Barriers to Vision Rehabilitation: A New Starting Point

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Abstract. It is generally accepted that only a small proportion of visually impaired people receive rehabilitation services that may greatly enhance their level of functioning and, consequently, their quality of life. Access to vision rehabilitation may be impaired by a variety of barriers, including lack of referral, inability to access services due to lack of transportation, and resistance in seeking help from agencies that provide services to "blind" people. Previous studies examining impediments to vision rehabilitation have generally fallen into two categories: (1) those that survey professionals, such as ophthalmologists and optometrists, regarding referrals to low vision clinics or full-service agencies and (2) those that are based on large surveys, typically by telephone. The response is used to estimate the number of visually impaired people in the population and subsequent questions may address the issue of service accessibility. The Montreal Barriers Study begins the data collection process at the point of potential referral to rehabilitation services and is exclusively gathering information from visually impaired individuals who are eligible for these services.

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1. Introduction

It has been shown that individual characteristics, such as visual impairment, are often the stumbling blocks in health-service access (Gutman, Milstein, Killam, Lewis, & Hollander, 1993). If vision impairment is a barrier to successfully gaining access to health services, then access to vision rehabilitation becomes an important issue to examine thoroughly. In Western countries, such as Canada, the vast majority of people who are visually impaired are elderly (Elliott et al., 1997; Fine, Berger, Maguire, & Ho, 2000; Kirchner, 1995). This creates a population with a “double vulnerability” – people who are elderly and who have a significant sensory impairment and are, therefore, at high risk of developing disability (Dahlin-Ivanoff & Sonn, 2004). Considering that the number of Canadians over the age of 65 will increase from 2.4 million in 1981 to between 4 and 5 million by 2021, a concomitant significant increase in the number of visually impaired Canadians will also occur (Elliott et al., 1998). Disturbingly, fewer than 10% of older people with a self-reported vision problem are availing themselves of any form of vision rehabilitation service. Only 30% report using an optical device (such as a magnifier or telescope), 21% use large print materials, and less than 5% use other technical aids such as talking books and talking clocks. The findings are especially worrying given the results from research showing that older people with low vision place high value on low vision rehabilitation services to assist with acquiring devices and integrating them into daily routines (Copolillo & Teitelman, 2005).

Access to vision rehabilitation may be blocked by a variety of barriers. A recent nation-wide study of the needs of people who are blind or visually impaired provided substantial data on barriers to vision rehabilitation service (CNIB, 2005). Almost one third (28%) of seniors reported that they “don’t know how to find them”. The next largest number of study participants (17%) judged that services are too far away, and transportation is a barrier to them. A smaller percentage (13%) stated that the services had not been suggested to them. The last point is important to consider because it reflects a lack of proper advice and referral from primary eye-care providers.

There are, no doubt, a number of reasons that lead to optometrists’ and ophthalmologists’ failure to refer their patients to low vision clinics or to full-service agencies for a comprehensive program of vision rehabilitation. In one study, when presented with the scenario of visual loss secondary to age-related macular degeneration, ophthalmologists substantially underestimated its effect on patients’ quality of life (Brown, Brown, & Sharma, 2000). In 2002, a survey examining the prevalence of visual impairment and utilization of rehabilitation services in Quebec determined that only 20% of potential clients ultimately received available services (Gresset & Baumgarten, 2002). The research indicates that, to a large extent, elderly visually impaired people are left to their own devices by eye-care specialists when it comes to finding and accessing vision rehabilitation services (Gresset, Jalbert, & Gauthier, 2005).
Barriers to accessing low vision services were also identified in an Australian study (Pollard, Simpson, Lamoureux, & Keffe, 2003). It was found that lack of referral was a major problem, as was the lack of understanding of available services by the potential clientele and by the general public. Some of the focus-group members in this study simply did not consider themselves to be visually impaired and, therefore, not in need of services. There is also evidence that related service-providers, such as agencies for the aged either are unaware of or do not effectively interact with agencies that provide services to visually impaired seniors (Biegel, Petchers, Snyder, & Beisgen, 1989). As was already noted, many factors may influence the disparate access to health services in general by various sectors of the population. These same factors are often implicated in unequal access to vision rehabilitation services. As an example, Bau (1999) noted the special needs of people from cultures outside of the mainstream and the responsibility of service providers to remain sensitive to cross-cultural differences in planning appropriate rehabilitation programs. In such situations, not only is good communication absolutely crucial, it is equally critical to recognize that everyone’s goals in vision rehabilitation programs may not be identical. Service providers must recognize that not everyone seeks to become totally independent, that different health beliefs and practices may lead to different perspectives on disability, and that family involvement in the rehabilitation process may have different meaning across cultures (Bau, 1999). Clearly, there is a risk that rehabilitation services themselves may unknowingly create barriers for their intended clientele.

The present study investigated the factors that prevent older people from obtaining rehabilitation services and making informed decisions about the use of assistive devices. As in general health disparities, it is important to examine the chain of events associated with environment, access (to, utilization of, and quality of care), and health outcome (Carter-Pokras & Baquet, 2002). It is expected that the research will identify opportunities to improve seniors’ access to low vision rehabilitation services and assistive devices and, therefore, reduce their vulnerability to adverse health outcomes.

A substantial amount of effort has already been expended toward developing rehabilitation services for visually impaired seniors, assessing their effectiveness, and examining problems that are encountered in this area of health-service delivery. Nonetheless, many issues remain unresolved and the current state of knowledge is based, to a large extent, on methodologically limited studies. Stelmack and her colleagues (2002) point out, for example, that the value of vision rehabilitation is often judged on the basis of anecdotal reports. Much research in this domain, including a recent study by the Canadian National Institute for the Blind (CNIB, 2005) provides valuable information regarding gaps in health policy relating to visual impairment, the need for better inter-disciplinary collaboration and improved promotion of rehabilitation services. This bank of knowledge serves as a solid foundation for further studies, but in itself, it is often qualitative in nature and based on small samples. The present study addressed several of the information gaps that remain regarding access to vision rehabilitation services by elderly people.

The basic premise of the study was that barriers to adequate vision rehabilitation can be external, such as lack of referral or problems with transportation, or they can be personal characteristics of the individual, such as poor coping skills or depressive symptoms. The first goal of the study was to identify, in a large and diverse sample of visually impaired people, the barriers encountered in access to vision-rehabilitation services. The second goal was to identify particular characteristics of these individuals through the interview process and through several psychosocial measures, in order to ascertain whether there exist particular differences among the groups of individuals who were not referred, those who were referred but did not avail themselves of services, and those who did receive services. For the purpose of this paper, we will focus on demographic data only.

2. Method and Results

Over a period of 12 months, more than 14,000 patient files were reviewed in four urban university-affiliated ophthalmology departments (SMBD Jewish General Hospital, Royal Victoria Hospital, Montreal General Hospital, Hôpital Notre Dame). Potential participants were identified on the basis of their file information or by the staff as meeting the definition of Visual Handicap, based on the definition by the Quebec Ministry of Health (best corrected visual acuity of less than 20/60 in the better eye or visual field limited to less than 60° in the better eye). Of the charts reviewed, 1,343 (approximately 10%) patients were eligible for low vision rehabilitation services. Categorizing these individuals by their visual acuity indicated that 725 (54%) had mild visual impairment (better than 20/200), 333 (25%) had moderate loss (20/200 to > 20/400) and 285 (21%) had a severe impairment (< 20/400).

To date, 411 participants (age 26 – 100, mean = 75) have been recruited into the study. The sample consists of 184 men (45%) and 227 women (55%). They completed a semi-structured interview, including a demographics questionnaire, as well as the following psychological measures, which have all been validated in English and French: (1) Visual Function Index (VF-14) (Gresset, Boisjoly, Nguyen, Boutin, & Charest, 1997; Steinberg et al., 1994), (2) Satisfaction With Life Scale (SWLS) (Blais, Vallerand, Pelletier, & Briere, 1989; Diener, Emmons, Larsen, & Griffin, 1985), (3) Brief COPE (Carver, Scheier, & Weintraub, 1989; Muller &
Spitz, 2003), (4) Center for Epidemiologic Studies – Depression Scale (CES-D) – Short Form (Andresen, Malmgren, Carter, & Patrick, 1994; Radloff, 1977). For the purpose of the present paper, only demographic data will be considered.

The central question at the beginning of each interview was whether the participant had ever heard of visual rehabilitation and, if so, whether he/she chose to utilize these services. Based on the yes/no answers to these items, participants were divided into three awareness groups: 1) those who had never heard of rehabilitation services, 2) those who knew about it but chose not to go, and 3) those who were aware and had availed themselves of rehabilitation services. Of the 411 participants, 119 (29%) were unaware of rehabilitation service, while 53 (12.8 %) were aware but chose not to avail themselves of these services. Only 239 (58.2 %) took advantage of Low Vision rehabilitation. Overall, 71% or participants had knowledge of vision rehabilitation services. However, these individuals had not necessarily been informed by their ophthalmologist but, rather, had gained their knowledge through peers or family members. The demographic variables indicated that persons with more severe visual impairment were more likely to have been informed about vision rehabilitation and had more likely accessed these services (see Figure 1).

Figure 1. Percentage of participants according to their level of visual impairment (VI) across three groups of awareness of vision rehabilitation services. Individuals with more severe impairment were more likely to know about rehabilitation and have accessed this resource.

Not surprisingly, those who had experienced the symptoms of their visual disorder for a longer period were also more likely to be aware of rehabilitation services and to have utilized them. It was interesting to note that a number of demographic variables were unrelated to the level of awareness regarding services nor to their usage. These included characteristics such as age, gender, education, income, and employment status. Finally, the distance between the individual’s home and the rehabilitation agency influenced neither the ophthalmologists’ referrals nor the patients’ decisions to take advantage of these services.

4. Conclusion

Generally, patients’ awareness of rehabilitation services was surprisingly high. However, this distribution is unlikely to be representative of the general population because these participants were already engaged in the medical system and were receiving regular eye-care within a hospital clinic. Furthermore, there is a Low Vision Clinic in two of the hospitals where the majority of the data have thus far been collected (JGH and HND). It is a reasonable assumption that the ophthalmologists in those departments would be more likely to refer patients to a colleague (literally down the hall) than they might have been otherwise. Even under these circumstances, the pattern of awareness clearly demonstrated a bias toward referring individuals with more severe impairment. This finding generally supports the anecdotal evidence that ophthalmologists tend to refer their patients for rehabilitation services only after these individuals have already lost a substantial amount of vision. This, in turn, may have significant implications on patients’ potential success in rehabilitation.

The observed pattern of service utilization may be due to several factors, such as biased referral by the eye-care professionals, perceived need of rehabilitation by the patient, stigma attached to services for the “blind”, personality profile of the patient, available social support, and possible other factors. It is important to note that the cost of services is not one of the barriers in Quebec, because the Ministry of Health covers all expenses...
associated with assessment, training and provision of assistive devices. Further data analysis will take additional variables into account, such as cultural identity, financial background, etc.

At present, it is clear that a substantial number of visually impaired people do not receive rehabilitation services in a timely fashion. In this field, it is generally accepted that, the earlier in the process of losing one’s vision a person begins rehabilitation, the higher will be the likelihood of a successful outcome. In point of fact, although this is an intuitively reasonable notion, there is scant substantiating evidence for this claim, leading to the need for well-designed and well-run studies on this important issue. Nevertheless, the clinical impressions of rehabilitation specialists concerning timely intervention should be seriously considered in the meantime and eye-care providers should be encouraged to improve their referral patterns when working with this vulnerable population.

References


