Special Article

Neuropathic Pain: A "Professional Patient's" Perspective

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The term "professional patient" conjures up all sorts of images—hypochondriac, doctor shopper, malingerer. Within the context of this paper, however, professional patient refers to a health care professional's viewpoint as a patient. When asked by the editor of The Clinical Journal of Pain to write about my personal experience with neuropathic pain, I initially questioned whether this would be of interest to the journal readership. He pointed out to me, however, that he had just come from a 3-day session with experts who had debated at length definitions of such terms as reflex sympathetic dystrophy (RSD), complex regional pain syndrome (CRPS), allodynia, dysesthesis, and hyperesthesia. As he so aptly stated, most of us who work with persons in chronic pain learn the definitions of these terms from the glossary of a textbook. We may listen to a patient describe these sensations and write in the individual's chart "patient overemphasizes" or "patient amplifies symptoms," whereupon the next health care provider who reads the chart automatically discounts about 50% of the information he or she hears from the patient thereafter. It was then that I agreed to write the following suggested dos and don'ts from a patient's perspective.

My experience with chronic pain began about 6 years ago, when my car was rear-ended by a large industrial truck with attached trailer. My car was sitting still at a red light when the brakes failed on the truck, causing both the truck and the trailer to crash into my vehicle. I saw the truck plummeting toward me at a high rate of speed and could do nothing to protect myself. After several weeks of traction, prescribed rest, and wearing a soft collar, healing began. The fear of driving in heavy traffic and seeing large trucks approaching in my rear-view mirror eventually healed also. Approximately 1 year later, while standing on a chair to add books to a newly acquired bookshelf, I was again injured when the shelves collapsed, sending books and computer flying on top of me—throwing me against a piano, with my lower back hitting the edge of the piano stool and my recently healed neck being flung against the edge of the piano keyboard.

I returned to the same neurosurgeon I had seen the previous year. He suggested 2 to 3 months of bed rest. I experienced right upper and lower extremity numbness, with loss of fine motor skills in the right hand and difficulty walking. I was concerned about muscle atrophy and asked for a referral for physical therapy. The neurosurgeon declined, telling me to "just relax" and to stop resisting the prescribed bed rest. I put myself on a walking program despite his well-meaning advice not to get out of bed for 2 months.

I continued to have chronic pain with occasional flare-ups. The problem finally culminated in necessary surgery after an incident in the spring of 1995 when I decided to build a patio lounge chair. The process of bending while lifting heavy materials proved too much for an already weakened spine. The result was a fusion at C4–C5, along with removal of a ruptured disc and removal of several fragments from the spinal canal. Premature nerve damage caused prolonged motor weakness and numbness. In addition, when the bone graft was removed from the iliac crest, nerves were injured, resulting in neuropathic pain in the left thigh and

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leg. It was during the subsequent healing months that I learned much about definitions of such words as CRPS, allodynia, dysesthesia, and hyperesthesia and about listening to patients in pain and believing their story. It is from that experience that I share the following dos and don'ts.

DOs AND DON'Ts FOR SURGEONS

Don't shout with glee, "YES! There's real pathology here!" while showing the patient magnetic resonance imaging (MRI) and x-ray results indicating that a herniated intervertebral disc is pressing into the spinal cord.

Don't build false expectations by telling the patient prior to surgery, "You'll be back at work in a week or so," if the patient is facing major surgery involving neuropathic problems that may take considerable time to heal. If working as a team with another surgeon, do coordinate instructions. One surgeon insisted that I return to work in 2 weeks; the other surgeon insisted on 24-hr nursing care for 4 weeks following the surgery and stated that I should lift nothing heavier than a fork or spoon. One surgeon insisted that I wear the cervical collar for 6 weeks; the other surgeon insisted that I "throw the collar away."

Do determine the appropriate size cervical collar prior to surgery. Immediately following surgery I was placed in four different cervical collars, three of which were too large. Finally, one nurse said, "If we get one any smaller we will have to go down to pediatrics," in a tone of voice that implied that I was being difficult by having a smaller-than-average neck.

Do send only trained personnel to apply the cervical collar properly. An untrained resident, assigned to adjust the last of the four collars, spent a considerable amount of time pulling, tugging, frowning, and groaning while he left my neck unsupported. He finally turned to the nurse and asked if she had ever seen "one of these new collars." I immediately asked him to stop and leave the room, and then called the nurse over and asked her to send someone who was already familiar with the collar rather than someone obtaining his training while practicing on me.

Do practice wearing a collar for more than 24 h to avoid making false claims such as, "These are very comfortable; they are made of a new type of fabric that is cool in the summer; they dry easily and quickly." I was told that I must wear the collar 24 h per day, including in the bed and in the shower. I was then reassured that the collar would dry quickly. That was a true statement—for the areas exposed to air. Unfortunately, the portions of the collar touching my neck were still damp 18 h later. I almost cried when the editor of this issue asked me months later why I was not given an extra collar to use in the shower in order to have a dry one for wearing afterward.

Do either become skilled in postsurgical follow-up care for pain or be willing to refer the patient to someone who is skilled in pain management. Don't tell patients the following and call it pain management: "Your x-ray and other tests look good; therefore, you shouldn't be having pain," or "You look great, i.e., attractively groomed; therefore, you must be doing well," or "My wife delivered by C-section one time and her scar was numb for awhile; you'll be alright in no time."

DOs AND DON'Ts FOR PATIENTS

Do learn to ask for help. Accept the help that is given from family and friends as being possibly the best that person can do. It is exceedingly frustrating for an independent, active, goal-oriented person to rely on others. Not only is it frustrating to have to ask for help, but often the help that is given is not done the way the patient would have done it. A tremendous help to me was to remind myself of Plato's statement, "Man always seeks the highest good." I am not entirely sure what Plato meant when he said this (or even if he said this), but I interpreted this to mean that we seek to do the best we can in any given situation. Our best at any given time is contingent on our resources, both internal and external, e.g., time, energy, motivation, desire, reinforcement, abilities. So it was during times of frustration that I consoled myself by thinking that this person may very well be doing the best he or she can do at this point in time. This caused me to view the situation from his or her vantage point and focus less on myself, causing me to be more patient and less irritable when things didn't go my way.

Do determine to do everything you can to help yourself. I began a walking program upon return home from the hospital. My first walk lasted less than 3 min. Eventually I could walk 30–60 min two to three times per day and walked indoors when the weather was inclement. Don't panic when taking a walk if an insect flies into the front hole of the new and improved Philadelphia Cervical Collar. Do panic if the insect is a bee.
DOS AND DON'TS FOR PAIN MANAGEMENT PROFESSIONALS

Do listen to your patient. Listen with a "third" ear. Listen with your heart. Listen to believe, and not to discount. Listen to discover the problem(s), instead of listening to impose a solution, because when we impose a solution we can create additional problems.

I am a firm believer that if you want to know what is wrong with patients, ask them; they will tell you. They may not use the terminology that you and I would use, but in their own way they can tell us much about what is wrong with them.

During the weeks following surgery I experienced the following symptoms, some of which sound bizarre even to my ears: (1) numbness and tingling in both upper and lower extremities to the extent that I could not sleep because I had to walk and move around every 30-60 min to "improve the circulation"; (2) a feeling as though a large, strong person was applying immense pressure to the area underneath my ankles and cutting off all circulation to that area; and (3) a burning sensation in my feet as though they were being held too close to a roaring fire.

During the healing process I experienced the following symptoms in the upper extremities, reportedly due to presurgical nerve damage. (1) I felt as though I had hit my funny bone (ulnar nerve) and then held my hands and arms high above my head for several hours while being forced to smell a large vat of ammonia. A feeling similar to that experienced when smelling ammonia permeated the entire length of my arms for many days. (2) I felt as though a very strong individual was pressing on the back of my neck and squeezing my biceps. I actually found myself looking at my arms occasionally to make sure I was not experiencing external pressure. (3) I felt as though blood pressure cuffs pumped as high as they could go were left on my biceps for several hours, cutting off the circulation and causing indescribable discomfort. (4) I felt as though my hands were being held to a sizzling-hot pancake griddle.

I experienced the following symptoms in my left thigh after removal of the bone graft from the iliac crest: (1) an intense burning, stinging sensation as though a swarm of angry yellow jackets was stinging profusely and unrelentingly; (2) areas of skin that felt hot and cold simultaneously; (3) a feeling as though soft puffs of cotton containing shards of razor-sharp steel were being rubbed agonizingly slowly over my thigh; and (4) a feeling as though a soft feather was being rubbed tortuously slowly and softly over my skin.

Currently any time cold air comes in contact with my skin in this area I feel lightening-sharp goose bumps like cactus spikes. I often feel as though little bugs driving electric bumper cars are racing each other at a high rate of speed up and down my thigh. The little bugs emit sharp electrical impulses each time they hit the cactus-spine goose bumps or any time they bump into another electric bumper car.

As a patient, I found myself feeling that no one would believe me if I told them how I actually felt. As a professional, I have never actually disbelieved patients who reported what sounded like bizarre symptoms. I have never actually disbelieved patients who reported that their pain "moved" or increased after receiving a nerve block, but unfortunately, I have doubted them—until I personally experienced these phenomena.

Following removal of the cervical collar my neck was stiff and I requested a referral to physical therapy. I initially had difficulty engaging in the exercise program until one of my pain management colleagues gave me some myofascial trigger-point injections and a spinal accessory nerve block. I found these injections to be greatly beneficial, not only in helping reduce the pain, but also in helping reduce the stiffness in order for me to succeed in my physical therapy program. It was then that my colleague gave me a bilateral femoral cutaneous nerve block for neuropathic symptoms in my left thigh that I experienced an increase in pain in that area. The pain also "moved" farther down my left extremity after this injection. We concluded that I may have begun to notice the areas with less intense pain after the more severe pain decreased following the injection. Another possible explanation we discussed was that the receptive field of the nerve may have changed.

Following the experience of receiving injections, I suggested that each of our pain treatment staff "practice" being a patient. If you choose to follow this suggestion, do disrobe and wear the skimpy little gown; do sign a permission slip stating that you understand the risks, including possible paralysis (sobering thought); and do hope that you are fortunate, as I was, to get a physician who talks you through the procedure, preparing you mentally each step of the way instead of slamming your backside with a cold alcohol swab and stabbing you with a needle when you're least expecting it.

After this experience, I gave some thought to the
pain questionnaires we ask patients to complete on their first visit to the Pain Center. I realized that many of the questions relate to the experience of chronic pain but do not seem to relate to CRPS symptoms. For example, “When is your pain worse? When: lying down/sitting/standing/walking/bending or twisting?” While these activities do relate to chronic pain, there is no mention of experiences that affect neuropathic pain such as encountering a sudden blast of water while in the shower, walking into an air-conditioned room, or walking outside on a windy day. Also, the questionnaires contain descriptions of chronic pain symptoms but not CRPS symptoms such as crawling ants, stinging bees, and soft cotton being rubbed across one’s skin.

As a psychologist, I never actually disbelieved, but did doubt, patients who told me they hurt too badly to comply with their relaxation and visual imagery exercises. As a patient, I learned what they meant. I found that when the pain reached an excruciating level of intensity, I had significant difficulty concentrating. It was also during times of extreme pain intensity that I felt that I was in danger of being consumed by pain. I felt as though the pain seemed to come in waves, and when I thought I could stand the pain no longer, I learned to ride the wave of intense pain and look forward to the subsequent wave of less intense pain.

I found that during these times of intense pain I could not concentrate well enough to engage in relaxation with visual imagery. This was especially true if I tried to visualize a pleasant beach scene or a mountain excursion since a pleasant scene was so orthogonal to my actual experience, it was then that I devised a new type of visual imagery. I recalled a ride at Epcot Center at Disney World that consisted of a roller coaster passing by various scenes depicting the history of mankind. I imagined myself riding the wave of pain and then riding past the pain, distancing myself from it instead of allowing the pain to consume me. When I had difficulty focusing on thoughts other than pain, I focused on controlling my pattern of breathing and then forced myself to state aloud positive affirmations. I stated the positive affirmations aloud as I took daily walks and even sang them at times to break the cycle of obsessing on thoughts of pain. I wrote positive affirmations and taped them to the door facing and inside the medicine cabinet as a constant reminder of what I wanted to become, i.e., healed, productive, and energetic, instead of feeling consumed by pain.

CONCLUSIONS

This personal experience with pain has certainly affected the way I work with my patients. I am more empathic. I listen with a different ear. I remind myself that if I experienced feelings of fear about overcoming the pain and concerns about being heard and understood by treatment professionals, I can only imagine how difficult such an experience must be for someone who has no prior knowledge of chronic pain management. Overall, one of the most beneficial things I gained was to listen to my patients and try to actually hear what they are telling me, instead of simply hearing the words they say in order for me to impose a known treatment on a familiar-sounding problem. Persons we may stereotype as being professional patients may simply be patients seeking our professional help.

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Editorial

... In The Eye of The Beholder

Dr. Livengood has written an insightful and courageous essay on her experiences of her own pain (1). She brings the training and experience of a health professional, but also has the courage to describe her experience in some terms which are too often regarded as unreal. Her essay should instruct and remind all of us dealing with pain patients that it is only the person experiencing the pain (or other sensation) whose experience (and description) is valid. Much effort has been expended in the literature to define “amplification”, as if this were a useful concept. All it does is serve to diminish that person’s experience, and impose some arbitrary boundary on the experience. If Dr. Livengood, articulate and literate as she is, is constrained by the language, how much greater must be the linguistic disability of the “average” patient, and how tempting it would be to dismiss the experience as amplified or fanciful. Such a response serves neither the patient nor the therapist well. The patient becomes aware that he/she is not valued, and the therapist will not obtain the necessary information. Pain patients are “difficult” because we may not have been trained, and may believe that we do not have the time, to listen with an educated and nonjudgemental ear to the real message.

We should use these insights to remember that the experience of pain is in the mind of the sufferer, not in the eye of the beholder.

But we know that.

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Editor-in-Chief

REFERENCES