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Age, Educational Level and Gender in Self-concept of People with Retinitis Pigmentosa

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Titulo: Edad, nivel educativo y género en autoconcepto de personas con retinitis pigmentaria.
Resumen: Puesto que el autoconcepto juega un papel importante en la personalidad y puesto que este concepto puede estar alterado por la presencia de una enfermedad como la retinosis pigmentaria, la principal cuestión que se planteaba el presente estudio era conocer la relación entre variables como la edad, nivel de estudios y el género en el autoconcepto de 35 adultos afectados por esta problemática. Se utilizó la Escala de Autoconcepto Tennessee (Fitts, 1965) y un cuestionario de información sociodemográfica. Los resultados mostraban que la edad estaba asociada al autoconcepto moral, siendo más alto en personas mayores, aunque más reducido su autoconcepto familiar. Las personas con menor nivel de estudios obtuvieron una media más baja en autoconcepto físico. En relación al género, los resultados mostraban que las mujeres tenían mayor autoconcepto físico que los hombres. Se concluye recomendando intervenir en los primeros años tras el diagnóstico de la enfermedad, para paliar sus efectos en el bienestar psicológico de los afectados y asesorar a ellos y a sus familias para evitar distorsiones en las vidas de ambos.
Palabras clave: Edad; educación; género; autoconcepto; retinosis pigmentaria.

Abstract: Since the construct of self-concept plays a key role in personality and because this concept can be weakened by the appearance of a serious disease such as RP, the research question of the present study was to examine the relationship between age**,** educational level and gender in the self-concept of 35 adults with this diagnosis. The instrument used was the Tennessee Self-Concept Scale and one questionnaire for demographic, socioeconomic and educational information. The results showed that age was associated with moral self-concept, which was higher in older persons. Family self-concept, however, was lower in older persons. Less educated persons had a lower mean physical self-concept. In relation to gender the results showed that women had a higher physical self-concept than men. We conclude that intervention during the initial years after diagnosis should be designed to palliate the effects of retinitis pigmentosa on psychological well-being and to provide counseling for individuals and their families to reduce disruptions in family life.
Key words: Age; education; gender; self-concept; retinitis pigmentosa.

Introduction

Retinitis pigmentosa (RP) is a degenerative disease of the retina that affects approximately 1 in every 5000 people, it is more common in men (65%) than in women (55%) (Fernández, 2007; Gutiérrez, 1995). With this disease a genetic alteration leads to photoreceptor degeneration (Adler, 2002) and clinical features 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 color discrimination (Geruschat & Turano, 2002; Rundquist, 2004).

Onset generally occurs between the ages of 6 and 12 years, but in many people, difficulties become notable at approximately 20 years of age (Fernández, 2007; Gutiérrez, 1995), an age when people begin to think about their future career and personal life. A diagnosis of RP during this period of life means that the individual, already facing substantial life changes (educational, social, work-related), must also cope with the consequences of a disease with symptoms that can have a considerably adverse effect on education, mobility, socialization and employment (Nemshick, Vernon & Ludman, 1986). For this reason special counseling is needed to help these people accept and adjust to the condition (Nemshick *et al*., 1986).

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In hierarchical self-concept models, a general construct such as self-concept represents a super-ordinate or high-order category under which subcategories of the self or low order dimensions are organized (Esnaola, 2008; Shavelson, Hubner & Staton, 1976). The construct of self-concept, the ordered set of attitudes and perceptions an individual holds about him- or herself (Harter, 1999), comprises three main elements: (1) identity of the subject or self-image, which refers to the perception or mental representation of him- or herself, i.e., the cognitive aspect of self-concept; (2) self-esteem, which is related to the value individuals attach to the particular manner in which they see themselves (González & Tourón, 1994), and which represents the affective or valuation component of self-concept (Amezcua & Pichardo, 2000); and (3) a behavioral component, which reflects how self-concept influences and conditions the subject's behavior. Self-esteem is related to how we feel about, or evaluate ourselves, in contrast to self-concept which is both descriptive and evaluative (González & Tourón, 1994). Self-concept was considered a unitary construct with a unidimensional structure; however, some studies have revealed the multidimensional structure of self-concept (Harter, 1999; Marsh & Hattie, 1996).

Self-concept is considered important because it has often been claimed to play a key role in the personal, professional and social life of individuals (Markus & Kitayama, 1991). It has also been said to provide a frame of reference from which to interpret external reality and one's own experiences; to influence educational, social and occupational performance; to motivate and guide behavior; and to contribute to health and mental equilibrium (Markus & Kitayama, 1991). A positive self-concept is related to the ability to cope

with the consequences of disability, a positive outlook on life, and a greater degree of commitment and social participation, whereas a negative self-concept has negative repercussions on physical and mental health and is related to depression and isolation (Smith, Nolen-Hoeksema, Fredrickson & Loftus, 2003).

Tuttle (1984) stated that although all people are susceptible to threats to the development of a positive self-concept, people with visual impairment are at an even greater risk. He stated that a sense of competence and the perceptions of others were important influences on the individual's self-concept.

Martínez & Sewell (1996) stated that the self-concept of people with visual impairment may depend on two possible factors. The first factor is the individual's perceived similarity to the group in which she or he operates. The second factor is whether or not that person has some forum in which to demonstrate competence.

Some research findings have indicated that people with chronic illness or physical disabilities tend to have lower self-concepts than those who do not suffer from these problems (Tam & Watkins, 1995). There have also been documented differences between adults with RP and adults without visual problems in family self-concept (López-Justicia & Nieto, 2006), although this study also found an absence of differences in the personal, moral, ethical, social and physical self-concept**.** However, it is not known how the degenerative character of RP may affect the self-concept of men and women with RP with respect to age. Nor is it known what role level of education plays in this process. This aspect is of interest since it may affect employment (Kirchner, Schmeidler & Todorov, 1999).

Longitudinal research has shown that behavioral and emotional adjustment in older adults who are visually impaired worsens over time (Heyl & Wahl, 2001). It is also known that age and gender influence how a person adapts to RP. A study of people with RP by Strougo, Badoux & Duchanel (1997) found that women showed more sensitivity to others (they felt inferior or more injured), more anxiety- and depression-related behaviors and more phobias than men with this disease, and that the problems worsened with age.

Earlier studies have documented gender differences in the self-concept of people with visual disabilities such as low vision and blindness. For example, Cálek (1980) found that blind men had a more positive and realistic self-concept than blind women. Rasonabe (1995) also reflected these differences in a study and found that women scored higher in personal identity, physical, family and social self-concept, while men scored higher in self-satisfaction and moral-ethical self-concept. In another study, López-Justicia & Pichardo (2001) found that young women had lower self-perception than young men in social self-concept, family self-concept and moral self-concept, although their physical self-concept was higher.

In relation to the impact of RP on education, Nemshick *et al.* (1986) found that students with RP felt that their visual impairment affected their school work, although in most cases their problem was still in the early stages.

Nevertheless, to our knowledge there are no published studies that analyze the relationship age, educational level and gender in the self-concept of men and women with RP. Because the construct of self-concept plays a key role in personality and since this concept can be weakened by the appearance of a serious disease such as RP (López-Justicia & Nieto, 2006), the research question of the present study was to examine the relationship between age**,** educational level and gender in the self-concept of adults with this diagnosis.

Method

Participants

This study involved a total of 35 people with RP (15 men and 20 women). These participants ranged from 19 to 60 years of age, with a mean age of 35 years (SD = 13.19). All had residual vision, although all had reductions in visual field (VF). Visual field was between 5 and 10º in 16 participants, between 10 and 20º in 11 participants and more than 20 º in 8 participants. Visual acuity (VA) was diminished in 23 people, ranging between 20/80 and 20/400 as measured with the Wecker Scale. All participants could comfortably read a larger size of type (between 14 and 16 points) with high contrast.

Regarding sociocultural characteristics, 27 of the participants were single and eight were married (four men and four women). Regarding level of education, 4 had primary school education, 15 had attended secondary or technical school, and 16 had some university-level education (10 women and 6 men).

Concerning employment status, eight participants were unemployed (economic support), seven were students, 16 were employed (in 3 cases as lottery ticket sellers and four had retired.

Participants satisfied the following inclusion criteria: aged between 19 and 60 years, diagnosed with RP but with some residual vision, diagnosed at least 3 years before the study, and no auditory or motor disability.

Materials

The instrument used was the Tennessee Self-Concept Scale (TSCS) developed by Fitts (1965). This instrument was chosen because it is easy to administer, has been standardized, and covers a complete range of psychological adjustment indicators (Fitts, 1965; Fitts & Warren, 1996). Validity of the instrument was verified by Garanto (1984), who found a reliability (according to the Kruskal-Richardson test) of .87 for physical self-concept, .80 for moral/ethical self-concept, .85 for personal self-concept, .89 for family self-concept, and .90 for social self-concept. The TSCS has been

used in other studies of people with characteristics similar to those of the subjects of the present study (Johnson & Johnson, 1991; López-Justicia & Nieto, 2006; Martínez & Sewell, 1996). This instrument provides information on the multidimensional structure of self-concept, a factor now considered essential in such instruments.

The scale consists of 100 statements, 45 of which are expressed affirmatively and 45 negatively. The remaining 10 questions are items related to self-criticism, and are from the L scale of the MMPI (Hathaway & McKinley, 1943). Subjects who score high on the entire 100-item scale are considered to have a high self-concept; low scores are taken to indicate the opposite. The self-descriptive items are classified in five specific components or subscales that evaluate specific aspects of self-concept. These are: personal self (valuation of his/her personality; includes items such as "I'm happy with who I am"), family self (how the subject feels in the family; includes items such as "My family will always help me"), moral/ethical self (moral or ethical valuation, moral worth or satisfaction with one's religion or lack of it; includes items such as "I think I do the right thing most of the time"), social self (social relations; includes items such as "I get along well with other people") and physical self (valuation of his/her appearance and physical condition; includes items such as "I like the way I look").

The self-descriptive statements allow the individual to portray his or her own self-picture using five response categories: "Always False", "Mostly False", "Partly False and Partly True", "Mostly True" and "Always True".

Information on demographic and socioeconomic characteristics was obtained with a questionnaire including items on age, duration of RP, visual capabilities, educational background, employment background, current employment and marital status. The questionnaire for demographic information was compiled for this study.

Procedure

The first step in sample recruitment consisted of an in-person contact with members of two chapters of the Spanish RP Association in two cities. After a meeting during which the aims of the study were explained, participants were randomly selected from all members of the two chapters of the Spanish RP Association. Each participant was given a copy of the questionnaire for demographic, socioeconomic and educational information, and a copy of the TSCS to be completed by participants who fulfilled the eligibility criteria. The format of the printed scale was adapted to improve contrast and a larger size of type (between 14 and 16 points), which the participants could read comfortably, was used. The investigators were always available in person, by telephone and via e-mail to deal with any questions that arose. Informed consent was obtained from all participants. They were informed that the results of the study might be published, and none were opposed to this for reasons of privacy. The participants supported publication since they felt it would increase knowledge and understanding of their condition

Results

For the comparison of subjects according to our research question and since they were taken as independent samples, we opted for the use of a nonparametric test. Mann-Whitney's U test was used because of the small size of the sample and, consequently, of the subgroups of subjects being considered.

Statistical analysis was effected with the SPSS statistical package, v. 15.0.1. The initial bivariate analysis of correlations showed that the variable age was associated with moral-ethical self-concept (r = .47, p = .00), indicating that the older the participant, the greater the score on this type of self-concept. Table 1 shows the mean values obtained for the complete sample, in the different components of self-concept, as well as the standard deviations. The sample was divided into two groups of participants using the 50 percentile as the cut-off point. Two groups, homogeneous in number of subjects, were obtained in this way, one of subjects under 35 years of age and the other of subjects 35 years of age or older. We tested differences between the means with Mann-Whitney's nonparametric U test. As shown in Table 1, the two age groups differed significantly only in the two components of moral-ethical self-concept (U = 72, p = .02) and family self-concept (U = 78, p = .04). Older age was associated with a higher score for the moral-ethical component, with mean values of 66.11 in those younger than 35 years and 70.86 for those above this age. In contrast, the mean score for the family dimension of self-concept was higher in the younger age group: 68.53 for those younger than 35 years and 63.50 for those above this age. On the other hand, as shown in Table 1, no significant differences were found in the physical self-concept, personal self-concept or social self-concept components.

Participants were also compared on the basis of educational level to look for possible differences in self-concept. The sample was divided into two groups: those with primary or secondary school education only (n = 17), and those with university-level education (n = 16). Again, the Mann-Whitney U test detected significant differences in physical self-concept (U = 73.50, p = .04) (Table 2). People with a lower level of education scored lower on physical self-concept (mean = 56) than those with a university education (mean = 62). No other comparison between these two groups for different components of self-concept was significant.

Table 1: Differences between age groups in the components of self-concept.

	Mean	SD	Mann-Whitney U	Mann-Whitney P	Mean score for two groups		SD
Physical self-concept	58.79	9.93	112.00	.44	35 years of age	60.26	8.59
					> 35 years of age	56.79	11.52
Moral self-concept	68.12	5.74	72.00	.02	< 35 years of age	66.11	5.48
					> 35 years of age	70.86	5.03
Personal self-concept	64.85	7.52	103.50	.28	< 35 years of ag	66.32	6.76
					> 35 years of age	62.86	8.28
Family self-concept	66.39	7.52	78.00	.04	< 35 years of age	68.53	6.45
					>35 years of age	63.50	8.12
Social self-concept	64.67	7.14	118.50	.60	< 35 years of age	65.47	6.75
					>35 years of age	63.57	7.75

Differences significant at $p < .05$

Table 2: Differences between participants of different levels of education in self-concept components.

	Mann-Whitney U	Mann-Whitney P	Mean score for two groups		SD
Physical self-concept	73.50	.04	Primary or secondary school education group	56	6.60
			University-level education group	62	12.01
Moral self-concept	120.50	.78	Primary or secondary school education group	68.69	5.12
			University-level education group	8.19	6.06
Personal self-concept	127.0	.97	Primary or secondary school education group	65.56	6.09
			University-level education group	64.94	8.48
Family self-concept	101.00	.31	Primary or secondary school education group	65.75	6.13
			University-level education group	67.75	8.48
Social self-concept	117.00	.68	Primary or secondary school education group	65.25	6.37
			University-level education group	64.69	7.84

Differences significant at $p < .05$

The final comparison sought to identify differences between men and women with RP. We found that the mean score for physical self-concept was higher in women (22.26) than in men (19.43), and that according to the Mann-Whitney U test this difference was statistically significant ($U = 77$, $p = .04$) (Table 3). No significant differences between men and woman were found in other components of self-concept.

Table 3: Differences between genders in self-concept components.

	Mann-Whitney U	Mann-Whitney P	Mean score for two groups		SD
Physical self-concept	77.00	.04	Men	19.43	3.52
			Women	22.26	3.61
Moral self-concept	98.00	.19	Men	67.36	3.47
			Women	68.68	7
Personal self-concept	103.00	.27	Men	66.71	6.06
			Women	63.47	8.32
Family self-concept	128.50	.86	Men	66.64	6.61
			Women	66.21	8.30
Social self-concept	102.50	.26	Men	66.21	6.25
			Women	63.53	7.69

Differences significant at $p < .05$

Discussion and Conclusions

Our results show that in our sample of people with RP, women perceived themselves in a more positive manner than men in terms of physical self-concept, with a better acceptance of their own body and their visual impairment, and taking greater interest in their physical appearance and fitness. This finding is consistent with earlier studies of adolescents and adults with different visual impairments (López-Justicia & Pichardo, 2001; Rasonabe, 1995), although it is necessary to point out that some differences exist between these studies and ours in terms of the visual condition and age of the participants. Rasonabe's (1995) study was conducted with blind students, whereas the participants of our study have low vision, and the participants in the study of López-Justicia & Pichardo (2001) were adolescents, while participants in our research study are adults.

With regard to men, we think that there are two possible explanations for the more negative perception of their bodies and their health. The first possibility is that they pay more attention to what makes them different from others, than to their similarities (Buss, 1980). The second possibility is that they have a more realistic self-concept than women. This point of view agrees with that put forth in Cálek's (1980) study.

When we considered educational level we again found differences in physical self-concept, a finding that may be attributable to a feeling of success or recognized status in a specific field and the perceptions of others (Martínez & Sewell, 1996; Tuttle, 1984). According to Nemshick *et al.* (1986), students with RP feel that their visual impairment affects their school work. If we observe the number of participants in the study, we can confirm that nearly half of them have universitary studies. It is easy to assume that if they were capable of completing their university studies despite the limitations and difficulties associated with RP, it was due to their strength and personal competence as well as

an acceptance of their own body and their visual impairment, which could have influenced their physical self-concept.

When we looked at the influence of age, we found that participants over 35 years old with RP felt more satisfied with their moral or ethical values, moral worth or satisfaction with their own conduct, and a sense of being able to control their own impulses and behavior (Fitts, 1965; Fitts & Warren, 1996). It seems that as they grow older, their beliefs or ethical values allow them to feel better about themselves. Although we did not find studies that analyzed this aspect in people with RP, according to other research (Heyl & Wahl, 2001; Strougo *et al*., 1997) behavioral and emotional adjustment in older adults who are visually impaired worsens over time.

The results for the family component of self-concept suggested that as persons aged they felt worse about their place in the family, were dissatisfied with their family circle, or showed signs of not feeling well accepted or well loved by other members in their immediate circle (Fitts, 1965; Fitts & Warren, 1996). Since previous research on participants with RP and without RP also found differences in family self-concept, we think perhaps it may be necessary for individuals with retinitis pigmentosa and their families to improve their personal well-being, and the quality of communication between family members and to favor better relationships (Cimarolli & Boerner, 2005; López-Justicia & Nieto, 2006). According to Reinhart (2001), who investigated different types of social support related to adjustment to vision loss, instrumental help from family members was associated with better adaptation to the situation.

The implications of the present study are important because they offer clues that can enhance the intervention process for people with degenerative diseases of the retina such as RP. Our findings underscore the importance of level of education in physical self-concept of people with RP, the effect of age on moral-ethical self-concept and the differences between men and women in physical self-concept. We think that this latter result is encouraging for women, especially in the light of the media's tendency to perpetuate the idea of a "perfect," eternally young, eternally healthy body as particularly desirable for women (Baz, 2000).

Another important implication of the present study is related to family self-concept. Future intervention efforts during the initial years after RP is diagnosed should aim to palliate the negative effects of the disease on family self-concept, and to provide counseling for individuals and their families to avoid serious disruptions in family life. We must not forget that according to Reinhardt (2001) instrumental help from family members was associated with better adaptation to the situation.

Although these findings are interesting, we are aware that the results reported here 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. Future research should also analyze consideration of employment status.

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