

# Psychologic Adjustment to Irreversible Vision Loss in Adults

## A Systematic Review

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**Purpose:** To summarize relevant evidence investigating the psychologic adjustment to irreversible vision loss (IVL) in adults.

**Design:** Irreversible vision loss entails a challenging medical condition in which rehabilitation outcomes are strongly dependent on the patient's psychologic adjustment to illness and impairment. So far, no study has systematically reviewed the psychologic adjustment to IVL in adults.

**Methods:** We reviewed all articles examining the psychologic adjustment to IVL in adults. We included articles published in English in peer-reviewed journals. We performed a keyword literature search using 4 databases (PubMed, EBSCO, Cochrane Library, and Science Direct) for all years through July 2014. We assessed risk of bias of selected studies using the RTI Item Bank for Assessing Risk of Bias and Confounding for Observational Studies of Interventions or Exposures and the Cochrane risk of bias tool for randomized controlled trials.

**Results:** Of a total of 3948 citations retrieved, we selected 52 eligible studies published between 1946 and 2014. The majority of studies were observational and cross-sectional in nature. Our review suggests that high levels of depression occur during the adjustment to IVL. Better adjustment to IVL was associated with greater acceptance of vision loss and use of instrumental coping, good social support, positivity, and use of assistive aids.

**Conclusions:** The overall findings indicate that IVL often has negative effects on patients' quality of life and mental health and that such effects tend to remain over time. Specific factors and variables associated with the adjustment to IVL need to be clarified through further in-depth and longitudinal research. *Ophthalmology 2015;122:851-861* © 2015 by the American Academy of Ophthalmology.



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Vision is one of the most important functions in human beings and supports the majority of everyday functioning and contact with external reality. Therefore, it is a serious impairment when an individual irreversibly loses sight. Irreversible vision loss (IVL) occurs when a serious medical condition or eye trauma progressively or suddenly decreases an individual's capacity to see. The most frequent causes of IVL are advanced age-related macular degeneration, glaucoma, and diabetic retinopathy. 3,4

Irreversible vision loss can lead to low vision or blindness, depending on the level of vision loss. Worldwide, approximately 285 million people are irreversibly visually impaired, of whom 39 million are blind and 246 million have low vision. According to the World Health Organization, low vision exists when (1) visual acuity is <6/60 and  $\ge 3/60$  in the better eye with the best correction or (2) the visual field is <10 degrees from the point of fixation. Blindness exists when (1) visual acuity is <3/60 in the better eye with the best correction and (2) visual field is  $<10^{\circ}$ . In the United States, vision impairment is defined as having <20/40 vision in the

better eye, even with eyeglasses.<sup>5</sup> The legal/statutory criteria for blindness in the United States requires<sup>6</sup> (1) best-corrected visual acuity of  $\leq 20/200$  in the better eye or (2) a visual field limitation such that the widest diameter of the visual field in the better eye subtends an angle no larger than 20 degrees, as measured with a Goldmann III4e or equivalent size stimulus.

Irreversible vision loss in adulthood tends to negatively affect quality of life and limit general functioning, including the ability to independently perform several daily life activities, such as work, walking, driving, reading, dressing, and cooking. The ability to develop new personal resources to compensate for the loss of functioning caused by IVL is strongly dependent on the success of psychologic adjustment to IVL. 11-13 The psychologic adjustment to IVL in adulthood is described as a process through which the individual activates psychologic capabilities and behaviors to accommodate, in a realistic way, changes and constraints imposed by vision loss. 14-19 The most frequent changes caused by vision loss operate on one's self-concept, life goals, and social functioning. 17-19 During the

adjustment process, people are at high risk of emotional distress<sup>20,21</sup> and social isolation, <sup>22,23</sup> and as a consequence can have psychologic problems, such as depression, anxiety, and sleep disturbances. <sup>24–27</sup> Such psychologic problems often encompass an additional source of disability for these patients and tend to interfere with vision rehabilitation and social reintegration. <sup>28,29</sup>

The psychologic adjustment to IVL has been approached by many studies with the aim of better understanding how people manage IVL and which factors better predict good adjustment. 14-18,30-32 To date, there has been no concerted effort to summarize the peer-reviewed literature on psychologic adjustment to IVL using a systematic review. Such a review could provide evidence regarding which adaptive mechanisms influence adjustment, adherence to medical treatment, and general rehabilitation. We have, therefore, undertaken a systematic review to (1) summarize the literature on psychologic adjustment to IVL in adults; (2) determine whether there is evidence in the literature of demographic, clinical, psychosocial, or medical factors that can predict the ability of an individual to adjust to IVL; and (3) evaluate the quality of the evidence in the literature.

#### **Methods**

## Eligibility Criteria for Considering Studies for this Review

We conducted a systematic review of all relevant studies that investigated adults' psychologic adjustment to IVL. We selected all studies that fulfilled the following inclusion criteria: articles published in English; peer-reviewed articles; studies of adults aged 18 years or older with IVL; and studies examining the outcome of adjustment or adaptation to vision loss, factors influencing adjustment to vision loss, the experience of vision loss, or coping with vision loss. We included all types of articles and study designs, except for nonsystematic reviews, case studies, and conference proceedings. We also excluded articles lacking sufficient details to determine whether all inclusion criteria were met, studies of individuals younger than 18 years of age, and studies focused on congenital visual impairments.

#### Search Methods for Identifying Studies

Two authors (H.S. and C.R.V.) systematically conducted a search of electronic databases to retrieve all articles published through July 4, 2014: PubMed, Science Direct, Cochrane Library, and EBSCO (including Academic Search Complete; ERIC; Library, Information Science and Technology Abstracts; PEP Archive; PsycArticles; Psychological and Behavioural Sciences Collection; and PsycInfo). We searched these databases using terms that are often used in visual impairment literature to designate vision loss and its adjustment process, including "vision loss" OR "sight loss" OR "visual impairment" OR "vision disorders" OR "blindness" OR "low vision" OR "partially sighted" AND "adjustment" OR "psychological" OR "adaptation" OR "experience" OR "coping."

#### Study Selection

We followed the *Cochrane Handbook for Systematic Review of Interventions*<sup>33</sup> to select studies to be reviewed. Two authors (H.S. and C.R.V.) independently reviewed titles and abstracts and then the full-text articles to identify the eligible studies. Results of both

researchers were compared, and clearly noneligible studies were excluded. Then, duplicates were removed. Next, the same researchers read the abstracts of the remaining article titles to determine whether they met inclusion criteria. Abstracts providing sufficient detail for exclusion were removed, and the remaining full-text articles were retrieved. Full-text articles were read to determine inclusion, and disagreements were resolved via consensus.

#### Data Collection and Risk of Bias Assessment

For each observational cross-sectional and cohort study and the randomized controlled trial (RCT), the following characteristics were extracted: year of publication, country where the study had been carried out, participants (type and size), control group, setting in which the study was carried out, study design, main outcome measures of psychologic adjustment, main quantitative results, and quality appraisal of studies. We also abstracted data on qualitative analysis for qualitative and mixed-methods studies. In addition, to exclusively assess the quality of reporting of observational cross-sectional and cohort studies, 3 researchers (H.S., P.F., and D.R.) independently appraised all articles using the STROBE statement.<sup>34</sup> The STROBE statement consists of a checklist of 22 items with guidelines to appraise the quality of reporting of observational studies. We assessed articles for only 21 items, excluding the item regarding the source of funding, because such information is not applicable to all articles.

The quality of observational cross-sectional and cohort studies was assessed using the RTI Item Bank for Assessing Risk of Bias and Confounding for Observational Studies of Interventions or Exposures. Two researchers (H.S. and F.B.) independently assessed the risk of bias of each study using the RTI Item Bank tool. This tool provides a list of 13 questions, each one addressing confounding or the type of bias that a study may present, such as selection bias, performance bias, detection bias, attrition bias, and selective outcome reporting. Also, to exclusively assess the quality of reporting of observational cross-sectional and cohort studies, 3 researchers (H.S., P.F., and D.R.) independently checked it.

Two researchers (H.S. and F.B.) independently assessed the overall quality of the RCT using The Critical Appraised Skills Programme (CASP) tools for appraising RCT studies.<sup>36</sup> To assess the risk of bias of the RCT study, the same researchers used the Cochrane tool for assessing risk of bias in RCTs.<sup>37</sup>

Three researchers (H.S., P.F., and D.R.) independently assessed the overall quality of qualitative studies, the systematic review, and the mixed-methods studies using the CASP tools for appraising qualitative studies <sup>38</sup> and systematic reviews, <sup>39</sup> and the checklist for mixed-method studies created by Long et al, <sup>40</sup> respectively. We did not assess risk of bias for the qualitative or mixed-methods studies or the systematic review. To the best of our knowledge, no specific instruments to assess risk of bias of type of studies are currently available.

#### Data Synthesis and Analysis

We synthesized findings from observational quantitative studies and the RCT on the basis of the information included in our reporting tables and considering the main quantitative results from reviewed studies.

Qualitative findings from qualitative and mixed-methods studies were synthesized using the interpretative metaethnography approach. This method of synthesis is focused on creating new knowledge based on interpretation of the themes identified across the papers. Two researchers (H.S. and P.F.) independently reviewed and thoroughly analyzed all qualitative and mixed-methods articles to get a grasp of the whole. After a first analysis of qualitative findings from all articles, we identified and categorized the themes that appeared more than once among

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