner. Nor is there a way to train patient, advocate leader, or a patient advocate leader to become a research partner. There are core things about patient engagement, about involving yourself, the family, involving people with low health literacy, people from diverse backgrounds. There are opportunities but there's also challenges and I look forward to talking with you about them.

Thank You!

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