Dificultades en el estado emocional de jóvenes afectados por degeneración retiniana y sus familiares

Difficulties in the emotional state of young people affected by retinal degeneration and their families

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Resumen

Varios estudios han resaltado los cambios emocionales y funcionales derivados de la pérdida visual en personas con enfermedades degenerativas de retina, como la Retinosis Pigmentaria (RP). El objetivo del presente estudio era determinar la posible presencia de depresión y/o ansiedad en jóvenes con Retinosis Pigmentaria y sus familiares frente a un grupo sin alteraciones visuales. La muestra estaba compuesta por 78 personas distribuidas en tres grupos: 22 personas afectadas por RP, 22 familiares y 34 personas que formaban el grupo control. Todos ellos fueron evaluados con el Cuestionario de Ansiedad STAI y el Inventario de Depresión de Beck. Los resultados, aplicando un MANOVA y pruebas post-hoc, mostraban depresión leve en los afectados y mayores niveles de ansiedad, como estado y como rasgo, tanto en ellos como en sus familiares. Se concluye recomendando evaluar estas variables tras el diagnóstico de la enfermedad y transcurrido un tiempo, con el fin de proporcionar el apoyo psicológico adecuado tanto a los afectados como a los familiares; ello permitirá resolver posibles problemas asociados al progreso de la enfermedad, mejorar su estado emocional y la calidad de vida de ambos grupos.

Palabras clave: Depresión, Ansiedad, Degeneración Retiniana, Retinosis Pigmentaria, Jóvenes.

Abstract

Several studies have highlighted the emotional and functional changes resulting from visual loss in people with degenerative retinal diseases such as Retinitis Pigmentosa (RP). The aim of this study was to determine the possible presence of depression and / or anxiety in youth with Retinitis Pigmentosa and their families against a group without visual disturbances. The sample consisted of 78 people in three groups: 22 people affected by RP, 22 families and 34 individuals formed the control group. All were assessed with the STAI Anxiety Questionnaire and the Beck Depression Inventory. The results, using a MANOVA and post-hoc tests, showed mild depression in those affected and higher levels of anxiety, state and trait, both in themselves and in their families. It concludes by recommending assess these variables after the diagnosis of the disease and after a while, in order to provide adequate psychological support to both the affected and the relatives, it will resolve any problems associated with the progression of the disease, improve your emotional and quality of life for both.

Key words: Depression, Anxiety, Retinal Degeneration, Retinitis Pigmentosa, Youth.

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Introduction

The stage of youth, especially the transition to adult life, is normally complex for any person, especially when they have a degenerative disease; it is a period in which changes are undergone, maturing and an attempt is made to occupy a position of equality in society (Garaigordobil and Bernarás, 2009). Understanding how young people affected by a degenerative retinal disease, retinitis pigmentosa (RP), feel emotionally and how they and their relatives face its consequences is the reason for this study.

RP is characterized by a progressive loss of vision that can often lead to blindness (Fernández, 2007). It consists of the degeneration of the retinal photoreceptors, giving rise to areas incapable of responding to light stimuli. The symptoms and degrees of involvement are diverse, the most common being loss of peripheral or central vision, difficulty seeing at night or in dim light, difficulty adapting to changes in light, or alterations in contrast sensitivity and in color discrimination (Geruschat & Turano, 2002; Rundquist, 2004). It is a disease with a relatively low incidence, since it affects approximately 1 in 3,700 people, being more common in men (65%) than in women (55%) (Fernández, 2007).

The advance and progress of this is unpredictable and entails a loss of ability to perform certain tasks, causing many affected to perceive themselves more negatively (Kiser and Dagnelie, 2008), perhaps due to their loss of functional ability to perform tasks of life. daily, or development in space, in which they usually have difficulties (Fuhr, Liu, and Kuyk, 2007; Rundquist, 2004). Currently there are no medical solutions or pharmacological treatments for this pathology, just as there are no solutions for other degenerative visual problems. Although it usually begins between the ages of 6 and 12, it is around the age of 20 when it acquires a more disabling character in a good number of people (Gutiérrez, 1995). At this time of great change, they are forced to face the consequences of a progressive disease whose manifestations can influence their education, mobility, socialization, and employment (Nemshick, Vernon, & Ludman, 1986); hence, the appearance of different psychological, educational and social problems is frequent when they are diagnosed and informed of their consequences (Gutiérrez, 1995; Nemshick et al., 1986; Strougo, Badoux, & Duchanel, 1997). Some frequent responses in this population are: social isolation, withdrawal, abandonment of studies or work, depressive symptoms, alterations in their self-concept, etc. (López-Justicia, Fernández de Haro, Amezcua, & Pichardo, 2000; Sacks, Wolffe, & Tierney, 1998), but these responses vary depending on their perception of their illness, personal and social resources, and control. that they exert on the events that affect them (Wahl, Becker, Burmedi, & Schilling, 2004).

If we had to talk about a very common disorder in young people and adults, we would necessarily have to refer to depression, which could become a chronic disorder

that would entail a high personal, economic and social cost (Vázquez and Torres, 2007). The risk of presenting it is greater in groups with special characteristics, justifying the implementation of preventive measures in the presence of a high number of depressive symptoms, even without reaching the depression criteria (Vázquez and Torres, 2007). It is estimated that 25.7% of those affected by RP suffer from it (compared to 10% in the general population), a figure similar to that of other chronic diseases such as diabetes, myocardial infarction and cancer (Hahm, Shin, Shim , Jeon, Seo, Cheng, & Yu, 2008).

Different studies (Hahm et al., 2008; Mogk, Riddering, Dahl, Bruce, & Bradford, 2000) have indicated that people who suffer from a degenerative disease that causes visual restriction have a higher risk of suffering from depression. This may be due to their loss of ability to perform daily or domestic tasks, the belief that they are a burden to their families and their dependence to perform other tasks; because, frequently, they are activities that are seriously damaged (Geruschat and Turano, 2002; Rundquist, 2004). In fact, it appears that it is the functional loss rather than the damage itself that produces the most pain or suffering (Zeiss, Lewinsohn, Rohde, & Seeley, 1996). Other studies have pointed out that people who have a low sense of self-efficacy seem to have a higher risk of depression (Horowitz and Reinhardt, 2000), while those who maintain a feeling of control over their visual condition experience less functional impairment (Wahl et al. al., 2004).

Negative psychological states, such as anxiety and depression, are associated with RP, as highlighted by the studies by Hahm et al. (2008) and de Strougo et al. (1997). The first concluded that their high risk of depression negatively affects the use of their vision and reduces their quality of life. While the second study indicated that women affected by RP had higher levels of anxiety and depression than men.

Despite the few studies that analyze the effect of retinitis pigmentosa on the psychosocial adjustment of affected people and their families, it does seem clear that depression and anxiety are common (López-Justicia, Polo, Fernández, Díaz, Chacón - López, and Chacón, 2011), although it should be noted that the period of greatest crisis or stress occurs during, or immediately after diagnosis (Nemshick et al., 1986).

As noted above, vision loss in RP is unpredictable and brings many changes to the lives of these young people; however, in this process there are social agents, such as the family, whose support or help favor adaptation to progressive vision loss and improve their quality of life (Reinhart, 2001). However, it must be stressed that the family does not always act in the right way. In this sense, Nemshick et al. (1986) pointed out that a very high percentage of those affected considered that the support provided by the family was high, while others complained of overprotection and highlighted that their relatives did not understand their condition, tried to ignore it, or denied the problem; therefore, they suggested that they also receive help, because the consequences of PR affected them equally. Hence, different studies have indicated that families must be trained and receive timely information to know the changes produced in those affected (associated with the degenerative nature of the disease), the capacities they maintain, avoid over-protective attitudes and know how to act to not interfere in their decisions (Cimarolli and Boerner, 2005; López-Justicia and Nieto, 2006).

Apart from these recommendations, it cannot be forgotten that chronic diseases have repercussions both on the well-being and quality of life of those affected, as well as on that of their relatives (Agudelo, Casadiegos, & Sánchez, 2009), making them more vulnerable to depression and / or anxiety.

The main objective of this study is to know the emotional state of adolescents and young people affected by RP, and of the relatives with whom they live. More specifically, taking into account data from previous studies, the objective is to detect the possible presence of depression and/or anxiety in these young people and their families. All this with the purpose of providing suitable information to guide psychological and/or educational intervention, in the process of achieving greater well-being and quality of life for this population and their families. Likewise, as has been highlighted, other investigations have highlighted that depression increases the probability of impairment of the effective use of vision, which would justify the convenience of evaluating this variable and influencing its treatment, if required.

Method

Sample

A total of 78 people participated, distributed as follows: a first group made up of 22 affected by RP, with a mean age of 23 years (SD=4472); a second group, made up of 22 family members of patients with retinosis (mean age=43.2 years; SD=11.25); and a third control group, made up of 34 people (mean age=29 years; SD=7.13), who had not had any contact or relationship with those affected by this disease.

The people affected by RP had a visual field restriction (VC), being between less than 5º and 20º, while all presented a VA between 1 and 0.05 in the best of their eyes, being a criterion for participation in this research have been diagnosed with the disease at least three years before the evaluation and not suffer from any other disease or disability.

Process

First, a meeting was held with the person in charge of the Andalusian Association of Retinitis Pigmentosa to explain the purpose of the study and the characteristics that the participants should have. Since there were some participants who were minors, authorization was requested from their fathers, mothers, or legal guardians. After convening the affected people and their relatives (in the case of minors), they were informed about the objective of the study and the activities to be carried out. Once they expressed their desire to participate voluntarily in the investigation, each affected person was summoned together with a family member. In a laboratory that met the necessary lighting conditions, both completed the different tests (all the questionnaires and answer sheets were adapted to a font size of 14 points, in the case of those affected).

To select the control group, students in the last year of the Psychology degree were invited to voluntarily select and evaluate young people who, homogeneously distributed by age and gender, did not present visual impairment and had not had contact with this problem. The students were trained and supervised in the

administration of the tests and before any indication of doubt about a correct evaluation, they were rejected. 34 participants were randomly selected.

All study participants completed a personal file, the STAI Anxiety test and, subsequently, the Beck Depression Questionnaire. Once corrected and analyzed, the people evaluated were summoned to inform them of the results found, not raising any objection to publishing them.

Instruments

A personal file was designed to obtain information on sociodemographic variables; this collected relevant data for the investigation, such as the year in which the disease was diagnosed or the presence of other health problems.

In order to detect rates of depression, the Beck Depression Inventory (Beck, Rush, Shaw, & Emery, 1979) was administered. The abbreviated version of 13 items was used, with a high correlation (0.96) between both forms (Beck et al., 1979). This version was chosen to make it easier for people with RP to read. In this one you have to choose a sentence from a set of four alternatives, ordered by their level of severity. Each item is evaluated with different response options from 0 to 4, giving a total possible score of 39 points. The following scores are taken into consideration: 0-4 absent depression, 5-7 mild depression, 8-15 moderate depression and >15 severe depression (Joffre, Martínez, García, & Sánchez, 2007).

To assess the possible presence of anxiety, the STAI (State-Trait Anxiety Inventory) State-Trait Anxiety Questionnaire (Spielberger, Gorsuch, & Lushene, 2002) was used, whose objective is to assess transitory states of anxiety in adolescents and adults. This test is composed of two separate scales that measure the independent concepts of state (A-E) and trait (A-R); both consist of 20 items with 4 response alternatives, ranging from 0 to 3. The range in each of the scales is the same, from 0 to 60, although the cut-off point differs: in A-R it is 25 in the population male and 32 in the female, in A-E it is 28 for the male population and 31 in the female.

Results

Below are the mean scores, corresponding to the variables of anxiety (state and trait) and depression, observed in each of the groups are included in Table 1.

Table 1. Mean scores and standard deviations in anxiety and depression of the three groups.

	Grupo RP		*Grupo familia*		*Grupo control*				
	Media	*DT*	*Media*	*DT*	*Media*	*DT*	*F*	*P*	*Potencia*
AE	18.53	10.823	18.14	9.046	12.44	8.232	4.71	0.011	0.776
AR	20.92	9.663	19.77	10.533	15.29	9.226	3.76	0.027	0.676
Depresión	4.9	4.210	2.50	4.728	2.06	2.752	4.85	0.010	0.788

First, the analysis focused on comparing the anxiety (state and trait) and depression scores of the three groups, applying a MANOVA, previously ensuring compliance with the assumptions of this technique (Box's M=21.89, p>0.05). The results indicated the existence of significant differences between the groups (Wilks' Lambda=0.301, F3, 83=63.0; p<0.001), showing that the groups differ in global terms in the three measures: state anxiety [F2, 85 =4.82 ; p<0.05], trait anxiety [F2, 85=3.66; p<0.05] and depression [F2, 85 =4.93; p<0.05] (Table 2).

Next, the differences between the groups were studied with post-hoc tests (Bonferroni test) (Table 2), confirming that the RP group scored higher on the three scales, finding significant differences with the control group on the three measurements: state anxiety (p<0.05), trait anxiety (p<0.05) and depression (p<0.05).

Table 2. Post-hoc tests of the three groups in the variables of anxiety and depression.

			Diferencia de medias	*Error típ.*	*p*	*IC al 95%.*	
						L. inferior	*L. superior*
AE	RP	Familia	1.43	2.734	1.000	-5.25	8.10
	Familia	Control	5.70	2.701	0.114	-0.90	12.29
	Control	RP	-7.12	2.431	0.013	-13.06	-1.18
AR	RP	Familia	1.95	2.692	1.000	-4.63	8.52
	Familia	Control	4.48	2.660	0.288	-2.02	10.98
	Control	RP	-6.42	2.394	0.026	-12.27	-0.58
Depresión	RP	Familia	2.38	1.070	0.087	-0.24	4.99
	Familia	Control	0.44	1.057	1.000	-2.14	3.02
	Control	RP	-2.82	0.952	0.012	-5.14	-0.49

Nota: AE – Ansiedad estado, AR – Ansiedad rasgo

Regarding the family group, the descriptive statistics showed that the mean anxiety scores were close to the RP group. In fact, post-hoc tests showed that there were no differences between these two groups in measures of anxiety ($p>0.05$). On the contrary, in terms of depression, the mean of the family group is closer to the control group, but when comparing the mean difference between the PR group and the family group, although not statistically significant, it is observed that the p- value is close to the critical value ($p=0.08$).

When comparing the scores between the family and control groups, we again find that, although the differences are not statistically significant in the state anxiety scores, the p-value is low (AE $p=0.114$; AR $p=0.288$). . A larger sample size could show

differences between these groups in anxiety. In the measure of depression, the differences between the control group and the family group are not statistically significant.

conclusion

The purpose of this study was, first of all, to know the emotional state of young people affected by RP in front of a group of relatives and another group of people without any visual disability. The results show that anxiety, both as a state and as a trait, is greater in young people with RP and in their relatives, and may be due to a feeling of threat or anticipation of future damage, understandable due to the degenerative nature of RP. If the RP group is compared with the control group, it is observed that the 1st moves away from the control group in the two measures of anxiety. Regarding relatives, it is detected that the anxiety scores are close to the RP group, coinciding with other studies that suggest that the effects of a chronic and progressive disease, such as the one analyzed, can negatively affect the well-being and family climate of the relatives. who suffer from it and those with whom they live (Agudelo et al., 2009; Nemshick et al., 1986).

Our results show the presence of mild depression in the affected young people (Joffre et al., 2007), while it is observed that the scores of the family group are close to the control group, obtaining a p-value close to the critical value when compares the family group and the RP group, data that indicates that the family group does not seem to show symptoms of depression.

It is confirmed that being affected by a disease such as RP seems to be a negative event in the lives of those affected, which undoubtedly can have some repercussion on their emotional state and on their vision of themselves, the world and the future; although their levels of depression (in the limit of that classified as mild) suggest that they may have adapted to the disease, but not to its consequences. According to the study by Nemshick et al. (1986), the period of greatest crisis or stress occurs during or immediately after diagnosis, which could explain our results, since the participants had been diagnosed at least three years earlier.

We believe that the psychological discomfort manifested by young people with RP, translated into higher scores in anxiety and depression, could be related to the fear of the progression of their visual problem, and its repercussion on functional autonomy or on their sense of self-efficacy. as other authors have pointed out (Horowitz and Reinhardt, 2000; Mogk et al., 2000; Rundquist, 2004; Wahl et al., 2004; Zeiss et al., 1996). Fear that family members also seem to show, which perhaps explains their anxiety scores.

We agree with other authors (Augustin, Sabel, Bandello, Dardennes, Maurel, Negrini, Hieke, & Berdeaux, 2007; Hahm et al., 2008; Nemshick et al., 1986; Strougo et al., 1997) in the suggestion to evaluate the aforementioned variables after the diagnosis of the disease, as they are considered indicators of the lack of emotional adjustment to the chronic disease (Sánchez, Aparicio, & Dresch, 2006). Knowledge of these variables would make it possible to prevent the risk of depression, since there are arguments that the presence of a high number of depressive symptoms increases the risk of presenting it later, especially in groups with special characteristics (Vázquez and Torres, 2007). Our results also allow us to suggest a new evaluation some time after diagnosis to find out how they are.

If we look at the data obtained, the recommendation to offer psychological support to reduce psychological pain, prevent depression (Augustin et al., 2007; Vázquez and Torres, 2007) and, in this way, improve functioning seems obvious. vision (Hahm et al., 2008). Since RP is a lifelong disease with no current medical or pharmacological treatment options, this type of support can improve the quality of life for those affected. Likewise, family members should receive some type of psychological intervention that allows them to be in a position to face the consequences of this pathology. Their anxiety scores alert us, showing similarities with the RP group.

Understanding how these young people feel, how they cope with their illness, and how they can be helped to understand and cope with their situation would mean improving their quality of life (Bittner, Edwards, & George, 2010). As Herse (2005) points out, the simplest of interventions can greatly improve your personal status and well-being. For all these reasons, collaboration and action with these young people and their relatives

to explain the peculiarities of the disease and offer expert advice becomes a fundamental aspect.

Regarding the implications derived from this study, we believe that it provides interesting data for psychological intervention with this population, although aspects such as the small size of the sample represent a limitation in the generalization of the results. Similarly, the intentional nature of the sampling, due to the fact that only volunteers belonging to an association of affected people have participated, prevents us from knowing how other affected people are doing. However, as a counterpart, an attempt has been made to balance the groups with respect to sociodemographic characteristics to ensure greater comparability.

On the other hand, the method for diagnosing depression has not been done following conventional criteria, but rather through a self-report questionnaire; however, this has been confirmed as a good screening method. Although an abbreviated version has been used, the correlation between the two versions is high (.96) (Beck et al., 1979). Another limitation may be that it has been evaluated only once, not finding out if depression was greater after diagnosis, as pointed out by Nemshick et al. (1986).

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