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Longitudinal measurement of the older patient's vision-related quality of life

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CHAPTER 8

Evidence-based outcomes

This chapter is a summary and adaptation of a systematic literature review:
Langelaan M, van Nispen RMA, van Rens GHMB.
Multidisciplinary rehabilitation and monodisciplinary rehabilitation for visually impaired adults.
Cochrane Database of Systematic Reviews 2007, Issue 2.
Publication of protocol, 2007; systematic review accepted pending revisions, 2009.

Abstract

Objective: To assess the evidence for vision rehabilitation programs in improving quality of life of visually impaired adults.

Method: Several large literature databases were searched until April 2008, i.e. MEDLINE/PubMed (from 1966), EMBASE, CENTRAL, CINAHL and PsycInfo (from 1980). To find additional trials, reference lists, journals (not in databases) and conference proceedings were manually searched. (Quasi-) randomized controlled trials (RCTs) were included. Two review authors independently extracted data and assessed trial quality.

Results: Twelve papers reported on effectiveness of vision rehabilitation programs in improving quality of life according to the RCT standards. The 12 papers were categorized into three groups of related intervention types: i) 'Educational group programs' tended to be preferable over individual programs or no treatment. ii) Some 'enhancing vision methods' were effective: adaptation of lighting, and conventional rehabilitation. iii) In two studies, comprehensive 'vision rehabilitation programs' were found to be effective for outcomes related to quality of life.

Conclusions: The evidence from RCTs that already exists does support the positive effect of rehabilitation on vision-related quality of life. However, this evidence is based on single studies, and the results should be confirmed in other studies. The complexity and diversity of patients' needs makes it necessary to adapt any rehabilitation program to individual patient profiles. Research should be conducted on prognostic factors to develop those patient profiles for specific rehabilitation programs. Not all improvements remained stable at long-term follow-up. This indicates the need for (better) aftercare programs or clinical follow-up of patients.

Background

In clinical practice, it is often suggested that the need for rehabilitation programs for visually impaired adults is self-evident. However, in order to develop an understanding of most effective health-care interventions for visually impaired patients, and to work towards the development of integrated and effective care, it is necessary to draw on all forms of relevant scientific evidence. An important reason for measuring health-related quality of life, also in low-vision rehabilitation, is the growing interest of governments and health-insurance companies in these outcome measures as parameters for quality of care^{1,2}. The increase in attention for the concept of vision-related quality of life has led to the publication of several studies. However, quality of life has not often been used to estimate the effect of visual impairment rehabilitation. Hence, a literature review based on the Cochrane methodology for systematic reviews was performed to find evidence for the effectiveness in randomized clinical trials (RCT) for various rehabilitation programs in improving quality of life of visually impaired adults.

The general objective of this review was to assess the effectiveness of monodisciplinary and multidisciplinary rehabilitation programs in improving (vision-related) quality of life in visually impaired adults.

Method

Electronic literature searches were performed in MEDLINE/PubMed (1966 to April 2008), EMBASE (1982 to April 2008), CENTRAL (1980 until April 2008 Issue 2, 2008), CINAHL (1982 until April 2008) and PsycInfo (1980 until April 2008). Reference lists of relevant articles; the Journal of Visual Impairment & Blindness, Visual Impairment Research and several proceedings of conferences were searched manually to find additional trials. Two review authors (M. Langelaan and R.M.A. van Nispen) independently extracted data and assessed trial quality of (quasi-) randomized controlled trials. The electronic search yielded 1,813 reports of trials. Based on titles, abstracts and the manual search, 37 full copies of articles were obtained for further assessment. In addition, after the search was completed, another trial which was published in May 2008 came to our attention. Consequently, 12 studies were included in the review and were categorized into three groups according to the interventions which were assessed: (i) Educational group programs (n=5); (ii) Methods of enhancing vision (n=3); (iii) Vision rehabilitation programs (n=4). Data-pooling was not possible because of incomparable interventions and outcome measures.

Results

In five papers the effect of 'Educational group programs' was described. In 1999, Brody et al. conducted a pilot study in which 92 older patients (mean age 79) with age-related macular degeneration were randomized to a self-management intervention or to a waiting-list. The group support program was based on social-cognitive theory and knowledge of the psychosocial impact of age-related macular degeneration on the daily lives of patients³. Subsequently, another randomized trial was performed to evaluate the effectiveness of the intervention in a larger population in comparison with two control groups, consisting of a tape-recorded education program and a waiting-list (n=252; mean age 81)⁴. The focus of this study was on mood and on the effects of the intervention on everyday functioning. Outcome was assessed immediately after finishing the intervention⁴ and at six-month follow-up (N=214)⁵. Participants reported less disability, improved mood and self-efficacy, less depression, and a small improvement in quality of life immediately after completing the self-management program. However, the disability effect was not seen at six-month follow-up, except for mood and self-efficacy indices. In the studies by Dahlin-Ivanoff et al. (2002) and Eklund et al. (2004) from the same trial^{6,7}, the goal was to investigate the impact of a health education program on perceived security in the performance of daily occupations. They used a problem-solving model as the basis for their health education program "Discovering New Ways". The control group received an individual intervention. They found an improved level of perceived security for the health education group in several occupations at the four-month evaluation (n=253; median age 79)⁶. Eklund et al. (2004) found comparable results at the 28-month evaluation (n=229), indicating long-term stability of the improvement of perceived security in daily activities after following a health education program⁷.

Three studies contained 'Methods of enhancing vision'. Reeves et al. (2004) compared the effectiveness of conventional low-vision rehabilitation with enhanced low-vision rehabilitation after one year (n=226; median age 82). Conventional low-vision rehabilitation was provided by optometrists working at the hospital eye service who prescribed low-vision aids. The intervention components for enhanced rehabilitation were the same except for an additional up-to-three home visits by a trained rehabilitation officer. A second control group was an enhanced-intervention controlled for additional contact time by a community care worker. They found few significant differences in quality of life outcome between the three study-arms; where differences were observed, these tended to favor conventional low-vision rehabilitation⁸. Brunnström et al (2004) compared additional lighting adjustments in the living room compared to no additional lighting adjustments (n=56; mean age 76). Quality of life improved for the lighting adjustment group at six-month follow-

up⁹. In the study by Smith et al (2005), two different prism spectacle groups were compared to a placebo prism matched in weight and thickness (n=243; median age 81). Prescription of prism spectacles was effective to improve reading skills, but not necessarily to improve quality of life¹⁰.

Finally, four studies assessed 'Vision rehabilitation effectiveness'. In the study by Griffin-Shirley (1994), a community or center based rehabilitation training for patients with macular degeneration was compared with a control group that received no training (n=38; mean age 75). After 15 months, the confidence level of performing ADL-tasks was assessed, but no significant difference was found between groups¹¹. McCabe et al. (2000) assessed the effects of vision rehabilitation using optometry, occupational therapy and social work services on functional ability and assessed the effects of involving families in the intervention (n=97; mean age 69; median 76). They compared pre- and post rehabilitation and found decreased dependency levels in older patients, but found no differences between groups¹². Pankow et al. (2004) found that participants (mean age 79) who received a comprehensive rehabilitation program (n=15) experienced a better psychological well-being and performed more independently on living skills after treatment than in a no treatment group (n=15), but they performed equally independent on orientation and mobility skills¹³. Finally, in a multicenter RCT, the Veterans Affairs Low Vision Intervention Trial (LOVIT) by Stelmack et al. (2008), 126 primarily male patients were either referred to an outpatient low-vision program or a waiting-list control group (mean age 79). The low-vision program consisted of a low-vision examination, counseling, prescription of low-vision aids and 6 weekly sessions by a low-vision therapist to teach the use of assistive devices and adaptive strategies to perform daily living tasks independently. The treatment group demonstrated significant improvement at four-month follow-up in visual reading ability, mobility, visual information processing, visual motor skills and overall visual function¹⁴.

Discussion

The systematic review revealed a relatively small number of papers in which the effectiveness of vision rehabilitation programs in improving quality of life was investigated according to the RCT standards. The methodology of the trials did not meet the criteria for high quality: There were problems with some of the RCTs with respect to allocation concealment, the randomization method, masking of outcome assessors and participants, and small sample sizes. All included studies were conducted in Western industrialized countries (Sweden, USA and United Kingdom), which may diminish generalizability. Some studies were difficult to evaluate because of inadequate or incomplete reporting, or lack of a real control group. Although

control groups may be considered unethical, because patients are withheld from a rehabilitation program, it seems to be the only way to prove the effectiveness of rehabilitation. Some argue that it may be more unethical to provide a rehabilitation program without knowing the effectiveness of this service¹⁵. A pragmatic solution would be to use waiting-lists, which was done in some studies. Then, rehabilitation is not denied, but provided in a later stage after the study. Another solution would be to use a cross-over design. Some studies performed their follow-up measurement immediately after finishing the intervention, which may increase the probability of a halo effect¹⁶, which means that people may overestimate their ability to perform skills that were taught to them in the relatively 'safe' environment of the rehabilitation center. Data-pooling was not possible, because of incomparable interventions and outcome measures. This resulted in that evidence for specific interventions is based on single studies.

Replication of RCTs and more quantitative outcomes of rehabilitation are needed to identify which programs are most successful and useful. Such results would help rehabilitation workers in choosing appropriate programs or to adjust existing ones. However, the 12 studies that were included in the review can be considered a good start of obtaining scientific evidence for low-vision rehabilitation. In the Netherlands at the ophthalmology department of the VU University Medical Center Amsterdam together with regional low-vision rehabilitation services (Sensis, Visio and Bartiméus), an RCT is currently conducted to determine the effects of training by using a new standardized protocol for low vision patients who learn how to read and work with a CCTV. The treatment-arm consists of a CCTV-training given by occupational therapists in the home-environment of the patient; the control-group is a waiting-list for three months. Outcome measures are (vision-related) quality of life, in addition to visual reading ability and other skills that are needed for using a CCTV.

Finally, the complexity and diversity of the needs of usually older patients makes it necessary to adapt any rehabilitation program to individual patient profiles. Research should be conducted on prognostic factors to develop those patient profiles for specific rehabilitation programs. Moreover, not all improvements remained stable at long-term follow-up. This might indicate the need for (better) aftercare programs or clinical follow-up of patients. In addition, cost-effectiveness of separate parts of the rehabilitation process has to be taken into account in future studies. It is considered unethical to spend many resources on an ineffective rehabilitation program, where more benefits could be obtained from other programs.

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