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Research Report

Knowledge and Use of Low Vision Services Among Persons with Age-related Macular Degeneration

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Visual impairment (blindness or low vision) is a leading cause of disability among older adults and is most often due to age-related macular degeneration (AMD). The prevalence of AMD is rapidly increasing with the aging of the population; from 1991 to 1997, it increased from 5.0% to 27.1% in a cohort of Medicare beneficiaries (Crews, 1991; Lee, Feldman, Ostermann, Brown, & Sloan, 2003). It is predicted that 2.95 million people will have AMD by 2020 (Eye Diseases Prevalence Research Group, 2004).

Compared to older people with typical vision, those with AMD report greater difficulty with a variety of daily activities (Williams, Brody, Thomas, Kaplan, & Brown, 1998). For example, in a community sample of 872 older people, those with AMD were 9.7 times more likely to have impairments in instrumental activities of daily living (such as taking medication and shopping) than were people with typical vision (Rovner & Ganguli, 1998). Unfortunately, there is no cure for AMD, nor can lost vision be restored. Although there are interventions to slow the progression of the condition, treatment is primarily rehabilitative.

Services for people with low vision include low vision rehabilitation, occupational therapy, social support programs, and orientation and mobility training. Assistive devices include magnifiers, large-print materials (such as books, clocks, and calculators), audio materials (such as books and magazines), electronic reading devices, and speech-output systems. Despite the availability of these rehabilitative services and devices, they are underutilized. A series of focus groups that were conducted by the National Eye Institute (NEI) indicated that many older persons with low vision have little or no awareness of these services, and, as a consequence, few take advantage of them (National Eye Institute, 2001). Similar findings were reported in the Lighthouse National Survey on Vision Loss (Lighthouse International, 1995). Among adults with low vision, only 30% were using optical devices, 21% were using large-print reading materials, and 6% received rehabilitation. The most common reason for the lack of utilization of low vision devices and services was the participants' unawareness of them.

Ophthalmologists may not be informing and educating their

patients about these resources. Some studies have reported that ophthalmologists refer only 28%-35% of appropriate patients to low vision rehabilitation services (Greenblat, 1988). Leinhaas and Massof (2001) found that only 15% of ophthalmologists and 21% of optometrists "always or often" prescribed low vision devices, and only 44% of ophthalmologists and 27% of optometrists "always or often" referred patients for low vision services. The goal of the current study was to obtain more detailed information on the use of low vision services and devices by older adults with AMD and to determine whether knowledge and use of such services are related to the severity of vision loss.

Methods

Sample

We studied 80 consecutive patients who were evaluated at the retinovitreous clinic of Wills Eye Hospital, Philadelphia, from September 2002 to July 2003. The patients who were included in the study had a diagnosis of AMD (atrophic or neovascular), were aged 65 or older, had no cognitive impairment, and were residing in the community. All procedures were approved by the internal review board of Thomas Jefferson University.

Of the 140 patients whom we contacted for possible participation, 80 were enrolled in the study. Of the 60 nonenrolled patients, 30 (50%) refused to participate, 15 (25%) could not be reached, 5 (8%) were cognitively impaired, 4 (7%) had severe hearing impairments that precluded telephone interviews, 2 (3%) were hospitalized, 1 (2%) was residing in a nursing home, and the remaining 3 (5%) were not included for other reasons. The participants

did not differ from the nonparticipants in visual acuity of the better eye or gender but were somewhat older [82.5 (*SD* = 5.2) versus 78.8 (*SD* = 5.6) years; $f(1,133) = 15.4$, $p < .001$].

Measures

A research assistant obtained demographic data on the participants--their age, sex, marital status, education, race, and whether they lived alone--by telephone. The research assistant also obtained information from medical records on the participants' clinical characteristics--bilateral versus unilateral AMD, visual acuity of the better eye (Snellen chart), and duration of the AMD.

An expert panel compiled a comprehensive list of services and devices. This panel was comprised of a retinologist, a geriatric psychiatrist with expertise in research on the emotional impact of vision loss, a clinical psychologist who treats people who are visually impaired, and two leaders of a local AMD support group. The principal investigator of this study (Casten) presented the panel with a working list of services and devices for AMD patients and asked them to comment on the suitability of the language of each item (such as "Talking Books" versus "books on tape") and to edit the list as appropriate. The final list consisted of 31 devices and services, and for each, the participants were asked whether they were aware of it (yes or no), their past and current use of it, and if they would like to use it (yes or no).

Frequency distributions were computed to characterize the rates of awareness, use, and interest for each service and device. One-way analyses of variance (ANOVAs) determined whether the use of a resource was related to the severity of the participants' visual impairment.

Results

The average age of the sample was 82.5 years (*SD* = 5.2); 70% of the participants were female, and 99% were Caucasian. The mean number of years of education was 12.4 (*SD* = 2.5). Almost half the participants (46%) were married, and 36% were living alone. The majority (94%) had bilateral AMD. The mean visual acuity of the better-seeing eye was .70 (*SD* = .54); a LogMAR of .70 corresponds to an acuity of 20/100. The average duration of AMD was 3.9 years (*SD* = 3.9 years).

Table 1 shows the rates of awareness and use of and interest in each service and device and demonstrates two important findings. First, awareness and use rates were low relative to the high rates of expressed interest. For example, although only 24% of the participants knew of low vision rehabilitation, 83% expressed their desire to receive this intervention. Second, although more than 80% reported using a magnifier or telescope, only 6% had magnifiers that were prescribed by an ophthalmologist or optometrist; most had purchased their devices at a pharmacy or obtained them from relatives.

We next examined whether the use of devices and services was related to the severity of the participants' vision loss. We grouped the participants according to whether the acuity in their better-seeing eye was above the median for the sample (20/70). Using this criterion, we found that 32 (40%) participants had "better" vision, and 48 (60%) had "worse" vision. For each participant, we computed the number of low vision services and devices that he or she used. A one-way ANOVA with better versus worse vision as the grouping variable indicated that those with worse vision used more

services and devices. The average number of services and devices for the worse group was 5.3 (*SD* = 3.8, range 0-15), compared to 2.6 (*SD* = 2.0, range 0-9) for the better group [*f* (1,79) = 13.9, $p < .001$]. A series of chi-square analyses determined which services or devices were more likely to be used by those with worse vision. Because of the large number of statistical comparisons, alpha was set at ≤ .002. The results indicated that those with worse vision were more likely than those with better vision to use magnifiers (96% versus 62%, $p = .002$).

Discussion

The results of this study confirm the findings of other studies that have demonstrated low rates of use of services and devices by older people with low vision. However, a large percentage of older people with low vision want to use low vision resources but are unaware of them (Lighthouse International, 1999). This finding suggests that health care professionals may either be unaware of rehabilitation options or fail to discuss them with their patients for other reasons. Although the participants with worse vision appeared to use more resources, the overall rates of usage were low even in this group. This situation is unfortunate because low vision rehabilitation can lead to the better-informed use of optical devices, a faster reading speed, and an enhanced mood (Horowitz, Reinhardt, & Travis, 2003; Raasch, Leat, Kleinstein, Bullimore, & Cutter, 1997).

All the participants were aware of magnifiers, and most (80%) were using them. However, few had prescription magnifiers, which calls into question whether they were using the best possible magnification for them. Only 13% had ever seen a low vision optometrist. That 83% of the

participants expressed a desire for low vision rehabilitation indicates that, with proper education and referrals, many could benefit from this intervention.

This study indicates that people with AMD are underutilizing available rehabilitation interventions that hold the promise of improving their visual function and quality of life. Efforts to educate them about available resources need to be increased, and removing obstacles, such as reimbursement and transportation issues, are needed as well. What is perhaps most important is that increasing ophthalmologists' awareness of the value of rehabilitation treatments and of their patients' desire to use them may be the first step in this process.

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