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

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## 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 eight 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 audiotaped 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.

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

### Keywords

retinitis pigmentosa; focus groups; coping skills; stress; blindness; low vision

## Introduction

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 paper reported clinical symptoms of 500 RP patients, many



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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 withdrawl, 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 due to difficulties with mobility and an increased fear of falling.[6] Decision-making abilities, environmental awareness, self-perception of skills, and overall mental 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.

In order 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 Folkman[3] distinguishes two 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's model identified two 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.[9] 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 since the slowly progressive and inexorable vision loss requires patients to continually make adjustments to how they perform ADLs. 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 previously used to determine the psychosocial effects of vision loss. For example, the National Eye Institute Visual Functioning Questionnaire-25 (NEI-VFQ) has three 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, in order 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, this 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 three online focus groups of adults with legal blindness due to 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, aged 18 years and older, who met the criteria for legal blindness due to constricted visual field (less than 20 degrees 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 one of three focus groups. Ten RP subjects were invited to participate, and the two who declined stated they were too busy and had difficulty joining the meeting due to 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 randomized 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 eight focus group members were Caucasian females and two were African American males. Their mean age was 49 years (range: 27-63 years old). The subjects' demographic characteristics and level of vision are listed in Table 1. Six of the eight participants were either not currently employed or retired. Best corrected visual acuities ranged from 20/20 to 20/500 binocularly, measured with the ETDRS charts. All participants had been diagnosed with RP for at least 10 years.

### Study Design and Procedures

The focus groups were held prior to the intervention programs, and were each approximately 90 minutes in duration. The three sessions took place within two weeks of each other in May-June of 2008. To minimize the burden of visits to our center during the study, we used live web conferencing to conduct all three of the focus group sessions. Participants were provided with a microphone headset. The first focus group session was held with four participants, but two of the participants were rescheduled due to audio technical issues. The second and third group sessions each had three participants. The same moderator (MG) led each of the three focus group discussions, and another researcher (LE) was present during the sessions to take field notes. The moderator and note taker had experience in conducting focus groups, but had not previously worked with RP patients. This may have helped to reduce bias resulting from familiarity with the participants or prior experiences with RP patients. The principal investigator was a non-participating anonymous observer on these calls who could have provided medical information and support had there been a need.

Each session began with an explanation of the purpose and confidentiality of the focus groups. Then participants and researchers introduced themselves by first name. The semi-structured and open-ended questions that were used are outlined in Table 2. Each focus

group session was audiotaped for later reference and analysis. Coding consisted of systematically reviewing the recordings and field notes to document emerging themes and categorize the responses of participants. Responses that were similar were then grouped together by code words to form thematic categories. The coding was performed independently by the moderator and field note taker. The themes and their interpretations were then confirmed by reviewing the results with all three of the study authors until consensus was achieved.

## Results

### Fluctuations in vision

The participants described several types of day-to-day visual fluctuations they encountered. These included intermittent diplopia (subject 6), a sense that their eyes had difficulty focusing and working together at times (subject 5), photopsias or light show phenomena described as flashes or moving patterns of light (subjects 3, 4 and 8), Charles Bonnet syndrome consisting of formed images and visual hallucinations (subject 2), periods when their vision went completely white due to high glare (subjects 4, 6 and 8), and time of day effects (subjects 6 and 8). The subjects with the smallest visual fields described that their vision was worst in the morning immediately upon waking and that it took several minutes to hours for it to gradually reach their usual function levels (subjects 6 and 8). These two subjects indicated that they would try to schedule important activities later in the morning or would wake up earlier than usual to allow their vision adequate time to adjust. Others described a different experience of best vision in the morning with gradually worsening vision throughout the course of the day into the evening, or noted no particular pattern. This variability in the time of day effects across patients is not well understood at this time.

The participants described several factors that they thought might be associated with their fluctuations in vision. Some noticed that if they pay less attention to their surroundings, as in times when there are too many distractions or things going on (i.e., deadlines, meetings), it can lead to ‘bad’ vision days. “When I'm under stress, I think I have a tendency to speed up what I'm doing instead of taking my time, and when I do, I miss a lot visually. Because when you have RP you do not have a wide field, so when you rush you see less and wind up getting yourself into trouble.” (subject 5) “At times like that I have to prioritize and tell myself to just look around.” (subject 1) “I've learned to slow myself down a bit in some instances. What has helped a lot is just waiting it out. Sometimes it will clear up enough so I will know what I am doing and other times it will not. But at least I am giving myself the opportunity.”(subject 4) Many subjects indicated that fast paced work caused stress and then a difference in visual function was noticed. Stress was also reported to sometimes cause an increase in flashes and floaters (subjects 3 and 8).

There was no clear consensus among participants as to whether cloudy or sunny weather affected ‘good’ and ‘bad’ vision days. Subjects 6 and 8 with the smallest visual fields noted worst vision in bright, sunny conditions. RP patients may be affected differently by bright or dim illumination, possibly depending upon the type of RP, specific genetic mutation in the retina, and degree of vision loss. On the other hand, the level of brightness does affect vision in RP, likely due to a loss of contrast sensitivity. Subjects indicated that they were affected by glare and when transitioning between light and dark environments, as would be expected with photoreceptor degeneration.

### Themes related to Vision Loss

From the focus groups we were able to identify two major themes: 1) “kicking and screaming” which captures all the ways that RP patients fight to maintain their independence

in the face of worsening vision, and 2) “there are so many worse things” which captures how RP patients keep their vision loss in perspective – how they are enduring, persevering, and resilient, using humor primarily to cope.

**Kicking and screaming—**In this theme, many RP patients indicated that the threat or actual loss of independence was a significant, stressful challenge, since they were used to doing things for themselves, and many aspects of their lives are affected by this type of loss. “It's a tough thing, a very tough thing, to give that independence up (talking about driving).” (subject 4) Some stated that they were not as fearful of losing sight, as losing independence. They used terms like “panic”(subject 4) and “devastating”(subject 5) to describe the emotions that they had experienced. The participants also indicated that the ability to obtain assistive technology and devices from low vision specialists and doctors was very helpful in allowing them to maintain their ability to carry out daily activities and independence (subjects 5 and 8). Several RP patients found it helpful to keep a constant hope for research to find a treatment. “I do have hope that research will find a cure for us one day.”(subject 5) To further exemplify this theme of ‘kicking and screaming,’ participants continued driving with their vision loss well beyond when they should have stopped, and eventually only gave it up after having an accident or very close call (subjects 7 and 8).

**There are so many worse things—**In the second theme there was a high degree of resiliency expressed, “My outlook on this whole situation is that there are so many more people out there with so many worse things than what I have. I deal with my vision the best way I know how to.”(subject 8) Subjects 5 and 6 realized the value of being able to turn their stress and anger into productive actions (e.g., volunteer work). “I get involved with as many things as I can. I have too much to live for and too many things left to do that I haven't done, to sit around and feel sorry for myself.”(subject 5) Some successful coping strategies involved “not to think of it as a ‘good’ or ‘bad’ vision day, just another day to get through.” (subject 6), and acceptance was expressed as, “I don't really classify it as a ‘good’ vision day or a ‘bad’ vision day because it's part of who I am and it's just something that I deal with every day.”(subject 8) One participant indicated that she tended to think altruistically at times; for example, “better me than my sister.”(subject 1)

## Coping Strategies

The use of coping strategies to manage the stress of vision loss was extremely common. The coping strategy most frequently discussed was humor. Participants stated they were able to come to terms with having RP through laughter (subjects 1, 5 and 6). This included being able to laugh at yourself, or acting goofy or silly at times to distract from the vision loss. Some used humor as a defense mechanism, or a form of displacement in which serious or distressing thoughts were avoided rather than disarmed. “I find that laughter, for me, is a very key part of the day.”(subject 8) Some indicated that it was nice to be able to use humor when around someone who can relate and understand the context for the humor (subject 4). “We can laugh at ourselves and I think that helps.”(subject 5)

An important part of the coping process that has been helpful for many RP patients has involved social support and communicating with others who have RP. “We know the context of our comments and that helps a lot.”(subject 4) Individuals with RP can participate in an online message board, which is an internet support forum known as the RP list (http://www.dixonvision.com/rplist/). It is widely known and used by more than 525 subscribers internationally to discuss symptoms, coping strategies, and potential treatments. Subject 2 indicated that using the RP list message board and attending social events for those with RP was helpful: “Knowing that you're not alone is one of the most important things.” Subject 6 stated that she benefited from gaining empathy from people with other

disabilities. Many indicated they felt that people without vision loss, including their spouse, could not fully understand what it is like to be blind or to live with a functional impairment (subjects 5, 6 and 7). Some also indicated the importance of being able to give yourself permission to have days to vent, gripe or complain, including the use of profanity (subjects 4 and 6), to help relieve stress and to cope.

Some thought patterns and cognitive strategies that RP patients in the focus groups used to help with coping included the ability to learn to "let it go," if something couldn't be done about it (subjects 1 and 6). If negative thoughts or feelings arose as a result of their impaired visual function, they expressed that they learned to sit and calm themselves down, take breaks or wait it out, slow down a bit to allow their vision to adjust, or simply just do the things that they could do. "You have to give yourself a break, and enjoy things you still can do, and appreciate before it's gone and then you have to learn the next step."(subject 4)

We learned from our focus groups that the impeding gradual loss of vision led to the threat of losing independence, leading to stress being described by the participants as "panic" and "devastating." Day-to-day visual phenomena (e.g., fluctuations in vision and photopsias) and difficulty with activities of daily living due to their current level of vision loss are also other causes of stress in some patients with RP. Table 3 lists the strategies that RP patients in our focus groups used to help with factors that were related to day-to-day decreases in visual functioning, and table 4 lists activities that they found to help reduce stress in general. Many of the stress management techniques listed in table 4 are forms of escape or distraction, used by the subjects to put themselves "in another world" and "tune out" their own world. "It does take me away from where I currently am... It does help me because it gives me the opportunity to put myself into someone else's shoes."(subject 8) Providers may offer the coping strategies listed in tables 3 and 4 to help patients with RP.

## Discussion

We conducted focus groups with legally blind RP patients to assess their experiences with periodic short-term fluctuations and long-term progressive changes in their vision, and explore their strategies that indicated successful coping and reduction of stress related to their visual impairment. Two primary themes to characterize how RP patients deal with their visual impairment and stress emerged from the data analysis: 1) "kicking and screaming" to capture all the ways that RP patients fight to maintain their independence in the face of worsening vision, and 2) "there are so many worse things," which captures how RP patients keep their vision loss in perspective – how they are enduring, persevering, and resilient; coping by primarily using humor.

The two themes that were identified may be used to help inform eye care providers, who should take such perspectives into consideration when evaluating and managing their RP patients' adjustment to vision loss. This is especially important for a disease that has no current proven treatment, as health care providers should instead focus on both maximizing function and on the psychosocial impact of vision loss. Given that the impeding vision loss is a cause of significant stress and anxiety for those with RP, it may be a disservice for providers to tell patients that they will be legally blind by a certain age, especially if this may not be attained as predicted. Alternatively, patients may be reassured that although they may lose some of their peripheral vision, most people with RP will retain good, detailed central vision (vital for reading) even later in life. Research has shown that among those over age 45, about half had visual acuity better than 20/40, while only 12% had vision measured at counting fingers or worse.[10] Patients may be reassured that it is not common to go completely blind from RP.

As identified by the first theme of "kicking and screaming," individuals with RP will struggle to maintain their independence and will often continue to drive with severe visual field loss, even after they have been diagnosed as legally blind. Previous research identified a statistically significant correlation between the severity of the visual field loss and the number of driving-related accidents.[11] Although the issue of driving can be a sensitive one to approach, it should not be avoided if the patient does not meet the legal criteria for driving or there are other reasons to suspect that they may not be safe. Eye care providers should routinely monitor Goldmann visual fields and obtain a driving history in these patients. RP patients with advanced visual field loss who are still driving in order to maintain their independence may also experience significant anxiety, as they acknowledge difficulty at times when traveling between dim and bright areas, as well as the chance that they may miss seeing a pedestrian. Most patients will appreciate providers who are willing to speak to them honestly about their driving even if they are initially resistant to the issue, and therefore providers should not avoid the issue of driving even though it can be a difficult one to broach. The eye care provider may suggest alternative options for transportation to help them stop driving, including local public transportation programs, or finding a driver either through family, friends, other volunteers (e.g. local Lions Club members) or individuals (e.g., online messageboard listings for drivers).

The theme of 'kicking and screaming' also applies for some initial refusal to accept the need for orientation and mobility training, and/or a white cane. It is important for vision care providers to make appropriate referrals for orientation and mobility training when it might be helpful, since there are proper techniques associated with the use of a sighted-guide and/or cane. The provider does not necessarily need to mention the words 'white cane' since it may evoke stress, and whether it is actually indicated for the patient will be assessed by the orientation and mobility specialist. An orientation and mobility evaluation does not need to be recommended for every RP patient, as patients early in the course of the disease typically still have an adequate visual field to allow successful navigation. The provider should ask the patient if there have been any falls in the past year, are frequently (i.e. more than rarely or sometimes) tripping or bumping into objects or people, or tending to rely on a sighted-guide in public, and use this history in conjunction with information from clinical measures of visual field size to try to determine if the patient is having any difficulty with mobility. It may be helpful for providers to suggest to their RP patients to communicate with others with RP (through online messageboards) who have faced the same issues. It is also not uncommon for some patients to reject the mobility training evaluation when it is first presented, and therefore providers should ask patients whether they are ready at subsequent follow-up visits.

A positive aspect of RP patients' fight to maintain independence is that they are often receptive to participate in research and clinical trials aimed at evaluating therapies to stop, slow, or reverse vision loss. It is important for eye care providers to remain up to date regarding clinical trials, as this is a common inquiry from those with RP. The RP patients in our study demonstrated willingness to help with research aimed at understanding RP (even if there was no potential benefit to their own vision) in order to help advance the knowledge about their condition and to help others in the future. As individuals with RP struggle to preserve their independence, this level of willingness may translate towards a level of acceptance to using rehabilitation devices and strategies to help with their visual functions, as the need arises. The fear of losing independence may be reduced in part by educating RP patients that low vision rehabilitation training and devices will help maintain their ability to perform many activities of daily living despite the gradual loss of vision. Providers should continually assess these patients' ever changing needs. If any visually impaired patient is having any difficulty with activities of daily living, providers should either provide relevant

information regarding new technologies or devices that may help, or refer to a low vision rehabilitation specialist.

Previously published studies of coping with vision loss have focused on the elderly, including those in whom vision loss was more recent and sudden. The participants in the current study were primarily middle-aged individuals, and their younger age and slow, gradual vision loss may have resulted in different coping strategies. Previous research in elderly patients with vision impairment found that family is important in the adaptation and coping processes initially, but at later times (6-18 months), friendship support appeared to be more important for adaptation.[12] Our participants appeared to be less likely to mention the positive aspects of support from family members, as this was only mentioned by one subject. In fact, these RP patients were more likely to indicate that their family and spouse did not understand what it was like to function with a visual impairment, and they were more likely than elderly to find support from friends or others with RP. Adults with visual impairment have previously reported a lack of understanding from others and the challenges this creates during social interactions,13 indicating a need to educate the general public, including the patients' family and friends, about the implications of having a vision impairment. The current group of RP subjects reported some of the same coping strategies previously identified by older adults with recent vision loss, specifically acting more cautiously, and talking/learning from others with visual impairment. On the other hand, these RP subjects did not identify other strategies used by these older adults, which included using sound to compensate or actively avoiding negative feelings.14 Perhaps the long-term, slowly progressive nature of vision loss with RP allows individuals over time to find successful ways in which to deal with and reduce negative thoughts and feelings when they occur, rather than to try to avoid them altogether. Alternatively, this may simply be a function of our small sample size.

The increased variability of vision in RP compared to normally sighted individuals without retinal degeneration has been previously documented for visual acuity, contrast sensitivity function and visual field.1,[15] Not only does the progressive loss of vision in RP contribute to stress and negative psychological states, but the uncertainty associated with day-to-day fluctuations in vision also plays a role and should not be discounted. At the present time, the factors that influence this type of variability in some RP patients have not been formally elucidated. One of the authors (AB) is currently conducting research to create a profile of RP patients who are most susceptible to day-to-day variations in vision and to determine which factors are associated.[16] Based on RP patients' observations, the factors that may play a role are stress, fatigue, time of day and changes in lighting. A previous survey of self-reported RP patients indicated that the factors that were most commonly reported to be associated with an increase in photopsias were similar, namely bright light, fatigue, stress, exercise and absence of light.17 It may be helpful for providers to be familiar with these phenomena and potentially associated factors, as patients may ask if others with RP also have the same experiences. Sometimes it's helpful for them to know that they are not alone in what they are encountering.

The RP patients who were invited to join these focus groups were also enrolled in a pilot study to evaluate the feasibility of intervention programs for RP patients involving mind-body stress reduction techniques or a series of eye exercises. Also, the patients were originally recruited from those who had received low vision rehabilitation services or had previously participated in research. Therefore, there is a potential selection bias toward individuals who had the time to volunteer for research and were interested in these types of interventions.

The participants in a focus group do not need to be necessarily representative of the entire population, and a particular group may be targeted instead. Since we were interested in successful coping strategies, we decided to include in our group those who were accepting of rehabilitation services and who were willing to help with research in general, as they may more likely present those who have demonstrated appropriate stress management and coping techniques.

The sample may be limited by its small size, but the repeated topics that emerged across the three sessions suggest that we were approaching saturation and redundancy, which is an indication of an adequate sample size for focus groups. Focus group methodology suggests that groups "be large enough to gain varying opinions and perspectives and small enough to allow each individual to participate fully and be heard."[18] By limiting enrollment to only legally blind RP adults we ensured an "optimum combination of homogeneity of interest and common ground with adequate diversity of experiences...critical to productive interaction among members. Homogeneity on key variables is more important than general heterogeneity of the group."[18] We also believe that the visual dynamics typical of a live in-person focus group might not have been operative in a group of legally blind subjects. In fact, web-based participation may produce more depth and breadth than typically found, in that it provides "more immunity so more disclosure takes place; the anonymity engenders an atmosphere that encourages honest airing of what could be critical personal views and negative experiences."[19] Given that the focus groups were conducted via webconferencing, we did not want the group sizes to be too large, since it may have been too difficult or confusing to control or determine who was speaking at a given time without visual cues between the moderators and participants. We were still able to achieve a non-directive style of interviewing, and obtained a variety of viewpoints on the topics discussed with the group members. We found that a lively collective interaction occurred among the three participants per group. This brought forth more spontaneous expressive and emotional views than would be expected in individual, often more cognitive, interviews. Ultimately, the litmus test for the adequacy of any focus group is whether rich data provides the researcher a new understanding of the unique experiences and perspectives of the subjects. We believe we met these criteria.

The use of web conferencing to conduct the focus groups is a novel approach. This methodology was helpful to facilitate participation since none of the eight subjects in this study were able to legally drive to our center due to constricted visual fields. A potential challenge with this methodology is that the moderator is unable to make eye contact with passive participants to encourage them, but this may not be as effective in a population with reduced vision. The moderator addressed this issue by indicating that everyone should be heard from, including those who had not shared their experiences. The methodology does indicate who is speaking and who is not, so the names are highlighted and the facilitator can monitor participants' involvement. Another potential limitation with using web conferencing is that the person taking field notes will not be able to see and record non-verbal communication, like body language or facial expressions. Also, there is a risk that the participants may be distracted by things going on in their home environment at the same time. One can hear background noises and sidebar conversations, so this level of non-verbal communication can be monitored. An issue that arose during our first focus group was poor sound quality, including loud echoes, which were so distracting that we chose to reconvene at another time once the audio issues were resolved. However, for this patient population, the benefits of a remotely-held web-based approach outweigh these potential limitations. It would be much more difficult to coordinate transportation and schedules for in-person group sessions with a population that does not drive due to their reduced vision. Also, some participants may be more willing to speak about their issues related to stress and coping since the group cannot see who they are and there is greater degree of anonymity.

## Conclusions

The findings that addressed the original aims of the focus groups were that (1) RP patients' recognize that stress will arise from their visual impairment, and while some stress management techniques are specific to their vision loss, most others reflect general ways to relieve stress, (2) some patients will plan activities around their daily fluctuations in vision, or will slow down to wait for their vision to recover, (3) the coping strategies most widely used were humor/laughter, social support from others with RP, using increased awareness or prioritizing, and (4) patients expressed preferences for different coping approaches for stress, and although various types of activities were mentioned, many were forms of escape or distraction. The cognitive themes that emerged and were specific to vision loss with RP were "kicking and screaming" to fight to maintain independence, and "there are so many worse things" to keep their vision loss in perspective. These various types of coping strategies identified by the RP patients during these focus groups may be helpful for eye care providers to understand the patients' viewpoint and situation. This information should also allow eye care providers to help those who are newly coping with their diagnosis or have questions about the visual phenomena they are experiencing. This data may also aid in the development of programs to help relieve these patients' stress and anxiety related to their slowly progressive, inexorable retinal degeneration.

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**Table 1**

Participants' characteristics

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

VA - OU: visual acuity with both eyes open;

GVF diam.: Goldmann visual field diameter with the III4e test target

## Table 2

Interview script for focus groups

| | |
|---|---|
| 1. | **Tell me about your vision.** *Are there "good vision days"? Are there "bad vision days"? What do you think are the factors that may influence a "good or bad vision day"? Direct discussion to stress (as well as mood states, anxiety, depression, sleepiness). Lots of people have stress and it affects them in different ways.* |
| 2. | **Stress is highly prevalent among many people in our country.** *How do you know you are having a stressful day? What are the physical or emotional signs and symptoms? How often are you stressed?* |
| 3. | **Factors that may influence perceived stress or negative psychological states:** RP-related *(length of diagnosis, knowledge of RP-related visual symptoms and prognosis), coping strategies (use of adaptive devices and techniques, social support from friends or family), or occurrence of major life events.* |
| 4. | **Your health care providers should provide you with the tools to take better care of yourself through self healing (in terms of quality of life and visual function status).** *Lead to discussion to stress reduction. What do you currently do to relieve stress? What would you like to learn to do? Or would you like to learn better/more effective techniques to release stress? Does anyone have any personal experiences they can tell us about any types of stress reduction? Is there any reason why stress relief approaches wouldn't work?* |
| 5. | **Is there anything that we haven't asked, or that hasn't been discussed, about the variability of vision and influencing factors (or stress and its reduction) that would be important for us to know?** *Probe: Are there things about RP or stress that you do not understand?* |

## Table 3

Factors associated with decreased visual function and coping strategies

| Factors Associated with Decreased Visual Functioning | Strategies |
|---|---|
| Too many distractions or things at once | Prioritize |
| Fast-paced settings | Increased mindfulness – pay attention, look around |
| Glare or dim environments | Slow down, or take time to adjust |
| Time of the day | Schedule important activities at times when vision is best |
| Psychosocial stress | Humor and laughter |
| | Social support from others with RP |
| | Don't dwell on the negative or things outside your control |
| | Appreciate what you have and can do |

**Table 4**

Activities identified by the participants to help with coping and stress management

| Activity | subject(s) |
|---|---|
| listen to music | 5, 7 |
| listen to books on tape | 8 |
| watch TV | 5, 6 |
| preoccupy with housework | 7 |
| find something interesting to do (e.g. look at old photos, work on genealogy) | 4, 6 |
| find comfort in the pleasant company of children | 7 |
| walking, going to the gym to exercise, weight lifting | 1, 5 |
| use of prayer or meditation | 2, 7 |