

The Science of Asking

Beverley Smith*

Alumni Association, University of Calgary, Canada

Perspective

Medical researchers often use questionnaires. Having filled out many, I have a bone to pick with the concept. Asking is great. How to ask is an art and doctors are not nearly as adept at it as lawyers sometimes. Have you stopped beating your wife? is a loaded question but they seem to forget that "Is the pain less at night?" is also loaded.

I have dystonia. It is the name for why my neck suddenly decided to tilt left, painfully pulling to a position I never chose. Spasmodic torticollis or as Rabelais called it, torty colly and twisted neck.

Nobody knows why this happens. After centuries of the condition appearing in paintings by Modigliani or novels like "The High Window" by Raymond Chandler, doctors still are mystified. And by that I mean they are not sure why it starts, or how to treat it, and so far sense no real direction on how to prevent it.

So they ask. I am glad they ask. Dystonia is rare and I'm grateful they take time from their neurological study of Parkinson's Disease, essential tremor, Tourette's, MS, Alzheimer's, brain trauma and tumors. My little dystonia is a lesser light. I am grateful any research is done but I want it to be effective research.

In the case of dystonia, blood tests, X-rays. MRIs, brain scans are nearly always normal. It is only in the last few decades that doctors found proof that this thing is not just imagined, 'hysterical'.

Recent studies have found a change in neurotransmitter levels in the brain. There's a change in blood flow, a *DYT1* gene oddity in some patients. Aha, there is proof, it is not just 'in our heads'. 'Always believe the patient'.

But dystonia is not suddenly now solved. It continues on its merry track of oddity, like a rebel teen who can be oh so polite in front of grandma and a back-talking terror in front of mom. Neck dystonia for me is not the same as for the next guy. Some tilt right. Some look at the sky while for others, the neck folds in and they're stuck looking at the ground. We all deal with vice like grip on us but the variety mystifies. For some the muscle affected is the finger, for others the vocal cords, for others, the eyelids. For some botulinum toxin injections work amazingly to relax the tight muscles. For other patients, the injections do not work well at all. So it seems particularly important to ask each patient how it is for them.

And with dystonia there is one other wrinkle, one so odd it may hold the key to the mystery. Sometimes the dystonia is gone for a minute. One man whose eyelids were affected found that nothing would keep his eyes open, not when he walked, ate, nothing except when he plucked his fiddle. For some reason when he held the fiddle in his hands and plucked it, the eyes shot open. There is a theory that each activity is just a tiny bit different in the brain and even when the eyelid muscles clamp shut for nearly all events, there is a special exception category, for specific and precise situations.

*Address for Correspondence: Beverley Smith, Alumni Association, University of Calgary, Canada, Tel: + 14032832400; E-mail: bevgsmith@alumni.ucalgary.ca

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One pianist found her right thumb was bending inward and it stayed curled inward, maddeningly, when she tried to shampoo her hair or use the computer. When she shook hands and it curled inward, people thought it was some secret handshake.. Yet, and this is where dystonia is odd, the thumb did not curl in when she swung her arm by her side. <https://www.youtube.com/watch?v=8T03h3eGi5o&t=392s>

An Italian journalist found his neck was tilting so badly that he could not interview people because he could not look directly at them.. He was in intense pain and the neck went into spasms. He could no longer drive and had trouble eating. One day he was walking down the street, neck tilted, wearing headphones and listening to music. He started bouncing to the music and as long as he kept doing that, the dystonia seemed gone. When he dances and only when he dances, his neck is fine. https://www.youtube.com/watch?v=IpcXkV_ex8Y&t=12s

An American marathoner developed dystonia in her legs and she could barely run any more.. Yet one day she noticed that if she tried to run backwards, that was easy. So she started to practice running backwards and has even competed in marathons, making good time, running backwards. <https://www.youtube.com/watch?v=FR3U09incRQ>

Dystonia is like that. Many patients find that there is a little gesture that for a second makes the dystonia muscle loosen.. With neck dystonia, this may happen if they touch their cheek or chin. The phenomenon seems illogical but brain scans lately confirm that it really is changing the messaging to the muscle. But why? That is what we need to learn. So researchers ask what these sensory oddities are for us, and how they work.

However asking is an art. Doctors are so immersed in their professional lingo that they may forget what it's like for us out here. If they asked if we are depressed, we may think they're just being sympathetic to our sadness but for them it's a clinical term and not casual at all.

Some questions show little experience with the condition. Nobody with this condition can sleep easily. It is hard to find a position that does not give spasms or tightness that distract from sleep. So asking us "Do you have trouble sleeping?" is like entry level insight. There is a problem if the question stops there. We want to tell more about the positions or heat or exercises that help us get to sleep or we want ideas for strategies. It is not helpful to just tally 87% of those asked said they have trouble sleeping.

Another problem is that some questions really are yes / no. Have you had an MRI? Yes or No. It is not something you have had partly. But science seems to love scales. Do you have tremors a bit, sometimes, often, a lot, all the time? Those differences may matter to some polling firm and be accurate 9 times out of 10 but does that help us? I want to know how to not have the spasms. I can tell you when I get them and how they feel but that may not always be reportable on a scale.

We are asked things like "On a scale of one to ten how great is your pain?" Well my pain is award winning. But I don't want to sound like a whiner so I might rate it at 6 or 7 not really sure what the precise number ranks would mean. The question may be less about pain as an absolute but, in effect, a personality quiz of how much you want help. Sympathy or want to look stoic.

When a study is done, if researchers just report numbers, I am not sure that has advanced understanding. "76% of those asked experienced pain level between 5 and 8." Yippee, over to you, now for the weather. I am concerned when some studies are funded by drug companies and the result of pain reduction after treatment is used as proof the medicine is great. I don't want a vested interest type of study or to take part in one vast ad.

Questionnaires sometimes seem designed by committee. "Do you feel uninterested in eating some of the time, most of the time, or all of the time?" Well, point one, what if I am not uninterested? Where the column for is not interested? If I am asked if I agree or disagree with a statement, and the statement is "I do not feel much energy during the day" my mind starts to reel "I disagree that I do not feel much energy" Does that not mean I feel energy?

In the area of mental health, people are wary of what will be done with the information or what the question means. If you ask us if we are reluctant to be seen in public because this condition is quite visible, most of us will say yes. But will researchers then write down we have 'social phobia'? If you ask 'Do you eat soft foods?' that may not capture what is done just because of dystonia. What if we always have eaten applesauce?

If you ask someone if they have 'unrealistic ideas'- there's a problem. If you believe you can fly, or the number 5 is lucky, then you think that is realistic. The question may need reframing. If you ask a person about their 'unconscious thoughts', how could they answer if they are not conscious of them? If you want to know if a person 'hears voices' asking them if they 'hear voices' may not tap the real answer. Of course they hear voices and that is how they are able to hear the question. It might be more useful to ask "When you turn on the radio do you ever hear someone talking just to you?" I have recently prepared a 'wish you had asked' questionnaire for people with dystonia. www.dystoniasurveys.org It was hard to write actually. I have new admiration for scientists who design questionnaires. Looking back at it, now that it is online. I see already that I too frame some questions poorly. But I try to nail down what could be usefully asked.

However even with its flaws, the response has been heartening. It seems like patients are just relieved to do an anonymous survey, just to be able to tell what they are going through. Some feel reassured others may have the same symptom. I contacted deans of medicine, biomedical engineering and human biology to suggest dystonia be more often included in the curriculum

and have had heartening results, posted on the site. This attention may speed up diagnosis which for some patients has often been delayed several years. If the surveys show patterns of actual disability then medical insurance providers may provide faster coverage of such claims.

The dream many of us have is that these surveys will help researchers provide treatments, theorize causes, and even conceive of cure. I have been told by one researcher, not to be insulted but they may wish to do another survey one day that meets the more rigorous standards of pure science. Absolutely, that is not an insult. I would love that. There are experts on asking questions and I am not one of them. But this is a start.

My heart goes out to the people with dystonia. Some days we seem stuck in a backwater with all the obstacles to research already there. Busy doctors, lots of pressing conditions to study, problems getting research funding and now COVID of course. I wanted to help advance this study, without those obstacles. A free study, online, anonymous, at patient convenience might move things along, create a database of the little details that might show patterns that matter.

It's been a huge learning curve. It is a joy to see that many patients are willing to help create this database. The website has had 6361 page views, from 62 countries and 854 surveys have been completed. I wish the questions were even better but they're tapping things that often are not asked.

The Michael J. Fox Foundation studying Parkinson's Disease is using a study like this. <https://www.michaeljfox.org/fox-insight>. There is a big study for COVID survivors using similar questionnaire strategy <https://www.cambridgebrainsciences.com/studies/COVID-brain-study>. This patient questionnaire approach to medical research seems a real resource to the medical community. It matters that we are asked and it matters how we are asked. Some patients are texting me hearts for trying. "Glad you asked"

Note: I have not named the people in the article though you may choose to do so. Dystonia has medical stigma for a few people so I hesitate to name names. However the links are for people who have already posted online about it or been interviewed by media.

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