

Living with retinitis pigmentosa: Visual perceptual difficulties

(scientific paper)

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Abstract: *The aim of this study was to determine the state of the visual perception of 26 people with RP and 31 without visual impairment, using the TVPS (Test of Visual Perceptual Skills), as well as to find out the subtests on which those affected by RP have more difficulties and those on which they have less. Another aim of the study was to determine the relationship between Near Visual Acuity (NVA), Visual Field (VF) and visual perceptive performance. The results showed differences in all subtests between both groups. A descriptive analysis showed that those affected by RP have greater difficulty on Form Constancy and on Figure Ground and least on Visual Memory subtests. Significant correlations were found between NVA (Spatial Relations and Figure Ground subtests), VF (Visual Constancy and Figure Ground subtests) and visual perceptive performance. It was concluded that the findings of the study have important implications in planning interventions and in designing training programs for activities of daily life, of movement, recreation and social life, since visual perception affects these activities, and in the technological or computerized development of assistance aimed at improving the use of residual vision.*

Key words: *Retinitis Pigmentosa, Visual Perception, Visual Acuity, Near Visual Acuity, Visual Field.*

1 Introduction

Current theories of visual perception suggest that the detection and knowledge of objects depends on a continuous exchange between the perception and comprehension of the external world. That is, there is a constant relationship between perception and cognition, so that visual perception is not a collection of independent processes, but rather the interpretation and recognition of what one sees.

To determine how this process is carried out has motivated a great number of studies, examining the developmental process of visual perception from birth, as well as the role played by one's internal development and the help provided by experience (Kellman & Banks, 1997).

There is no doubt about the relationship between perceptual skills and the activities of daily life carried out by a human being, since these skills are involved in mobility, in reading and writing, in driving, in situations in which one must determine the distance and speed of objects, or distinguish between objects in different positions (Martin, 2006). It has even been noted that people with visual impairment walk more slowly and bump into more obstacles than people without visual impairment (Fuhr, Liu & Kuyk, 2007).

Retinitis Pigmentosa (RP) is an eye disease in which the photoreceptors of the retina (cones and rods) degenerate, causing loss of function and considerably affecting the quality of vision (Adler, 2002; Fernández, 2007).

RP is congenital and progressive, but usually becomes apparent around the age of adolescence. Clinical features are heterogeneous and vary from one person to another. The most common symptoms include involvement of both eyes, loss of peripheral or central vision, weakened vision at night or under poor lighting conditions, problems adapting to changes in lighting, and changes in colour discrimination (Fernández, 2007). These are features that could have a considerable influence on education, socialization, employment (Nemshick, Vernon & Ludman, 1986) and mobility (Geruschat & Turano, 2002, Runquist, 2004).

So far, there is no medical solution or pharmacological treatment for this pathology. However, visual perceptive training procedures have been applied to adults with low vision, with specific emphasis on figure-ground discrimination (Trudeau, Overbury & Conrod, 1990), concluding that practice and training could improve the functional use of residual vision; although it was also observed that people who were more actively involved in the training made better use of their residual vision (Conrod, Bross & White, 1986). Thus, both practice and motivation seem to be decisive factors in improving the use of residual vision. These results agree with points of view that support the hypothesis that it is possible to improve the use of an organ or of a function in adults through physical, mental, and social activity (Redolat y Carrasco, 1998); in fact, for some years it has been highlighted that the interaction of

an organism with its environment shapes the brain and that an enriched environment as well as learning seem to influence the capacity to establish cerebral connections, since use contributes to the maintenance of synapses between neurons (Bauer, 1996).

With respect to VA (Visual Acuity) it has been observed that reduction in this capacity is strongly associated with limitations of the visual performance of people with visual impairment (Laitinen, Sainio, Koskinen, Rudanko, Laatikainen, & Aromaa, 2007), whereas peripheral field loss is associated with limitations of the performance of mobility tasks (Haymes, Guest, Heyes & Johnston, 1996). Long-term changes in VA of people affected by RP have also been studied (Grover, Fishman, Anderson, Tozatti, Heckenlively, Weleber, Edwards & Brown, 1999), affirming that the loss of VA is not immediate; on the contrary, a large number of people retain some residual sight until the end of their days, despite the fact that in other cases it is minimal. This information is of unquestionable value in planning the rehabilitation of these people since they can use their visual potential in different activities of daily life. In the same way, knowledge of their visual perceptive state has significant applications in putting into practice of psycho-educational treatment programs and in the technological or computerized development of assistance aimed at improving the use of residual vision.

The loss of vision in RP is unpredictable and its progress entails a loss of the ability to carry out certain tasks, diminishing self-confidence and self-control of those affected and possibly leading them to perceive themselves in a negative manner (Kiser & Dagnelie, 2008). It must not be forgotten that people affected by RP go through a complex process after being diagnosed with the disease, which usually affects their personality (López-Justicia & Nieto, 2006; Strougo, Badoux et Duchanel, 1997), perhaps due to their perception of the loss of ability to carry out the tasks of daily life, to the feeling of being a burden to their families and their dependence on them for carrying out certain domestic chores, for reading, or for getting around. Difficulties in these activities, in driving a car, or simply crossing a street, and in mobility in general, are frequent (Fletcher & Schuchard, 2006; Fuhr et al., 2007; Geruschat & Turano, 2002; Rundquist, 2004). In fact, it seems to be the loss of function more than the damage itself that produces more pain or suffering (Zeiss, Lewinsohn, Rohde & Seeley, 1996).

There are not many studies that analyse the visual perceptive difficulties of adults with RP, since traditionally children have been the focus both of studies and of the efforts of visual rehabilitation (Greer, 2004). But the changes that have been made, stemming from the contributions of studies carried out (Aguilar, 2005; Trudeau et al., 1990), suggest the advisability of determining the use that people with RP make of their visual perception, since it is known that limitations in visual perception may affect mobility, daily activities as well as recreational and social activities (Brown, Rodger & Davis, 2003; Martin, 2006). For these reasons, the aim of this study was

to determine the state of visual perception and the areas or subtests in which people have greater difficulty, and those in which they show greater potential. Depending on the findings, training could be offered the training permits them to improve visual function and educational, professional and social integration, given the difficulty that this problem entails for people who suffer from it (Nemshick, *et al.*, 1986). Another aim was to study whether or not the visual perceptual performance of people with RP differs from that of people without visual difficulties. Finally, the study aimed to determine if NVA (Near Visual Acuity) and VF (Visual Field) had any relationship to visual perceptive activity. According to our research hypothesis the control group was expected to obtain higher scores on all scales.

2 Methodology

2.1 Participants

The sample was formed by 26 people with RP (22 women and 4 men) and 31 people without visual impairment (21 women and 10 men).

People with RP (who made up the experimental group) had a Near Visual Acuity (NVA) ranging between .0 logMAR (equivalent to VA distance 20/20) and 1.3 logMAR (equivalent to VA distance 20/200) (Median = .20; SIR = .11) in the better eye as assessed with a conventional Chart Near Distance and using best- corrected vision. Two of the participants had cataracts, 4 had myopia and 4 had presbyopia (long-sightedness) as well as RP. Their VF was between 5 and 40° (Median = 10.00; SIR = 5). Table 1 shows the scores of each participant on NVA and VF.

Participants satisfied the inclusion criteria of being diagnosed at least 3 years before the study, ranging between 18 and 53 years of age ($M = 41.6$ and $SD = 12.0$), and having NVA between .0 logMAR and 1.3 logMAR and VF of 5 degrees or better.

The group formed for people without visual impairment (control group) ranged between 19 and 49 years of age ($M = 24.5$ and $SD = 7.3$). Eight of them were family members (6 spouses, 1 brother and 1 daughter).

Table 1. Scores of each participant on NVA and VF in RP group

Participants	NVA logMAR	VF
1	.50	10.00
2	.40	5.00
3	.70	5.00
4	.20	10.00
5	.00	15.00
6	1.00	10.00
7	.20	30.00
8	.40	10.00
9	.70	5.00
10	.20	10.00
11	1.30	5.00
12	.00	10.00
13	.00	10.00
14	.20	5.00
15	.40	5.00
16	.20	10.00
17	.40	15.00
18	.00	40.00
19	.20	20.00
20	.40	15.00
21	.20	5.00
22	.40	10.00
23	.20	10.00
24	.20	15.00
25	1.30	10.00
26	.00	40.00

2.2 Instruments

A personal questionnaire was drawn up including items on age, gender, duration of RP, and educational level.

Visual perception was evaluated using the TVPS-3 (Test of Visual Perceptual Skills) (Martin, 2006). This is a standardized test used to assist in determining, in school-age children, the capacity to recognize, interpret or give meaning to what is seen. It uses 112 designs in black and white selected from two levels of a previous edition (*TVPS-R*, Gardner, 1996; *TVPS-UL*, Gardner, 1997). The test contains seven subtests, each of which includes 16 items arranged in order of difficulty. The contents of the seven subtests are listed below.

Visual Discrimination (DIS): Ability to note similarities and differences among forms and symbols and be able to distinguish exact characteristics of two forms among other forms.

Visual Memory (MEM): Ability to recall dominant features of one item or be able to find this form from an array of similar forms.

Visual-Spatial Relations (SPA): Determining the position of objects in relation to each other.

Visual Form-Constancy (CON): Ability to recognize the same form even though it may vary in size, directions, position, or be partially hidden.

Visual Sequential Memory (SEQ): Ability to distinguish a group of forms for immediate recall from similar groups of forms.

Visual Figure-Ground (FGR): Ability to distinguish an object from its background.

Visual Closure (CLO): Identifying forms or objects from incomplete representations.

Their reliability (Cronbach's coefficient alpha) ranges from .75 to .88 for subtests, and .96 for the overall test (Martin, 2006). In relation to validity, the authors indicate that the instrument can be used with confidence to assess visual perception of school-age children (Martin, 2006).

This test was chosen because of its usefulness for both diagnostic and research purposes (Martin, 2006) and because it is the only procedure that can be used for people up to 18 years and 11 months old. Although this test was designed for use up to this age, its application in adults can contribute information related to their visual performance as well as other existing tests (Greer, 2004; Quillman, Mehr & Goodrich, 1981; Trudeau et al., 1990). However, the present study used Raw Scores, rather than standardized scores, because the participants were over the age of 18.

2.3 Procedure

This research study was approved by the Institutional Review Board of the University of Granada. A meeting was held with members of the Andalusian RP Association and their families, to explain the aims and the objectives of the study. Having showed their willingness to participate voluntarily, the sample was selected from those affected with RP who had residual vision. Each of those affected was evaluated for ophthalmology in the parameters of NVA and VF. The monocular and binocular kinetic VF was measured with Goldmann perimetry. Although it is habitual to explore NVA and VF on monocular and binocular vision, in this case we considered only binocular information, because the Test of Visual Perceptual Skills is applied in this way.

The sample formed for people without visual impairment was a group of students selected randomly. They were informed of the characteristics of the study and none were opposed to the use of the information for publication. First they were evaluated on visual perception in order to determine their performance in each subscale. Then each of those affected with RP was asked, together with a family member who did not have RP, (this was confirmed by an ophthalmologic evaluation) to complete a personal questionnaire and both were evaluated in the parameter of visual perception. They were evaluated in separate rooms, to avoid interference. The NVA evaluation and visual perception evaluation were performed at a distance of 30 centimetres with their appropriate correction for refractive errors and accommodation anomalies in the RP group. Informed consent was obtained from all participants.

3 Results

In Table 2 the mean scores and standard deviations are included for each of the subtests for the control group and the RP group. On analyzing the mean scores of each subtest for the RP group, we can see that the subtest with the best mean score is the Visual Memory test ($M = 10.23$, $SD = 3.37$), followed by Visual Discrimination ($M = 9.58$, $SD = 4.10$) and Spatial Relations ($M = 9.54$, $SD = 4.13$). On the other hand, the subtests with the lowest mean scores are the Form-Constancy test ($M = 7.15$, $SD = 3.77$) and the Figure-Ground test ($M = 7.38$, $SD = 4.14$) (see table 2). We can also observe greater standard deviations in the RP group on all scales, which is an indication of greater variability between subjects with RP when compared to the control group with normal vision. We have also included the confidence interval for each subscale in both groups. We can see that none of the intervals overlap, which is evidence of statistical differences between both groups on each of the scales.

We analyzed the number of participants in the RP group whose TVPS was outside the 95% confidence interval for the control group in each of the seven domains. The scale in which there are more participants outside the limit of the confidence

interval is the Visual Discrimination scale, with 24 participants. Next is the Visual Sequential Memory scale (22 participants) and the Visual Closure scale (20 participants). The Visual-Spatial Relations scale, Visual Form-Constancy scale and Visual Figure-Ground scale have 19 participants of the RP group outside the confidence interval of the control group. The Visual Memory scale is the one that shows most overlapping, with only 17 participants outside the confidence interval (Table 2.).

Table 2. Mean, Standard Deviation and Confidence Intervals in Two Groups

	RP Group (n = 26)				Control Group (n = 31)			
			95% Confidence Interval				95% Confidence Interval	
	M	SD	Inf	Sup	M	SD	Inf	Sup
DIS.	9.58	4.10	7.92	11.22	12.06	2.26	11.24	12.89
MEM.	10.23	3.37	8.86	11.59	13.29	1.94	12.58	14.00
SPA.	9.54	4.13	7.87	11.20	13.42	1.78	12.76	14.07
CON.	7.15	3.77	5.63	8.67	10.48	2.05	9.73	11.23
SEQ.	8.31	3.52	6.88	9.72	11.97	1.45	11.43	12.49
FGR.	7.38	4.14	5.71	9.05	11.58	2.59	10.63	12.53
CLO.	8.65	4.41	6.87	10.43	13.42	1.84	12.74	14.09

After a descriptive analysis of the results, a contrast of two median scores was conducted to study the differences between the control group and the RP group (Table 3). Since the supposition of normalcy in the scores was not fulfilled (Siegel, 1991), the non-parametric Mann-Whitney test was applied which analyses the differences in range of the scores between the two groups.

Considering a 0.05 alpha level, it can be concluded that there are statistical differences between the control group and the RP group on all of the subtests (see Table 3).

Table 3. Median Score and Differences between Two Groups

	RP Group (n = 26)	Control Group (n = 31)		
	Med	Med	U	P
DIS.	9.50	12.00	252.0	.007
MEM.	11.00	13.00	190.5	.000
SPA.	10.50	14.00	149.5	.000
CON.	6.50	11.00	191.0	.000
SEQ.	8.50	12.00	124.5	.000
FGR.	6.00	12.00	160.0	.000
CLO.	9.00	14.00	134.0	.000

We also explored the role of NVA and VF in visual perception. To analyse the possible relationship with NVA and VF, the Spearman correlation coefficient was calculated between all subscales in the RP group (table 4). The variables that show a greater correlation with NVA are Spatial Relations ($r = .495$; $p = .010$) and Figure-Ground ($r = .405$; $p = .040$); both present a positive and statistically significant correlation ($p < 0.05$). The remaining subtests show a positive though moderate correlation except Visual Memory, while none are statistically significant.

Table 4. Correlation between NVA, VF and TVPS domains

	NVA (logMAR)		VF	
	Correlation	p	Correlation	p
DIS.	-.356	.074	.107	.602
MEM.	-.147	.473	.073	.725
SPA.	-.495(**)	.010	.349	.080
CON.	-.306	.128	.416 (*)	.035
SEQ.	-.282	.163	.232	.254
FGR.	-.405(*)	.040	.393 (*)	.049
CLO.	-.334	.096	.296	.142

* Correlation is significant to level 0.05 (bilateral).

** Correlation is significant to level 0.01 (bilateral).

The variables that show a greater correlation with VF are Form-Constancy ($r = .416$; $p = .035$) and Figure-Ground ($r = .393$; $p = .049$); both present a positive and statistically significant correlation ($p < 0.05$). The remaining subtests show a positive though moderate correlation except Visual Discrimination, while none are statistically significant.

4 Discussion and Conclusions

The first objective of this study was to determine the state of visual perception of people with RP. The results found support our research hypothesis, since we have confirmed poor scores in people with RP on all of the subtests evaluated, compared to people without visual impairment. Despite the necessity to highlight the great variability that exists among affected people, their difficulty in the interpretation and recognition of what they see was observed. This is made clear on observing that the confidence intervals calculated for each group do not overlap on any of the scales.

Another aim of the present study was to determine on which subtests the participants had most difficulty and on which they had least. The mean scores obtained by people with RP show greater difficulties on Form-Constancy ($M = 7.1$) and on Figure-Ground ($M = 7.3$) concluding therefore, that they have greater difficulty finding an object among others when the size, length, or rotation of the object is varied (Martin, 2006). They showed similar difficulties finding an object among others against a complex background. On the other hand, the subtest on which they showed better performance was Visual Memory ($M = 11.2$), leading us to affirm that they have a good ability to remember or recognize a stimulus after a brief period of time (Martin, 2006). Likewise, the high scores obtained in the areas of Visual Discrimination and Spatial Relations by the RP group suggest that they demonstrate a good ability to find differences and similarities between objects and to determine the position of these (Martin, 2006). This data is also of interest and should be taken into account when planning interventions with these people, in putting into practice psycho-educational treatment programs and in the technological or computerized development of assistance aimed at improving the use of residual vision. The control group also scored better on the Visual-Spatial Relations and Visual Memory domain, and worse on the Visual Form-Constancy domain, when compared to other domains, and these differences appear to be relative and consistent across the groups.

With regard to the final objective of the study, to determine the possible relationship between NVA, VF and performance on the subtests, we observed that as NVA diminishes, people with RP obtain worse results on the Visual-Spatial Relations and Figure-Ground tests, results that alert us to the necessity to pay attention to these aspects when there is evidence of changes in NVA. The Figure-Ground score coincides

with the study by Quillman et al. (1981) which suggested that VA could be an important factor in the ability to complete these tasks. With respect to VF we can also observe its relationship with the domains where the RP group obtained worse results (Visual Constancy and Visual Figure-Ground). For this reason we can conclude that VF restriction influences and determines the performance on these tasks of those affected since peripheral field loss is associated with these tasks (Haymes, et al., 1996).

As has been shown, there are not many studies that analyse the deficiency and the perceptive potential of adults with RP, since their efforts have traditionally focused on the training of children (Greer, 2004), which impedes us from comparing our results. Nevertheless, we think that the findings of our study have important implications in planning interventions and in designing training programs for activities of daily life, of mobility, recreation and social life, since visual perception affects these activities (Brown et al., 2003; Martin, 2006) as well as in the technological or computerized development of assistance aimed at improving the use of residual vision. Neither must one forget the repercussions that this problem has for the education and employment of those affected by it (Nemshick, et al, 1986), or that the training to improve visual function may favour their social and professional integration. However, we are aware that the results should be considered with caution because the size of the sample was small. Additional studies with larger samples will be needed to confirm our findings. Other limitations of the present study are that the majority of the participants are women and the average age of the participants of the control group was younger.

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