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Emotional Challenges of Acute Inpatient Rehabilitation

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This is the first part of a two-part post on my experience in rehabilitation.

I spent the last 2.5 weeks as a patient in an inpatient acute rehabilitation facility. It was a remarkably successful experience but emotionally challenging. I'd had surgery to remove a fairly large benign tumor from inside my spine. The trauma of the surgery left me with limited sensation from my waist down. I could stand and walk a few feet with people holding me up. I needed to learn to walk again and to wait for sensation to return.

I was optimistic and expected to be walking in just a few days. Nevertheless, the first day hit me hard.

Being dependent on people to help me with very basic life tasks was a blow to my sense of who I am. I am a person who takes care of himself and his family and helps other people. I hated having to ask strangers to help me in and out of bed, to help me dress, and especially to take me to the bathroom.

The loss of physical privacy was very difficult for me. I think the most common question in rehab is: "When did you move your bowels last?" I wanted to answer "None of your business." I understood that constipation is a common and potentially serious problem after surgery and that the doctors, nurses, and nursing assistants needed to know what was happening with my bowels. But it violated my personal sense of privacy and was just plain embarrassing to have to report the number and nature of my bowel movements.

Even more distressing, I needed help to get to the toilet. Fortunately, I did not need someone standing next to me while I urinated or defecated, and I was stable enough on my feet that the nursing assistants who made sure I sat safely on the toilet would kindly avert their eyes when I pulled my underpants down. Still, I felt like a little boy being trained to use the potty.

I also needed help dressing, because I am not allowed to bend or to twist. Fortunately, I quickly learned to use various assistive devices to undress and to put my under and over pants and my shoes and socks on, thereby regaining a little of my personal privacy.

Not for showering, however, which I did as infrequently as I could tolerate because I needed someone to get me on a rolling shower seat, help me remove the hospital gown that covered me on the trip down the hallway to the shower, adjust the water temperature, and dry me when I was done. Fortunately, I could wash myself, and did not suffer the indignity I experienced in the hospital when a very kind and gentle woman washed my genitals.

For me, being dependent and being naked in the presence of strangers were a blow both to my inner sense of dignity and to my public persona.

Learning the reality of my condition was also difficult. The neurosurgeon and his staff told me that I might be able to go directly home from the hospital or that maybe I'd need a few days in rehab. The post-operative instructions told me that within a week or two I should walk an hour a day. I had visions of slow strolls downtown. The fact that I might be in rehab two weeks or longer was always tagged on as a caveat, but I expected a much better outcome.

At the rehabilitation facility, the physical therapist who evaluated me said that my discharge goal was being able to get around my apartment using a walker without someone holding me to prevent falling. That, she said, could take two weeks.

Tears welled up when I realized how limited I would still be when I left rehab and how much time I would have to put into my recovery. Rehabilitation would be my full-time job. Accepting that was very difficult. As a social worker, social advocate, and teacher, making a contribution to the well-being of others has been my full-time job and given meaning to my life. Having to focus primarily on my own recovery felt like a loss of meaning.

Loss of autonomy was also a challenge for me. I prefer to decide when and what I eat and what I do with my time. In rehab, as in almost any hospital, meals come when it is convenient for the facility. (It may be, of course, that dinner at 5:30 is good preparation for a future of early-bird specials.) I was given a schedule of occupational and physical therapy, and I was not allowed to keep my own medications or trusted to take them regularly. Hrmph! I thought I was an adult.

In addition, I was not permitted to leave to go to a restaurant, a store, or a movie. I couldn't get together with friends unless they came to visit. I was in a sense a "captive" of the institution, a great place to be a captive if you need the care, but captive nevertheless.

Most important, being unable to share a bed with my wife left me feeling very lonely from time to time.

Remarkably, by the third day I had made the emotional adaptation necessary to avoid falling into dysfunctional distress. One of the nurses told me that in this regard my experience was typical. People arrive in pain, confused and frightened about what to expect, and distressed about dependency, loss of privacy, and the rest. By the third day, she said, they are usually focused on

their rehabilitation goals and regain a sense of control by going to therapy and working to recover.

Unfortunately, my Internet search turned up virtually no research on the normal emotional responses to being in acute inpatient rehabilitation, so I can't speak with confidence for all of the 600,000 people per year who go to acute inpatient rehabilitation. [1] But conversations with both patients and staff while I was a patient led me to believe that the emotional challenges I had to deal with are quite common and that most people make a successful emotional adaptation.

Would it have helped to be able to anticipate the emotional assault of the first couple of days? I certainly would have preferred to know what to expect. And I think that doctors should make it a point to be clear about the likely outcomes of surgery and about the experience of rehabilitation.

My next post will focus on what the rehabilitation facility did to foster psychological adaptation.

Reference:

[1] Medicare Payment Advisory Commission. Chapter 9: Inpatient Rehabilitation Facility Services in [Report to Congress Medicare Payment Policy](#). March 2012.

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