Denouement: A Patient-Reported Observation

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Editor’s Note

Cynthia Chauhan is a patient advocate for the North Central Cancer Treatment Group. She is also a cancer patient with unique insights and articulate impressions regarding the assessment of patient-reported outcomes (PROs). The following is intended to tie together the material in this body of work to remind all of us that at the heart of all that we do in assessing PROs is a human being. In short, it’s all about the patient.

A Patient Advocate’s Response

It has been my privilege to work with the Mayo/FDA Patient-Reported Outcomes Consensus Meeting Group, observing and learning how you as professionals view, interpret, and relate to my reality. You are all obviously bright, well-intentioned, altruistic people who are concerned about patient well-being, and I thank you from the bottom of my heart not just for myself but for all patients. I have watched you struggle with concepts and fight for opportunity and recognition. I want to respond to and perhaps invite you to reframe some of the issues I have watched you address and shy away from.

I know a lot about struggling, fighting for opportunity, and claiming recognition. I happen to be a patient with multiple diagnoses related to each other only by the fact that they share my body and shape my life experience. They include two cancers, glaucoma, asthmatic bronchitis, idiopathic neuropathy, and a few others. But you get the picture.

First of all, I do understand this is an effort about drug labeling and how to incorporate what the patient reports are experienced as a result of using that drug in the labeling. You name that patient experience “symptoms” and you have spent a great deal of time differentiating or arguing against differentiating symptoms from health-related quality of life (HRQL), much less quality of life (QOL). I understand the need for partializing in problem-solving as long as one holds onto the knowledge that the whole is equal to and perhaps greater than, the sum of its parts. In that context, I do not think symptoms can be separated from those two things, HRQL and QOL, in the real world.

The symptoms with which I live, some illness-induced, some drug-induced, are real parts of my every day life and they do affect my quality of life. They affect how I go about my life and the expectations I can reasonably set for myself and others. However, it is equally important to note that the quality of my life affects my tolerance for many of those symptoms. Dr. Sloan of the Mayo Clinic has indicated elsewhere that there is presently a controversy surrounding how to measure hot flashes activity that women may not perceive [1]. An appropriate use of Dr. Sloan’s hot flash perceiver example would be to use it to help women look at and consider what is going on in their external and internal environments when they do and do not notice the flashes.

Different symptoms affect me to different degrees, and something you did not address is that the hypothetical possibility of symptoms also affects me and choices I make about medications. I know you said that you deal in realities, by which I understand you to mean concrete and quantifiable, not hypothetical situations; but hypotheticals do impinge on patients’ realities. For example, I use a drug called bimatoprost in my left eye to forestall blindness from glaucoma. I have had sapphire blue eyes all of my life. One of the side-effects of bimatoprost in blue-eyed people is turning of the iris to brown. On one level, it’s a no-brainer that I will take the drug because going blind is worse than having a brown eye. On another level, there is emotional distress associated with potentially losing what has been a positively defining aspect of self. The eye color change may not qualify as a PRO, but the distress does and it affects quality of life. I use this example to urge you to consider and be wary that you do not lose the whole person in your quest to give PROs free-standing autonomy, but understand they are an artificially extricated part of a complex whole.

On the other hand, I get seriously nauseated and somnolent when I take one of my pain medicines and experience cognitive deterioration when I take one of the others, so I will tolerate a great deal of pain before I resort to the medications because while they provide

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primary symptom control, their concomitant symptom inducement seriously compromises my quality of life.

Symptoms and QOL are inextricably intertwined for the patient. If I were to modify your theoretical framework [2], I would put a large balloon for QOL holding a smaller inset balloon for HRQL holding yet a smaller one for symptoms. Or perhaps I would show multiple smaller balloons of symptoms attenuating and distorting the other balloons as they do our lives.

In your quest to differentiate and honor symptoms, I caution and urge you not to validate the ancient Indian tale of the nine blind men who sought to describe an elephant by each touching one part of the elephant. They did come up with interesting creative descriptions and observations which each held to as inviolably true. But, in fact, those observations did not translate to the reality of the elephant. No matter how much it wiggles, an elephant’s tail is never a snake. Hence, I ask you to keep in mind the entire person perspective as you do your valuable work on working through the details of individual PRO assessment.

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References