

Coping strategies to manage stress related to vision loss and fluctuations in retinitis pigmentosa

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KEYWORDS

Retinitis pigmentosa;
Focus groups;
Coping skills;
Stress;
Blindness;
Low vision

Abstract

BACKGROUND: Vision loss in retinitis pigmentosa (RP) is a slowly progressive and inexorable threat to patients' independence. It is not surprising that RP patients, many of whom are young when diagnosed, are at high risk for stress related to their vision loss. To address these issues, eye care providers need to be aware of what coping strategies RP patients use to successfully manage their vision loss.

METHODS: We held focus groups with 8 legally blind RP patients to help us better understand how they cope with the stress that is generated from their progressive vision loss and fluctuations in vision. Focus group sessions were audio-taped and resulting notes were coded using conventional qualitative analytic techniques.

RESULTS: Two themes were identified: (1) "kicking and screaming" captured the ways in which RP patients fight to maintain their independence in the face of worsening vision; and (2) "there are so many worse things" describes how RP patients keep their vision loss in perspective. These RP patients demonstrated high levels of resiliency. In particular, they often used humor as a coping mechanism.

CONCLUSION: Understanding the ways in which RP patients manage their gradual, impending vision loss may lead to improved quality of care for this patient population.

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Patients with retinitis pigmentosa (RP) continuously face a slowly progressive loss of vision for which there is no currently available cure. They are aware of the increasing threat of potential loss of independence (as their vision loss progresses), which can result in considerable stress. A landmark article reported clinical symptoms of 500 RP patients, many of whom stated that stress caused a decrease in vision and that vision improved when the stress was alleviated.¹ As RP patients start to lose their central visual acuity, there is an increase in day-to-day fluctuations in vision, adding another element of uncertainty to their ability to perform daily activities.²

Stress may begin when an objective event involving a loss, challenge, or threat (such as the diagnosis of a disease) requires an adaptation. Stress occurs if the appraisal of the demands and burden of the disease exceed the patient's self-management and coping abilities.³ This results in a biological activation of the sympathetic nervous system or vagal withdrawal, including changes in blood pressure, heart rate and the release of the stress hormone cortisol, as well as negative mental and emotional responses, potentially leading to depression.^{4,5} Fortunately, most people are able to adapt successfully, most of the time.

Individuals with RP experience different levels of stress. Those with advanced RP may experience stress because of difficulties with mobility and an increased fear of falling.⁶ Decision-making abilities, environmental awareness, self-perception of skills, and overall mental

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effort may be some of the factors that contribute to difficulty with orientation and mobility for patients with vision loss from RP.⁷ Reduced peripheral visual field requires RP patients to fixate over a larger area to view surroundings and identify targets.⁸ Thus, stress among people with RP may be related in part to the increased mental effort and information processing needed to compensate for limited visual information.

To manage the various stressful aspects of their retinal degeneration, RP patients can develop several types of coping strategies. The Stress and Coping Model of Lazarus and Folkman³ distinguishes 2 dimensions of coping: *problem-focused actions* taken to counteract the source of stress (i.e., loss of visual function) and the *responses* to alter the emotions produced by the event. Suls and Fletcher's⁹ model identified 2 different dimensions of coping: *approach coping responses* focused on the source of stress and reactions to it and *avoidant coping responses* designed to place focus away from the source of stress and reactions to it. These models provided the conceptual framework for this project.

The goal of this study was to conduct focus groups to explore the successful ways in which legally blind RP patients manage their vision loss and the stressful challenges that ensue by means of effective coping strategies. RP patients were chosen for this research because the slowly progressive and inexorable vision loss requires patients to continually make adjustments to how they perform activities of daily life. They also experience various types of visual phenomena, including fluctuations and photopsias, that may change or interfere with their ability to function on a day-to-day basis. Quantitative methods have been used previously to determine the psychosocial effects of vision loss. For example, the National Eye Institute Visual Functioning Questionnaire-25 (NEI-VFQ) has 3 items to inquire about the extent to which the patient is stressed, using the terms *worry*, *irritable* and *frustrated*; however, there are no items to determine how the patient copes with these feelings. Qualitative methodology allows a much richer description than quantitative methods, with an ability to capture fears and problems encountered by patients when faced with chronic disease. The aim of this research method is to describe a concept, phenomenon, or situation, as it is constructed by participants, and to explore how individuals experience the phenomena. Focus groups facilitate interaction between subjects, to elicit similar or different viewpoints or opinions on a topic. They are also used to help identify group norms and salient aspects of a particular issue.

The focus groups aimed to (1) better understand RP patients' perceptions of stress and management, (2) identify how fluctuations in vision impact daily life, (3) determine which coping strategies are most widely used, and (4) explore preferences for different coping approaches. To the best of our knowledge, this is the first published report of the use of focus groups to explore these topics in individuals with RP. Improving health and quality of life in patients with chronic, disabling diseases involves more than

identifying treatments and cures. Therefore, these data could assist health care providers who care for RP patients. Rather than telling RP patients that nothing can be done for them, eye care providers and rehabilitation specialists may find it valuable to use the information from these focus groups to help manage the psychological and functional difficulties experienced as a result of their retinal disease.

Methods

Patients' characteristics

Two moderators convened 3 online focus groups of adults who had legal blindness caused by RP. Participants were previous patients of the Johns Hopkins Wilmer Eye Institute's Low Vision Service or had participated in previous research at this institution. Inclusion criteria included individuals with RP, age 18 years and older, who met the criteria for legal blindness because of constricted visual field (less than 20° in both eyes), and had binocular visual acuity better than 20/800. The Johns Hopkins Institutional Review Board approved this research project, and all subjects provided written informed consent.

Eight RP subjects participated in 1 of 3 focus groups. Ten RP subjects were invited to participate, and the 2 who declined stated they were too busy and had difficulty joining the meeting because of computer-related audio issues. The RP subjects in the focus groups self selected to also participate in a pilot study involving PC-based vision assessments, and after the focus groups they were randomly assigned to an intervention involving either a mind-body stress reduction program or a series of eye exercises, which is not reported here. Six of the 8 focus group members were white women and 2 were black men. Their mean age was 49 years (range, 27 to 63 years old). The subjects' demographic characteristics and level of vision are listed in Table 1. Six of the 8 participants were either not currently employed or retired. Best-corrected visual acuities ranged from 20/20 to 20/500 binocularly, measured with the Early Treatment Diabetic Retinopathy Study (ETDRS)

Table 1 Participants' characteristics

| Subject | Age | Sex | VA - OU | GVF diameter |
|---------|-----|-----|---------|--------------|
| 1 | 27 | F | 20/20 | 20° |
| 2 | 53 | F | 20/20 | 20° |
| 3 | 47 | F | 20/20 | 20° |
| 4 | 56 | F | 20/30 | 15° |
| 5 | 63 | M | 20/40 | 10° |
| 6 | 56 | F | 20/50 | 3° |
| 7 | 43 | M | 20/100 | 20° |
| 8 | 43 | F | 20/500 | 2° |

VA - OU = visual acuity with both eyes open; GVF diameter = Goldmann visual field diameter with the III4e test target.

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