Barriers to Vision Rehabilitation: A Qualitative Approach

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Abstract. The objective of this study was to better understand the factors that influence the awareness of low vision rehabilitation in adults who have an untreatable vision loss. Previous studies have demonstrated that vision rehabilitation programs increase social participation levels of individuals with low vision, decrease their dependence on family members, and decrease health care costs created by secondary and tertiary disabilities. Although adults with low vision place high value on these services, disturbingly few actually employ rehabilitation. For this study, we conducted focus-group discussions to explore the individualized experiences and perspectives of adults who have low vision and who have entered the health care system. We conducted four audio-recorded focus groups, each lasting approximately 90 minutes in duration. All participants had a visual acuity of less than 20/60 in the better eye with best standard correction and were fluent in English. Each focus group had approximately four participants, and at least one participant from each of the following distinct rehabilitation-referral categories: a) people who were unaware of low vision rehabilitation; b) people who received a referral for rehabilitation, but did not initiate the process; and c) people who received a referral, and went for low vision at rehabilitation. The focus group questions probed issues such as: how participants initially learned of rehabilitation services, what obstacles prevented them from gaining this knowledge, and what could be done to improve awareness of rehabilitation services. The focus group transcripts were prepared and transferred onto Atlas-ti 5.0, a software program designed for the analysis of large bodies of textual material. The data were analyzed using a constant comparison approach to content analysis. This paper summarizes the salient obstacles to the awareness of low vision rehabilitation services and reflects upon the implications for individuals with low vision. Specifically, the importance of peer support, psychological readiness and independent accessibility are discussed.

Keywords: Barriers, Rehabilitation Services, Access, Qualitative Research;

1. Introduction

Even though vision rehabilitation services are widely available in Quebec and the expense is covered by the Régie de l'assurance maladie du Québec, not every eligible person with visual impairment avails themselves of this opportunity. Recently, the Canadian National Institute for the Blind (CNIB) reported that only 28% of surveyed seniors knew how to access vision rehabilitation (CNIB, 2005). Furthermore, 17% indicated that travel distance to the service delivery agency posed a problem for access. In the Province of Quebec, it is estimated that only 20% of eligible clients actually access rehabilitation (Gresset & Baumgarten, 2002). Their awareness of these services was generally low and eye-care professionals were not always supportive in the patients’ quest for additional information (Gresset, Jalbert, & Gauthier, 2005), a finding that has been reported previously on the national level as well (Gold, Zuvela, & Hodge, 2006). These numbers are comparable to a population-based study conducted in West Virginia, USA, in which only 19% of individuals with low vision symptoms were aware of vision rehabilitation, with only 12% having received these services (Walter, Althouse, Humble, Leys, & Odom, 2004).

Frequently, research into barriers to rehabilitation access is quantitative in nature, whereby eye-care professionals are surveyed about their referral pattern, or clients at rehabilitation agencies are interviewed about possible barriers they experiences, now that they have overcome them (Adam & Pickering, 2007; Gold et al., 2006; Keeffe, Lovie-Kitchin, & Taylor, 1996; Koenekeop & Gomolin, 1995; Overbury, Jackson, & Santangelo, 1987; Sundling et al., 2007). However, very little work has been done from a qualitative perspective. In Australia, Pollard et al. (2003) conducted focus group interviews with 17 individuals, ranging in age from 25 to 88, about issues relating to access barriers. The main topics that emerged were general perception of rehabilitation, overcoming distance and travel to services, and interaction with eye-care professionals as well as service agencies. The authors describe problems with identity, whereby individuals affected with partial sight-loss did not consider themselves “blind” and were reluctant to utilize services that seem geared towards the severely impaired. In addition, the topic of transport to the service agencies was repeatedly mentioned, whereby especially older individuals reported difficulties traveling independently due to fear of getting lost.

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Furthermore, communication problems with eye-care professionals were reported by the focus-group participants; generally, information was not made available or was provided late in the referral process, at the point where “nothing more could be done” from the medical perspective.

One particular point of interest in the study by Pollard et al. (2003) was that the initial goal of participant recruitment was to identify persons with low vision who had not accessed rehabilitation services. However, the authors were only able to recruit five such individuals, even though announcements had been made over a local radio station. The present study included participants from three awareness groups, including those that had accessed rehabilitation services, those that were aware of them but chose not to take advantage of these services, and those who had never heard of low vision rehabilitation. The goal was to expand on the findings by Pollard et al. (2003) and to investigate the perspectives of barriers to vision rehabilitation access among these three awareness groups.

2. Method

The study received ethical approval by the Institutional Review Board of the SMBD Jewish General Hospital, Montreal, Canada. Four focus groups were conducted between September and December 2007. A total of 14 individuals participated, ranging in age from 38 to 92. All participants had been recruited as part of an ongoing larger study focusing on barriers to rehabilitation access in the greater Montreal area. After written consent was obtained, the focus groups were audio-taped and then transcribed and analysed using thematic analyses and Atlas-ti 5.0, a software program designed for the analysis of large bodies of textual material.

3. Findings

Preliminary analyses of the focus group transcripts reveal three important themes: barriers inherent to health care delivery; barriers borne out of situational aspects of daily living; and barriers associated with vision loss stigma. In the present section, we describe and present examples of these themes. First name pseudonyms have been used to protect confidentiality.

Barriers related to health care delivery – In each focus group there were lengthy discussions about failings of vision health care delivery that created obstacles to patients taking up rehabilitation services. For example, some participants described how they did not understand the long-term consequences of their particular vision impairment and that this delayed the search for help.

Stella: I didn't realise really at the time the consequences. I wasn't prepared for it. I didn't realise that I could lose the vision in my eye. I thought that it would just make it worse, and my glasses would be bigger and that is it. Usually I look after myself very much.

Other participants implied that optimism about planned (or prospective) medical interventions and subsequent improvements in functional vision could delay or impede seeking help for low vision problems.

Stephen: They tried to talk to me. One young lady, I have her name, but I do not remember it, she told me lots of things. She was well educated. Maybe she understood me better than anybody else. [...] she tried to help me, but I said, “I'm going to try. I am going to go to Europe and I'm gonna go to the United States.” I went to Chicago. I was ready to go to Russia once, because I heard that they have artificial cornea.”

Many participants stated that ophthalmologists are simply too busy to advise patients about rehabilitation services. Their workload, however, is not a reasonable (or acceptable) excuse for a failure to provide the necessary information about rehabilitation services.

Laura: It was very hard for me because I know that he is a very very good doctor, but it is not the patient's fault if you have 150 clients a day. [W]e have a right to ask you some questions. And to get a response.

Stella: [If I could start over] I would talk to them. I would see my doctor. But my doctor is so busy. That is the problem they are so busy. They don't have time.

Other participants were bitter about the vision health care provided by their ophthalmologist. According to these participants, it is the doctor's responsibility to pass on all information about available services.

Natasha: I know now. I only found out recently. But I have been here for 30 years and no one ever told me... to be here for 30 years and not know that there is a low vision clinic. I was shocked when I found out. Where is it exactly? I still don't know where it is. Is it on this floor? Do patients actually go there and use it?

In general, the vast majority of participants felt that their healthcare professionals could do a better job informing their patients about rehabilitation.

Barriers that arise in situational aspects of daily living – A second theme that arose from the focus group discussions centred on personal and situational aspects of daily living that created barriers to taking up low vision rehabilitation. For example, many participants did not seek help (or had delayed help-seeking) because
of a perception that they were actually functioning well. These individuals seemed to be extra resourceful and more open to ask for help from strangers when necessary.

**Natasha:** I was in the mindset that my husband will take care of everything. I am in my little square. I am comfortable. I want to stay there... I think I was happy at the time... I didn't have to go out... I think in my case family members are the last ones to recognize my disability. Because they don't see that I'm blind. Because at home, I am very functional. I am running around everywhere. I know where everything is.

In addition, many participants spoke of debilitating psychological and emotional responses to the “loss” of independence and autonomy.

**Laura:** I am going to be 77 years old. I had my eyesight for 76 years. And now I lost it, I am losing it. And when I found out I felt like my whole world was crumbling underneath me.

**Stephen:** Listen. Take a bird. Put it in a cage in your house. One day, cut its wings, and tell it “fly”. That is the way that I was feeling.

The participants made it clear that during these times of upset that they were not going to initiate or be receptive to the prospect of rehabilitative services.

**Barriers related to the stigma associated with vision loss** – The final theme that arose from the focus groups centred on propensity (or not) to reveal vision loss to other people. Many participants described how they concealed the vision loss to protect their pride.

**Stephen:** I try to cover, you know. Everything I tried to cover. I don't know if I am wrong or right. I tried to cover my problem. To hide my problem I should say.

**Stella:** I couldn't go to my sporting club any more, mostly because I didn't want the pity of the people that I knew. And I didn't want them to be saying “the poor lady. The poor woman”.

**Stephen:** My problem is, some times when I go into the street I will go on the sidewalk. Let's say I have my wife beside me. So when we go from the sidewalk to the street, there is a little step there. Sometimes she tries to help me. I say, “Don't even touch me.” I taught her to go a step ahead of me, so that when I see the body go like this [his wife's body going down] I am going to do the same. Lots of times I bump into the sidewalk or other things. But especially, I don't want her to say to me, in front of other people, “Watch your step.”

Other participants indicated that there is a transitional period (or a process) whereby it takes time before a person with vision loss is prepared and comfortable to use adaptive aids or to ask strangers for help.

**Laura:** Two years ago at Rosh Hashanah, I am going to make my order for the holidays... And there was going up and down the aisles and I was getting more and more frustrated and I was breaking out in a sweat because [...] 90% of the time the stuff that you need is either way up there or way down there. And it took me about an hour and a half to pack maybe 10 objects. I said “I am not doing it.” [...] I left my cart. And as I was ready to leave [the store], but I said to myself “Put your pride in your pocket and go over and speak to the manager.” And I did. And I told him how I liked the store... And he said, “I want you to know that any time you come in here and you are having a difficult time, you just come to the front cash and I will send someone to help you pick your products.” and he gave me somebody to go with me to finish up the rest of my order... and now I don't hide it. I tell everybody that I'm visually impaired. And you'd be surprised what good help it is.

**Stella:** I have never tried to ask anybody for help... I can't bring myself to do it.

Other people who were aware of low vision rehabilitation services decided not to access or follow-up because they were functioning well or because they had other priorities.

4. Discussion

Relatively few adults access low vision rehabilitation services (Gresset & Baumgarten, 2002). In order to best serve the needs of adults with low vision, a better understanding of the barriers to access is required. Pollard et al. (2003) reported obstacles to low vision rehabilitation associated with transport, doctor-patient consultations as well as participant fear of being perceived as blind. In general terms, this study substantiates the findings of Pollard et al., and provides a special focus on vision loss disclosure.

The present focus groups found that ophthalmologists could improve upon basic communication with their patients. This result has been reported elsewhere (O'Day, Killeen, & Iezzoni, 2004). When consultations are less than five minutes in duration, after medical procedures have been completed, there remains little time for questions. However, what is more troublesome are complaints that hospital staff are not demonstrating basic respect to patients. It is not implausible to suggest that this could also serve as a barrier to rehabilitation.

Interestingly enough, transportation did not come up as a major barrier theme in the present study. Numerous studies have reported that physical access serves as a barrier to rehabilitation services (Pollard et al., 2004; O'Day et al., 2004). Although the Montréal transit commission might take this as a compliment and attribute this to outstanding facilities and service, perhaps it is also a reflection of a dense metropolitan city where it is easier to get from Point A to Point B.
Finally, it is interesting to note differences in the “identity” theme described in Pollard et al. as opposed to those in the present study. While the identity issues discussed in Pollard are primarily associated with the label of blindness, the discussion in the present focus groups centred on symbols of vision loss (e.g., white cane) and vision loss disclosure. The stigma literature suggests that disclosure of stigma is dependent upon personal and situational factors and is, in large part, determined by the extent that a person buys into prevalent stereotypes. For example, one is likely to be more inclined to acknowledge and disclose their vision loss to others if they have accepted their vision loss and incorporated this “difference” into their self-identity. This point is perhaps best expressed in a poem that the participant Natasha shared, entitled In my eyes only: coming to terms. The poem presents “I”, the Natasha with normal vision whom she introduces to strangers; and “me”, the Natasha with vision loss that she keeps hidden. The following are three excerpts from this poem: 1) Natasha’s reflecting on an encounter when a stranger helped her cross the street; 2) Natasha’s realization that concealing her vision loss was self-destructive; and 3) Natasha coming to terms with the symbols of vision loss and disclosure.

I feel uneasy and unsure. What did you think of me? Did you think that I was drunk, or perhaps clumsy or afraid? If we ever meet again, will I recognize your face? Will you even want to acknowledge that we ever met?

In my attempt to feel assimilated, and not stand out as being different from others (visually impaired) I was responsible for my feeling different by not accepting the invisible part of me, the disabled me - the true me, the me I kept hidden for no one else to see.

I feel different now you see. I am not alone anymore. I have a friend. A friend who identifies me - the me I kept hidden from thee. The friend I refer to is always in my right hand. My white cane is my friend - it makes me feel different. As you now can see - I am visually impaired - my friend acknowledges this to thee. No more second guessing, no more assumptions, no more presumptions. I am just like you, as you can see. The only difference - is my friend that is always with me. A friend who identifies me.

These reflections provide vital clues of the vastly complex adaptations people bear when they acquire a progressive vision loss. Although there are some applicable theories and conceptual models on stigma from social sciences (e.g., Major & O'Brien, 2005) to our knowledge very few (or zero) studies specific to low vision have been conducted. Vision loss disclosure offers an exciting and intriguing opportunity for future research.

References


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Financial Support

Graduate Student Fellowship support to KS was provided by the Fonds de la Recherche en santé du Québec (FRSQ, # 10268) and the Canadian Institutes of Health Research (CIHR, STP # 53875). Graduate Student Fellowships to WW were provided by the Canadian Institutes of Health Research (CIHR, STP # 53875). The Réseau Vision of the Fonds de la Recherche en santé du Québec (FRSQ, # 9745), as well as the McGill Tomlinson Foundation and the Canadian National Institute for the Blind (CNIB).