

Bridging Personal and Professional Perspectives: A Continuous Process

The author introduces her narrative:

I hope that I am getting smarter personally and professionally as a result of adding to my academic preparation in gerontology the experience of aging-related crises within my own family, role modeling by disabled and older colleagues, and lessons learned from the progressive deterioration caused by my own late onset disability. No longer can I expect to accomplish "business as usual" in quite the same way, but in this narrative I describe how I have become a more goal--directed person and professor as a result of these painful experiences.

by
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I had hoped my disability could remain invisible. Indeed, I was able to hide obvious symptoms for a decade. Now, at age 56, my disability has advanced to the point of forcing me to "disclose" my situation by using a "handicapped" parking placard, changing to a more accessible office, and using a cane. Eleven years ago, after driving with too few stretch breaks from Oregon to Philadelphia, my joints were aching from osteoarthritis. The following year, I was diagnosed as having Multiple Sclerosis (MS). Multiple Sclerosis is a disease of the central nervous system that results in compromised motor and, at times, cognitive function. While my arthritis is merely annoying and painful--that is, a socially acceptable disease--the MS is a "real disease"--that is, a stigmatized disease--one that I quickly discovered could become visibly apparent at any time. Then, a year ago, I was grazed by a cab that tried to beat a yellow light in the intersection where I was walking. It is not the MS that now compels me to walk with a cane, but rather the mobility impairment resulting from that injury.

For the first decade, I told only a few people about

having MS. I was so relieved just to have a diagnosis--any diagnosis. I did not want anyone to feel sorry for me because I have a central nervous system disease or to think "MS" before remembering my name and other characteristics. Professionally, I did not want anyone to expect less of me or to assume that I could not manage the responsibilities of my job. Most of all, I didn't want my mother to add my name to those on her "Worry List."

Now, I manage quite well, thank you, except when I get overheated. The only two commonalities among persons with MS are the high likelihood of optic neuritis (sudden and profound vision loss) and the inevitably debilitating effects of heat. Everyone with MS needs to remain as cool as possible at all times. Each summer when the heat begins, people with MS find out how much ground they have lost during the preceding winter. In my own case, my levels of muscle fatigue increase year round, but become visible determinants of my movement patterns and balance control only after it gets warm indoors or outdoors. It's tough to keep up appearances during the summer months. At times, I stagger

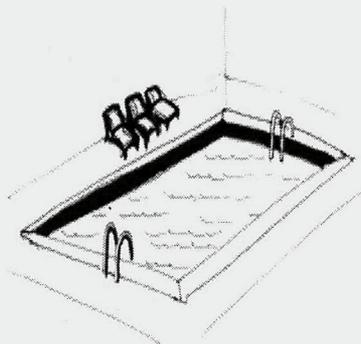
and pitch, occasionally even falling, for no particular reason. Summers are scary for me and cause others concern.

Three processes have helped me to bridge my personal and professional perspectives of aging and disability. First, I will relate the cumulative and interacting effects of disability on my professional life; second, the contrast between teaching about the caregiver role and my experiences as a caregiver; and third, my ongoing pursuit of better data and role models.

Adjusting Professional Activities To Accommodate Disability

As an academic program administrator and professor, I teach gerontology and spend a lot of time with older persons. I have lectured for many years about the interacting and cumulative effects of a wide range of sensory changes and chronic conditions. Now that I am experiencing MS and arthritis first hand, I have a clearer concept of sensations resulting from vision impairment, muscle fatigue, pain mixed with numbness, and imbalance. Although I am unable to articulate adequately the subjective sensations that result from these conditions, my efforts to do so are more successful each year. Being increasingly able to describe what it feels like to have muscle fatigue, in particular, is a positive outcome of coping with a negative personal experience. Of course, I was trained to identify and to analyze pertinent journal articles and other academic resources,

but now I also can speak from personal experience on those rare occasions when it is appropriate to "disclose." While I find myself better able to conceptualize and describe the complex dynamics of fatigue, pain, numbness, imbalance, and other consequences of various chronic diseases, a related symptom of MS is gradually emerging: Difficulty finding the right word at a particular time. Teaching at night is increasingly difficult, especially when I am hot, tired, or stressed. Fortunately for me, graduate students have welcomed the opportunity to schedule courses on Saturday mornings as well as week-



day evenings. One benefit of my changing capabilities was that I had no choice but to give away all my shoes with heels and thereafter limited myself to flat, rubber soled, wide box shoes. How wonderful it was to have an excuse to do just that! To complement my heavy-looking walking shoes, I switched over to slacks with colorful shirts and jewelry more often than dresses or skirted suits. As a result of adapting my wardrobe to fit my needs, I now assume that certain

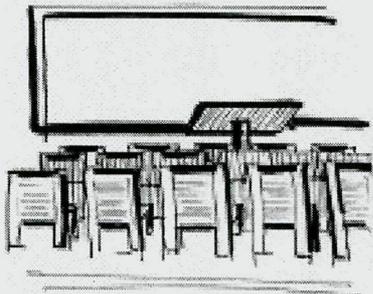
avenues of professional advancement are closed off forever because I no longer can wear high heels with my dresses and skirted suits. I make this assumption because from time to time I overhear criticisms of my relatively informal and, at times, nontraditional attire. Another consequence of having MS is that I have had to adjust my body image and mobility patterns to accommodate my changing abilities, my need for remaining cool, and my growing levels of pain and numbness, especially in my legs and feet.

Shortly after my diagnosis, as a preventive strategy, I started working out faithfully, twice a week. In addition, I signed up for a swimming class offered by the local MS Society. Once there, I was able to observe a wide array of body shapes and movements that characterize persons experiencing more advanced stages of MS. Only recently have I had to begin driving the short distances that I walked with relative ease a couple years ago. Another result of having MS is that during bouts of long-term vision loss in one eye and extreme glare sensitivity in the other, I have to limit my outdoor movements to daylight hours. On one occasion, participating in a professional conference took on humorous aspects. During one of my four bouts to date of optic neuritis, I was forced to try to identify colleagues by their walks rather than by their other physical features or by the sound of their voices. Fortunately, I discovered that people's walks are as unique as their signatures. So I

walked around with an enigmatic smile on my face for the duration of the five-day conference!

Studying Caregiving vs. Providing Care

As an educator, I have been conversant for some time with the research literature pertaining to various aspects of caregiving, and in 1985 (Bader), a paper I wrote on the topic of respite care for caregivers was published. More memorable, however, are the lessons learned from being a caregiver when my own family members were in crisis. My stepfather, Jack, was paralyzed from the waist down for the last several months of his life. As my mother's only



daughter, single, and a gerontologist who was supposed to know how to be helpful and to promote home safety, I rushed to the other side of the country to "help" my mother. My goals were to ensure that their home was safely and efficiently managed; that his medications were the correct ones, compatible and

well organized; and that both Jack and Mom were receiving as much medical attention and social support as they needed. While I was in Philadelphia, my mother, who was Jack's primary care giver, suffered a broken hip when a chair leg came unglued under her slight weight. She decided to have her hip pinned so that she could return to caring for Jack sooner than a complete hip replacement would have permitted. Then, to speed her recovery process, she exercised even more than usual. Unknown to us at the time, one of the surgical pins had become dislodged within a week of her surgery. Weeks later, during the routine post-surgery visit, her surgeon blanched when he examined the x-ray that had been taken at another hospital within two weeks of mother's surgery. Her intensifying pain and the x-ray clearly showed that one of the pins had become dislodged early on. Of course, Mom had to return to the hospital immediately for a full hip replacement and another several weeks of in-patient rehabilitation, followed by prolonged recovery at home. During most of this process, I stayed on the east coast. Everyone was amazed when my boss at the time suggested that I needed to be with my family for as long as it took, so long as I met my previously scheduled professional responsibilities. I did just that--and remain grateful for the privilege and the lessons learned by spending time with my older family members during a prolonged period of crisis. Routinely, I would spend a fourth of the

day with Mom, voluntarily staff one of the otherwise expensive "home care" shifts for a third of the day, and run errands for Mom and Jack when not fitfully sleeping. Neither Jack nor Mom had any energy to spare for any purpose beyond coping with the physical and emotional pain in their own lives. For four months, their life space was bound by the walls of the adjacent dining room and breakfast nook, which we had converted into hospital rooms for them. But they conversed with one another. The birds just outside, a resident chipmunk, and a neighbor's amazingly attentive cat gave them no end of pleasure. In addition, condominium owners in their community arranged a rotating schedule of food preparation for Mom and Jack. Casseroles, milk, and fruit just appeared in the refrigerator, one after another. The community was remarkable in another way too. Usually twice a day, a neighbor would make a welcome five-minute visit. Those short visits cheered my whole family. Then Jack died. My mother continues to grieve deeply for him and, at least at first, she was angry that her own body had betrayed her when she wanted to devote all of her strength and caring to him. From the moment the chair broke and she fell to the floor to the moment he died, she remained unable to bend down to kiss him--a fact that causes her tears today.

After Jack's death, I returned to my job at the University of Minnesota. In keeping with my academic commitments

and interests, within three days of returning to Minneapolis, I accepted an invitation to review a book of which I previously had been unaware: Sankar's (1991) *Dying at Home: A Family Guide for Caregiving*. I wished I had known about "Dying at Home" three months earlier! Then, within a year of Jack's death, I relocated to a new job in Long Beach and a year later, my mother moved into a continuing care retirement community located within a mile of her previous home. Gradually, she began to regain her physical stamina and emotional independence. For at least three years, however, she cared too much about my opinions regarding every little thing. Her emotional dependence was apparent to everyone and burdensome to me. Then one day, with no prior warning, her speech pattern while talking with me on the telephone 3500 miles away clearly showed that she was re-energized, goal directed, and once again in charge of decisions affecting her life. During the time that Jack was ill, I did not want my mother to worry about anything except Jack's and her own well-being and then, after his death, her own recovery. Therefore, I told no one in mother's community that I had MS, lest the word get back to her. But I did feel compelled to tell a handful of friends in various parts of the country what was going on with me. Just opening that escape valve and letting out some of the pent-up thoughts about my diagnosis and about my caregiving experiences were therapeutic. Although I cannot imagine how

the responsibilities of being a caregiver could have been more physically and emotionally demanding during my mother's and Jack's crises, it probably would have been even rougher if I had not known that a few friends cared about me, too, independent of my being a caregiver, and that they also knew about my MS. Nevertheless, each time I told a friend about my still-novel diagnosis and caregiving experiences, I asserted my right to determine when and how to share that information with others, effectively denying my friends permission to do so. One of those whom I trusted with "my story" unintentionally mentioned my diagnosis to my mother in a telephone conversation. When their conversation ended, Mom immediately called me and asked four questions: "What was my official diagnosis?" "What was the disease like?" "Was she in any way responsible for my having 'it'?" "Was I receiving good medical attention?" Since that telephone conversation, without any prompting from me, the only reference she has made to my MS is to confirm that I am aware of new medications as they become available. Not bad! Each time I ask myself anew why I resisted telling her what was going on with me, I come to the same conclusion: As stated above, I did not want my name to appear on her "Worry List."

The Pursuit Of Data And Role Models

The third process that has helped me to bridge my per-

sonal and professional views of aging and disability began before I had any inkling that I, too, would develop a disabling chronic condition. This process might be described as an ongoing one in which aging and disability data and indirect experiences are the primary players. There are accepted "facts" and "demographics" about both topics; interested parties espouse conflicting value systems and investments; and there is not yet any effective integration of perspectives. My discovery process began long before I was diagnosed with MS. First, I read *Rehabilitating America: Toward Independence for Disabled and Elderly People* (Bowe, 1980). That book strongly sparked my interest in disability. Then, my boss, mentor and friend went from being an avid runner to being quadriplegic after a driver who had been cited repeatedly for the same offense ran a stop sign. She must have chosen at some level of awareness to survive, or she wouldn't have lived. It took all my mentor's intellect, energy, and finances to cope with recovery and re-entry into her roles as a senior professor, wife, mother, and soon thereafter, widow. Although it never was her style to become an advocate or even to talk much about any personal or emotionally laden topic, I acted on the lessons she taught me by example. I began to organize conferences on disability and aging and started a statewide interest group to coalesce professionals and consumers in the fields of disability and aging studies and practice. These activities provided me with ave-

nues for meeting people with personal and professional expertise regarding disability; they afforded me opportunities to spend time discovering what pertinent disability studies and policies existed. While I continued to read about disability, more important was the fact that I met active, visible advocates, academics studying disability-related issues, and many people of all ages with disabilities. The advocates aggressively challenged my assumptions, my disability-related lexicon, and my beliefs and behaviors. Although my MS remained fairly invisible for a decade following diagnosis, I was told early on after moving to Long Beach that "coming out" was essential for me and for the good of the Independent Living Movement. By visiting diverse agencies and organizations, I continued to learn more about the Movement and about the nature and implications of several chronic conditions. Then to my surprise, I discovered that only a minority of people with disabilities were aware of the availability of Independent Living Centers or of the basic tenets of the Independent Living Movement. These tenets include the right of disabled individuals to retain decision-making power regarding all aspects of their lives, willingness to expend a great deal of scarce energy to ensure enforcement of existing legal mandates, and demands for accessible environments and "reasonable accommodation" in housing and employment. It became my goal to continue to learn more about disability and about aging with

a disability. But research data and other information on these subjects were and remain scarce. Nonetheless, I "put myself out there" by collaborating with two faculty colleagues to write and later to completely revise a chapter for a second edition of an edited volume on the continuum of long-term care. In both versions, we summarized the histories, assumptions, issues, and contexts of aging and disability policies. It never occurred to any of us to mention our own disabilities. Our personal experiences did not qualify as "data" for that kind of publication (Bader & Torres-Gil, in preparation; Bader & De Jong, 1996).

Again in accord with my role as an academic, I capitalized on information, programs and role models available in Southern California to develop a course, "Independent Living for Disabled and Elderly Persons," a course title I inherited when I moved to California State University, Long Beach. Although the course does require a few readings, it relies less on published materials than it does on experiential learning opportunities that include site visits, the examination of a wide array of assistive devices, intense discussions with guest lecturers, completing safety checks of private homes and local businesses, redesigning forms for legibility and readability, and other experiential exercises. As always, I learned as much or more from teaching this course than did the students. In this instance, all of us learned more about "the facts" regarding aging and dis-

ability, about the interactions of aging and disability, and about the challenges and benefits of "independent living." Among the many issues explored in the course, one issue is of particular interest to me: While many younger adults with disabilities demand simultaneous recognition of the social dimensions as well as the medical aspects of disability, their legal rights and their personal potentials, they seem unwilling to be identified with aging, or as having anything in common with older people. In fact, they do not want to talk about aging. At the same time, many older individuals with functional limitations do not want to be thought of as having a "real" disability or as condoning the more assertive methods of younger disabled individuals and groups, even though their needs often are identical. In this era of scarce resources, it seems to me that these two "communities" could do a much better job of working together on resource and coalition building, when appropriate. (For further discussion of some pertinent theoretical and policy issues, I recommend Kennedy & Minkler, 1999.) I understand that there is much more to learn and do about personal and societal aging than to solve disability-related issues. I also understand that there is much more to learn and do about the individual and societal consequences of disability than to solve aging-related issues. But needless competitions between the two communities, insufficient data on both topics, and unnecessarily complex sup-

port systems could be remedied to everyone's advantage. As Bowe (1980) advocated two decades ago, the results of collaboration between the aging and disability communities could be beneficial for the aged in gener-



al and for people of all ages with and without disabilities. On the other hand, failure to collaborate would continue to be costly to individuals, families, and taxpayers. In my view, scholarship regarding human aging and disability studies needs to grow at an accelerated rate in order to provide adequate data for effective planning in anticipation of the aging of the vast number of Americans born between 1946 and 1964: the "baby boomers." Many from this group will age with early- or late-onset physical or mental impairments and with aging-related chronic conditions such as arthritis and vision impairment. For others, delaying the onset or slowing the progression of disease, disability, mental illness, and chronic conditions could amount to huge family and financial cost savings. My professional contribution is research, now in progress, to identify practical suggestions, products, and policies that will accommodate their needs, those with and without disabilities, who will

survive longer than their forebears dreamed possible.

I have taken the first steps in squaring my personal and professional perspectives on the issues. Even overcoming my initial reluctance to write this paper reflects emerging readiness to accept the facts that my personal and professional perspectives on aging and disability are valid, hopefully worthwhile, and interactive. In truth, however, it was not until I wrote this paper that I became conscious of the interrelationships of the various personal and professional events that I have described. Also, through the writing of this narrative, I have strengthened my commitment to bridging personal and professional perspectives on aging and disability. As a person with MS and a professor of gerontology, I ponder how I can encourage my younger colleagues, with and without disability, to ask questions and, hopefully, help answer questions essential to societal understanding of aging, disability, and their confluence. At the same time, I reflect on ways that I can encourage disabled people of all ages to help those of us in the academy to "get it right" and not just smilingly share in-jokes and criticize our lack of understanding.

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