CASE REPORT

Adaptation to Loss: Occupational Therapy as a Way of Life

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This report, written from my personal perspective, describes how I used my occupational therapy training to reduce the problems and losses created by brain cancer.

Before June 19, 1989, occupational therapy was the service I provided; after that date, it became my personal way to cope with loss as well. That morning I began writing the last in a series of three papers about state guidelines for school-based occupational therapy. One paper had been accepted by the American Journal of Occupational Therapy, and a second paper had been submitted to the same journal the previous week. I was working on the third paper on my computer when, instantaneously, I was unable to spell or write anything that made sense, although I could still read. I continued typing for a few seconds and then sat and waited for whatever was causing the agraphia to pass. The episode lasted probably less than a minute but seemed longer than that. During that time, I shut down my computer without saving what I wrote, thereby losing the first four pages of the new paper and whatever was written during the aphasic-like episode.

A series of tests was arranged, the first being magnetic resonance imaging (MRI). The internist called 2 days later to report two lesions in the brain. He also cancelled the remainder of the tests, because he believed that no further testing was necessary to confirm the diagnosis of brain cancer. In that short conversation, he reviewed the test results, recommended a course of radiation treatment, prescribed 4 mg of dexamethasone (a steroid) every 6 hours beginning as soon as possible to decrease brain edema, and directed me to report immediately to the radiologist.

I arrived at the radiology-oncology center less than an hour later and, together with the radiologist, studied the two lesions on the MRI films. The clarity of the films was impressive, as were the sizes of the lesions. It was hard to believe that a person could function with so much of the brain destroyed. While examining the MRI results, I experienced the first loss of my independent function. The radiologist asked quietly, “You are not driving, are you?” I answered that I was, and he responded by saying that I could drive home, but then no more. “Not drive until when?” I persevered. “At least until your treatment [course of radiation] is finished,” he replied. Treatment began that morning, along with a lengthening list of losses and insults.

Medical History and Clinical Findings

At 62 years of age, I worked full-time as a school-based therapist and performed assessments part-time for a private psychiatric hospital, for a total work week of 60 hours. Slow decrements in my functional motor performance had been apparent to me for some time.
and during the last 6 months were accompanied by increasing fatigue. My father had died of Alzheimer disease, and I had been concerned that this might also be my fate.

I had had surgery for colorectal cancer 2½ years before, which resulted in a permanent colostomy. Subsequent tests and checkups remained negative, until the diagnosis of brain cancer. No tests of the brain had been performed, despite the finding that "metastases to the brain occur in 20 to 30 percent of patients with systemic cancer" (Patchell et al., 1990, p. 494). Two masses were identified: one in the left parietal lobe measuring 2 cm, located at the gray matter-white matter interspace, and the other adjacent to the right anterolateral margin of the pons, next to the dural surface of the clivus, measuring 15 by 15 by 20 mm. The radiologist noted that the masses had different characteristics and might not necessarily be metastases.

A neurosurgeon reported that I showed no history of serious injuries, and his review of my neurological system was negative for contributing pathology except for blurred vision, diplopia, and headaches associated with the present illness. The cranial nerve examination was negative for contributing pathology, with the following exceptions:

- Cranial nerves III, IV, and VI—A subtle degree of a right third nerve paresis, manifested only in the extraocular muscles.
- Cranial nerve V—An equivocal decreased sensation of pinprick in the distribution of the fifth cranial nerve on the right.

The remainder of the neurological examination was essentially negative for contributing pathology, and the neurosurgeon recommended no surgery.

Prognosis

For several weeks after the diagnosis, I did not have a clear clinical picture of my situation. The physicians did not address my questions about my prognosis until a young oncologist agreed to talk to me about the course of brain cancer. I learned that life expectancy generally is between 3 months and 2 years (it seldom exceeds 2 years), depending on how far advanced the cancer is at the time of diagnosis, its growth rate, and other health factors. Infection in the brain or spinal cord places the person at great risk. The life expectancy given by this oncologist, however, may have been overly optimistic (Cairncross & Posner, 1983; Silverberg & Lubera, 1988; Walker, Robins, & Weinfield, 1985), because in a recent editorial, Posner (1990) summarized:

> Once a cancer has metastasized to the brain, the outcome is usually rapidly fatal. Earlier studies indicate that the median survival among patients not treated is about one month. By controlling brain edema, corticosteroids double survival, to two months. When steroids are combined with cranial irradiation, two thirds to three fourths of patients have a salutary response initially, but their median survival is only about 3 to 4 months. (p. 544)

Having found a physician who would talk about difficult subjects, I have chosen to retain him as one of my two primary care physicians. Such a relationship does not preclude independent reading about my illness, but allows opportunities to clarify and update my understanding.

Losses

My occupational therapy background and experiences influenced how I dealt with the losses I sustained and helped me to prioritize them, from most disturbing to least disturbing, as follows:

1. Dependence on others.
2. Psychological responses to steroids.
3. Motor losses due to steroids and clinical condition.
4. Hair loss.
5. Imposition of others’ assumptions of my capabilities.

Dependence on Others

Radiation continued daily for more than 3 weeks. The inability to drive was the first loss of my independence and continued to be the most important loss for that period. My daughter drove me everywhere. She dropped me off, did her own errands, returned to get me, and never hovered. Even so, being unable to drive at will obviated whole sequences of independent actions. For example, when information was not on my bookshelf, I did not have the option of visiting several libraries. The topic of my driving privileges headed my list of concerns when I visited the internist. He finally negotiated my release from this restriction 2 weeks after the radiation ended, at which time the radiologist was no longer concerned about possible seizures. Only then did I realize that it was my need to be mobile that was important, not the act of driving itself.

Steroids

The second loss to my independence resulted from the use of steroids, which caused me to alter my diet and activities of daily living and tampered with my personality and feelings. The steroids did, however, allow me to function during treatment. I was painfree, generally able to do what I wanted to do, and intellectually motivated. During this period of being on a steroid high, I slept a maximum of 3 hr a night; ate less and lost weight; and was overly friendly, talkative,
and agreeable. I often commented that I was talking too much but continued to talk. One effect of the steroids—that of being able to divorce my thoughts from my feelings—was both helpful and harmful. While on steroids, I could express myself verbally and think about topics that might otherwise be too sensitive. Later, after I was off of the steroids, I could readress the same or similar topics comfortably. The negative side of this, however, was my lack of sensitivity, which allowed me to inform many people of my brain cancer by mentioning it casually in conversation. By observing the quick intake of air, loss of eye contact, or silence of the person to whom I was speaking, I would realize that I had challenged his or her coping skills.

Conversely, the reduced sensitivity prepared me for comments and questions of curious people. For example, a salesperson in a computer shop looked at my head covering and greeted me by saying, “You have cancer—you are going to die.” “So will you,” I responded, “But first I need a 10-volt battery.”

Motor Losses

I had noticed a decrease in strength months before the diagnosis. This decrease made it increasingly difficult for me to rise from the floor after working with a child. I was unprepared, however, for the weakness that accompanied the slow tapered withdrawal from steroids. The weakness was generalized but was especially evident in the proximal muscle groups of the upper and lower extremities. Subsequent muscle testing documented general improvement from poor to fair or from fair to good, and although my progress was remarkable, both the physical therapist and I knew the improvement was due more to the withdrawal from steroids than to my diligence in exercising. Problems associated with strength and endurance, especially against resistance or gravity and with the resulting fatigue, remain the biggest obstacles to independence and the ones least understood and recognized by supervisors, co-workers (including other therapists), and others not continually observing my performance.

My occupational therapy co-workers eventually noticed my common energy savers and substitutions, such as walking up my legs with my hands to stand, moving my car seat back before exiting the car, carrying therapy equipment on a luggage cart, and waiting for others to open doors for me.

Hair Loss

My hair fell out in a 15-min period, after 3 weeks of radiation. I had prepared for this eventuality by buying wigs, a recommendation that is made often by those working in oncology. I also purchased several 100% cotton head coverings and cotton cloche hats to match my clothing, which protected my head from the sun and from constant heat loss, even while sleeping. I chose the wigs, which were styled by my hairdresser, to match my natural hair color. After enduring such effort and expense (a total of $160), however, I wore a wig only once, when I spoke at a conference, and felt too uneasy and embarrassed to wear it again. From that day, I wore no head covering, which coincidentally was at a time when many fashion models were sporting ultrashort haircuts or shaved heads. Shortly thereafter, my hair began to grow back, and every week or two I would style my new curly, somewhat darker hair differently. I found wigs to be too warm in the humid Louisiana climate. I have recently donated my wigs to the American Cancer Society, who, after thanking me, mentioned that the greatest desire for wigs was from people who either had not yet lost their hair or had sustained permanent hair loss. I believe that less money would be wasted on wigs if experienced patients would organize to counsel new patients who have not yet lost their hair.

During an occupational therapy evaluation that I was performing, a 5-year-old student looked up at me from his work and said, “Your scarf makes pretty hair.” I thanked him and he went back to his work. I appreciated his acceptance.

Others’ Assumptions

When I returned to work and before the first preschool clinic, I talked to our team as a group. I explained the things that I could not do and that I would be requesting help as needed. My co-workers were receptive and have always been available to assist with a child.

Other situations, however, were not as easy. Because I appeared to be well, I often had to ask for help. Most people have responded positively, but some have not. A taxi driver in Savannah, Georgia, was incensed when I asked for his help in opening the cab’s door, even though I explained that I lacked the strength to open it myself.

Another assumption was made by an acquaintance who wrote me a “sympathetic” message saying how badly I must feel that the cancer had recurred. Fortunately, because I had received this message during the time I was on the steroid high, I did not identify with the message and thought that it revealed much more about her attitude toward death and cancer than mine. How often do we deprive another person’s independence of thought by imposing our attitudes?

Progress Report

A year after my diagnosis, I was employed by the school system; had recently completed a chapter for
an occupational therapy textbook; with a physical therapist, had written a booklet for parents on school-based occupational therapy, and was revising a handbook for school-based therapists. The last quarterly MRI showed no change in the lesion in the pons but showed continued enlargement of the lesion in the parietal lobe. Headaches when leaning over and symptoms of aphasia portended changes in condition and treatment. Suggestions for alternate treatment approaches were chemotherapy, neurosurgery, a conservative course of waiting and observing, and increased doses of dexamethasone. Further irradiation was negated because the full dose had been given initially. Steroids caused motor weakness and, eventually, the effect in controlling edema was lost and death would occur. Among the alternatives, I chose neurosurgery, which has the highest risk factor but offers temporary improvement, as opposed to an assured, slow decrement.

At the time of this writing, it has been a month since my surgery and I am on summer break. I am off all medication and am walking a mile daily. Difficulty in finding the right words to convey my meaning remains my most irksome speech problem. Losses identified earlier reappeared after surgery but were resolved in a shorter period of time due to my experience with such problems.

During the two recuperative periods after radiation and neurosurgery, I found the treatment and accompanying patterns of loss to be similar, although I am continually reordering their priority. As the course of the cancer progresses, I anticipate that my occupational therapy background and experiences will continue to influence the adaptations I make as losses recur.

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References


Editor's Note. To continue the Case Report department, we need and welcome reports that document the practice of occupational therapy for specific clinical situations. Guidelines for writing case reports are available from the Editor.