Living With Low Vision:
A Personal and Professional Perspective

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Unlike most readers of this special issue, I have been both a consumer and provider of rehabilitation services. A retinal hemorrhage that occurred when I was in my late twenties signaled the beginning of delayed-onset retinopathy of prematurity—a condition that has been further complicated since that time. In this article, I offer a glimpse of what living with low vision is like by describing activities in my own life and accommodations I have made. My hope is that therapists will learn more about the realities of living with low vision and will seek our additional information that they will incorporate into their practice.

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I am not typical of most readers of this special issue who are occupational therapists wanting to learn more about low vision. Unlike them, I was familiar with low vision before I was aware of occupational therapy. Born prematurely, I developed mild cerebral palsy-like symptoms after a brain hemorrhage at 3 months of age. Although cranial nerve damage restricted my vision throughout my life, I never considered myself as having low vision until a retinal hemorrhage in my late twenties signaled the beginning of delayed-onset retinopathy of prematurity. At that point, my functional status changed. I eventually left a career as an academic librarian to enter the uncharted waters of living on disability payments and pursuing volunteer work that led to a career in occupational therapy. During my years of occupational therapy practice in psychiatry and gerontology, my vision has been further complicated by glaucoma, cataracts, and continued retinal deterioration.

Having been both a consumer and provider of rehabilitation services, I, like others in similar situations (Stetten, 1981; Weinapel, 1989), find it unnerving that most of the rehabilitation services and information that the client with low vision obtains is self-initiated. A number of factors contribute to this situation.

Traditionally trained in the medical model, ophthalmologists have only recently become aware of the necessity for rehabilitation referral for persons they cannot cure (Fletcher, 1989). Additionally, they may view clients with low vision as untreatable on the basis of their own feelings about vision loss (Stetten, 1981).

Optometrists have been in the forefront of providing low vision rehabilitation in a medical setting (Faye, 1984; Jose, 1983), but the client leaving the ophthalmologist’s office may not know that these services exist. Traditional rehabilitation agencies, long based in the charitable sector, are also an option for some clients with low vision. However, many clients do not have visual changes considered serious enough to meet these agencies' criteria or may wish to avoid the stigma associated with vision loss.

Consequently, many persons with low vision remain unknowledgeable about services available to them or adaptive equipment that could greatly enhance their functioning and quality of life. As an occupational therapist with low vision, I find this situation a challenging dilemma, both professionally and personally. Although other traditional service providers in the field of vision rehabilitation (such as rehabilitation teachers and orientation and mobility instructors) may view other health care professionals entering the field as either a threat or as unnecessary, I believe occupational therapy has a clearly defined role in this practice area. Whether based in a low vision clinic or working with numerous populations in acute or chronic care, occupational therapists can identify functional capabilities and work as part of an interdisciplinary team to provide holistic treatment.

What can occupational therapy offer the client with
low vision? To answer that question, one must first have an understanding of the functional impact of low vision on a person's life. Although this impact will vary immensely with each person, I would like to provide a glimpse of what living with low vision is like by describing activities in my own life and accommodations I have made in the following areas: mobility, work, activities of daily living, and leisure.

Mobility

To the casual observer, I travel independently. I do not use the obvious mobility aids of a guide dog or white cane. However, I consider myself less independently mobile than persons who are fully sighted. Most of my perceived independence is achieved through a combination of environment, planning, and choice. Not having driven in 15 years, I am reliant upon public transportation and family members and friends for commuting to work, running errands, getting to leisure activities, and other travel needs. My choice of living in a city with a large bus, subway, and rail system is dictated by my desire to be as independent as possible.

Even with these options, planning ahead is essential for travel. A person with low vision must be able to read transit schedules, identify transit stops, and read transit signs. A telephone call to the transit schedule information number or reading schedules with a magnifier will accomplish the first task. Transit personnel, fellow travellers, or handheld or mounted telescopic devices can all be helpful in performing the other tasks. Once on the transportation vehicle, the person with low vision may need assistance with identifying stops if he or she is unable to read street signs or identify landmarks. Memorizing and counting of subway and rail stops may also be useful.

Travel on foot presents its own challenges. Although I wear sunglasses out of doors, direct sunlight and glare decrease my residual vision; therefore, I am more likely to choose to walk on the shady side of the street during the day or on the side of the street that does not face headlights at night. I use color contrast whenever possible to maximize safety, especially in negotiating stairs and curbs. I plan a route to my destination that will be either familiar or easy (one with sidewalks, traffic lights, etc.) whenever possible. Walking on ice or snow is also complicated by my poor balance; I am more likely to rely on someone with a car or take a cab in such weather.

I also rely on auditory signals such as traffic pattern recognition because my ability to see traffic lights depends on weather conditions and my fluctuating vision. Olfactory cues, such as scents from the coffee bean store or the cologne counter in a department store, are also helpful to me in identifying destinations.

My degree of independence in indoor mobility depends largely on my familiarity with the territory. I move most quickly and safely within those areas where I spend most of my time (i.e., my home and the hospital in which I work). Even within these known environments, I rely on a combination of residual vision and other sensory systems to travel safely. I also find that concentration, required for safe travel, decreases with fatigue, so I incorporate as many energy-saving techniques as possible into my daily routine. At work, I use an elevator and perform most tasks while seated. At home (currently a three-story townhouse), I use electric stair glides (originally installed for my husband who has postpolio syndrome) to both conserve energy and maximize safety.

Inevitably, however, some traveling remains difficult or impossible. Not all destinations are accessible by public transportation. Large, noisy, crowded places such as malls or darkened restaurants and movie theaters present sensory overload and hazards. In these instances, my need for concentration and my reliance on others increases, as does my level of fatigue.

Work

I am employed in a private psychiatric hospital as a staff occupational therapist. Until 1 year ago, I did not need overt accommodations to accomplish my work. However, complications from unsuccessful cataract and glaucoma surgeries left me unable to read any print other than the boldest of headlines. After obtaining the services of an optometrist who specialized in low vision, I developed a plan to accomplish reading and writing tasks. For clarity, all my documentation is written with a black felt-tip marker. My chart work on the unit is done with a 4 x or 7 x high-quality magnifier obtained through a low vision optometrist. Although these magnifiers are more expensive than those purchased in stores, they are of better quality and provide more clarity.

At work, my longer reading and all of my writing tasks (with the exception of a brief weekly progress note in unit charts) are facilitated by a closed circuit television (CCTV), which I obtained under the Americans With Disabilities Act of 1990. A self-purchased CCTV and a personal computer with a speech board facilitate my leisure and professional work at home. Because I can no longer see a computer keyboard clearly (even with large print key labels), I am enrolled in a touch typing correspondence course.

My current caseload is divided into two parts. Part of my job involves evaluating and treating clients on a geropsychiatry unit. The only adaptation (other than the above-mentioned documentation methods) I have needed to make is enlisting the aid of an occupational therapy fieldwork student or staff member for patient transfers during activities of daily living evaluations. In the other
part of my work—in prevocational services—I facilitate a patient-run mental health resource library (for which I draw upon my previous professional experience) and evaluate and treat inpatients and outpatients in prevocational and vocational areas. Rather than being a handicap, I have found that my disabilities provide me with empathy and personal knowledge of life changes and the rehabilitation system that are beneficial to my clients.

Activities of Daily Living

Although there are no tasks I cannot perform, there are some I have chosen to give up and others that I now must perform differently. Again, color contrast, lighting, and planning are key factors in maintaining my independence. I prefer diffuse natural light with a direct light source for close work such as writing or food preparation. My house is light and uncluttered. The furniture and appliances are in contrasting colors to the colors of the carpet and counters. Soap, shampoo, and towels contrast in color to bathroom tiles and fixtures. I avoid patterns or harsh colors to reduce eye strain and fatigue.

To save time and energy, I employ a housecleaning service on a weekly basis. I do not carry laundry and groceries independently up and down stairs but facilitate these tasks with the use of electric stair glides. My grocery shopping is done in bulk once a month at a familiar store. My kitchen cabinets, shelves, and refrigerator are organized by type of food and dishes, and I use my residual vision and memory to provide access to items.

As an avid vegetarian and ethnic cook, I use color contrast effectively in food preparation and serving (e.g., bright food items on a white cutting board, white dishes on black place mats). Because reading recipes is difficult (my CCTV is not in the kitchen, and I find use of a magnifier cumbersome while cooking), I often enlist my husband’s eyes for this task. Consequently, he has become more involved in menu planning and now enjoys cooking.

Most of my clothing is purchased from catalogs (read with the CCTV). In addition to saving time, this method also allows me to structure my shopping at malls, thereby reducing fatigue. Since I cannot distinguish many colors clearly, I purchase neutral or bright colors that I can mix and match. I have worn my hair in a permanent for years because of preference and ease of styling. I apply makeup through a combination of my residual vision and tactile skills.

Leisure

Although many of my leisure activities have not changed substantially, I find that my spontaneity in performing them has. Needlework (even with magnification) is a thing of the past. I can no longer pick up a book and curl up on the sofa with it or read it on the subway on the way home from work. I need the CCTV to read it. Although extremely beneficial, this method is slower and far more tiring than normal reading. As a result, I, a former librarian, am now much more selective about what I read in print. If asked to pick the loss I mourn the most, the ability to read print unassisted would top the list. Most of my leisure reading is done on tapes supplied from the National Library Service and Recording for the Blind.

Although I regularly eat in restaurants and enjoy folk music concerts and movies, I have cut back on my attendance for visual and nonvisual reasons. I find that I have limited energy and want to be selective in how I expend it. For instance, I no longer attend foreign language movies; straining to read subtitles is not worth the effort. I may have a leisure activity planned after work but feel that my energy and concentration are not sufficient for independent travel; consequently, I may take a cab.

Oddly enough, one of my newer leisure pursuits is highly visual. Combining my love of books and cats, I have established a regular freelance writing position as a contributing editor and book reviewer for a national cat magazine. All of this work is done with the CCTV and talking computer and has led to other writing projects. I have found that this creativity is a good counterbalance for the lack of choice and spontaneity I sometimes find in other aspects of my life.

Clinical Implications

Occupational therapy could be involved in every area mentioned above and at all levels of intervention, from evaluation to treatment and referral. Many of the techniques and adaptations I have mentioned are basic common sense and familiar occupational therapy modalities. Others may be new to occupational therapy personnel.

My hope is that therapists seeking knowledge about low vision to incorporate into their practice will become knowledgeable through both literature searches and community contacts. Although books and journals provide basic information, visiting a low vision clinic or a vision rehabilitation agency can provide new learning and networking opportunities. Personal or professional contact (either on an individual or group level) will enable therapists to learn more about the realities of living with low vision: the adaptations that can and cannot be made, the societal stigma, and the stress and challenges involved in living with a chronic illness.

In the final analysis, I consider myself to be a functional, capable human being living in a society that often does not view me in this way. Occupational therapy, with its long history of function-based holistic treatment, has much to offer clients like me, with low vision.

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References