



Commentaries

Do Quality of Life Measures Measure Anything We Want To Measure?

For many years I've been sharing a thought with some of my Parkinson's disease patients who complain about their problems in walking. Advanced Parkinson's disease patients have trouble walking, and I always try to ask about falls, not that I can often do something about it but sometimes I can. Appreciating and sharing the misery is helpful in and of itself, I think, and probably more important is knowing that the problem has been acknowledged and addressed, whether successfully or not.

I have observed that the patients who complained the most were those who had isolated episodes of inability to walk, not the ones who could barely walk all the time. It was the paroxysmal nature of the problem, it seemed to me, rather than the disability itself, that was more trying for the patients. Those who could walk some of the time but not all the time felt like they should be able to walk all the time, whereas those who could barely walk, but were like that all day, learned to bear their disability. The hard thing was to have a disability which fluctuated. Now I can walk, now I can't, and yet the legs are strong! I don't know how much of this is the obvious frustration of living with a variable deficit, and how much was the concern that others wouldn't understand and assume that their was a bit of fakery involved.

I used to share this observation with these patients. I told them that I thought that if they had lost their legs in a car accident they'd have accommodated better to their disability than if the problem came and went, so that sometimes they walked reliably without a cane, while at others they needed a walker or even a wheelchair, when they turned "off" and their PD medications stopped working.

A recent article in *Neurology* (F. de N. Abrantes-Pais et al. *Neurology* 2007;69:261) supports this, albeit I am certainly warping their observations and deductions to fit my own thoughts. These authors had been impressed with their observation that tetraplegics seemed to be more contented with their lives than paraplegics, and that the higher the level of the spinal cord lesion, the better the pa-

tients accommodated to their disability, the greater their optimism and the higher their quality of life. It was a small study involving only 41 subjects, 20 with "high cord," 10 with "low cord" and 11 able-bodied controls. They compared a number of measures of quality of life and optimism, and found that the higher the level of the cord transection, the better and more optimistic the subjects felt. Not only that, but the cord transected patients endorsed a higher quality of life than the able-bodied controls!

This was obviously counterintuitive, so they eliminated any subjects who had also suffered traumatic brain injury, to keep brain changes from confounding the issue. No change. Then they decided to examine the issue of "high cord." In this study, "high cord" was defined as T6 or above. The lowest level in this category had numbness and paralysis from a level between the nipples and the umbilicus down to the toes, and therefore includes paraplegics and tetraplegics. All subjects had complete cord transections, that is, no feeling and no voluntary movement at all below the level of the injury. In the final subgroup analysis they compared only those with cervical injuries above C6, and therefore were tetraplegic (or at least couldn't raise their arms, although they might be able to use their hands). In all subgroup analyses, the higher the level of the injury and therefore the greater the disability, the better the patients felt.

We know that certain brain injuries are self-protecting with regard to insight into the disability. The most classic of the neurological syndromes, due to a right parietal lesion, usually a stroke, the patient suffers left-sided paralysis, can't see to the left and acts as though the left side of the universe doesn't exist, including the left side of their own body. The worse the deficit, the better the patient feels. In dementing syndromes, as patients lose insight into their disabilities they sometimes change from being depressed to being happy, manic even, causing great problems in their care because of their lack of awareness of their limitations. But a spinal cord injury should not cause problems above

the level of the injury, other than an anticipated grief or depressive reaction.

This article was not alluding to inappropriate reactions to injury, but rather the opposite, the lack of what outsiders would consider appropriate resignation and anger.

Then Supreme Court Justice William Douglass suffered a right middle cerebral artery stroke, with left hemiparesis, left hemianesthesia, denial and neglect, like most such patients, he felt great and couldn't get back to the court. "Nothing wrong with me," he said, that is, *nothing wrong that he was aware of*. And the press ate it up. But this is obviously different.

How can we understand this? On the one hand we can cheer. "Isn't it terrific that these guys (these subjects, and most seriously injured Americans are male) are reacting so well?" But it is a bit disturbing, isn't it, that they feel better than able-bodied controls? What's going on?

The authors of the article thought that the greater the amount of spinal cord separated from the brain, the better the patient felt, but couldn't explain why. I can't either. They wondered if it had to do with sympathetic disconnection from the brain. I guess that parasympathetic disconnection would work just as well. My own thought is that there are hormones, peptides, growth factors, unrecognized chemicals, humors, if you will, that are secreted by non-central nervous system tissue controlled, indirectly from the brain via the spinal cord, and when they are disconnected they produce some rose-colored tint to life. It is not likely to produce an evolutionary advantage. Until the last century, anyone with a spinal cord transection died from infections, either in the skin or the bladder, or renal failure. This trick of the body must be unrelated to evolution.

Another question that arises, which the authors failed to ask is: how useful are the measures of quality of life, despite passing every statistical test in the books on validity? Would you ask your neurosurgery friend to transect your spinal cord to trade up to a better score on a quality of life scale?

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Disclosure of Financial Interests

Joseph Friedman, MD, Consultant: Acadia Pharmacy, Ovation, Transoral; Grant Research Support: Cephalon, Teva, Novartis, Boehringer-Ingelheim, Sepracor, Glaxo; Speakers' Bureau: Astra Zeneca, Teva, Novartis, Boehringer-Ingelheim, GlaxoAcadia, Sepracor, Glaxo Smith Kline, Neurogen, and EMD Serono.