

Research Report

The Self-concept of Spanish Young Adults with Retinitis Pigmentosa

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Retinitis pigmentosa (RP) is a degenerative disease of the retina that causes the severe impairment of visual functioning similar to low vision, leading, in many cases, to blindness (Geruschat & Turano, 2002; Rundquist, 2004). The disease induces the breakdown of the photoreceptors (rods and cones) in the retina. Because these structures are highly specialized, any defect in their function, no matter how slight, can affect vision. Changes in the structure and metabolism of the photoreceptors are the result of alterations in genes, and the failure of any of the many genes that are involved in the functioning of the photoreceptors can lead to changes in vision (Adler, 2002).

The symptoms and degrees of impairment can vary, the most common features being the loss of peripheral or central vision,

weakened vision at night or under poor lighting conditions, problems adapting to changes in lighting, or changes in color discrimination (Geruschat & Turano, 2002; Gutiérrez, 1995; Rundquist, 2004).

RP is one of the more common retinal dystrophies in the world (Gutiérrez, 1995). In Spain, there are as many as 15,000 known cases, and there are an estimated 480,000 carriers of the gene who are potentially able to pass it on to their offspring (Gutiérrez, 1995). The progressive nature of RP and the degree of associated disability lead to substantial lifestyle changes in persons who have the disease and to the appearance of psychological, educational, and social problems once these individuals are diagnosed and informed of the consequences of RP (Gutiérrez, 1995). People differ in how they cope with especially problematic or stressful life events, depending on their individual characteristics, heredity, education, upbringing, and social relationships (Smith, Nolen-Hoeksema, Fredrickson, & Loftus, 2003). As a result, many persons who are faced with visual impairment, including RP, have difficulty coping and display characteristic responses, such as social isolation, withdrawal, quitting education or work, depressive symptoms, and an altered self-concept (Wolffe, 1996).

Because the construct of self-concept plays a key role in personality (Harter, 1999; Machargo, 1997), this study was designed to measure self-concept in a group of young adults with RP. The term *self-concept*, the ordered set of attitudes and perceptions that an individual holds about himself or herself (Harter, 1999; Machargo, 1997), is comprised of three main elements: (1) identity (self-image)--individuals' perceptions of themselves in relation to cognitive aspects; (2) self-esteem--the values (expressed as affective or valuation components) that individuals attach to the manner in which they see themselves; and (3) a behavioral component, reflecting how self-concept influences and conditions individuals' behavior (González & Tourón, 1994). The concepts of self-esteem and self-concept are

interrelated and complementary, such that a positive self-concept implies positive self-esteem, and vice versa (Machargo, 1997).

Self-concept can be considered important because it has often been claimed to play a key role in a person's personal, professional, and social lives by favoring the sense of the person's own identity. It has also been said to provide a frame of reference from which to interpret external reality and one's experiences; to influence one's educational, social, and occupational performance; to motivate and guide one's behavior; to condition one's expectations; and to contribute to one's health and mental equilibrium (Machargo, 1997; Markus & Kitayama, 1991). A high self-concept is related to the ability to cope with the consequences of a disability, a positive outlook on life, and a greater degree of commitment and participation, whereas a low self-concept has negative repercussions on physical and mental health and is related to low self-esteem, depression, and isolation (Smith et al., 2003).

Earlier studies documented an altered self-concept in children, adolescents, and adults who are blind or have low vision (Beaty, 1992; López-Justicia, Pichardo, Amezcua, & Fernández de Haro, 2001; Tuttle, 1984). However, in other studies (Martinez & Sewell, 1996; Sherrill, Hinson, Gench, Kennedy, & Low, 1990) of adults who were visually impaired, differences in self-concept were not found. Although some studies have documented the effect of visual impairment on the self-concept of people who are visually impaired, no studies have examined the effect in people with a degenerative disease, such as RP. The nature of this disease and its degenerative nature make it important to identify its effects on self-concept, and the present study was designed to investigate this important variable in young adults who had RP for several years.

METHOD

Participants

The participants were 45 Caucasian adults aged 19-35, who were studied in two groups: 22 people with RP and some residual vision who had no other impairments and had been diagnosed with RP at least three years before the study, and 23 with no known visual impairment. The socioeconomic and educational levels were the same in both groups. The participants were matched for age, level of education, marital status, and gender.

The group with RP consisted of 10 men and 12 women who were all members of a local chapter of the Spanish Retinitis Pigmentosa Association. All had residual vision, although all had diminished visual fields. Visual acuity was decreased in 10 individuals, with values ranging from 20/80 to 20/400, as measured with the Wecker Scale. Only six of these participants had received orientation and mobility training, a service given in Spain exclusively to members of ONCE (Organización Nacional de Ciegos Españoles).

Twenty of the participants with RP were single, and 2 (1 man and 1 woman) were married. Three participants had a primary school education, 7 had a secondary school or technical school education, 7 were college graduates, and 5 had graduate degrees.

Of the 22 participants with RP, 7 were unemployed and receiving economic support, 3 were employed by ONCE as lottery ticket vendors, 8 were employed in the labor market, and 4 were students.

The control group of 23 people with no known visual impairment or other impairment consisted of 12 men and 11 women aged 19-35, who were chosen at random among persons in the cities of Oviedo and Granada who agreed to complete the questionnaire. Of the 23, 19 were single and 4 (2 men and 2 woman) were married. Seven individuals had a primary school education, 7 had a secondary school or technical education, 4

were college graduates, and 5 had graduate degrees. With regard to their employment status, 15 were employed, 4 were students, and 4 were seeking employment.

Instruments

The instrument used, the Tennessee Self-Concept Scale (TSCS) developed by Fitts (1965), was chosen because it is easy to administer, has been standardized, and covers a complete range of indicators of psychological adjustment (Fitts, 1965; Fitts and Warren, 1996). The reliability and validity, according to the Kruskal-Richardson test, are between .88 and .98 (Garanto, 1984).

The scale consists of 100 self-descriptive items that are classified in five subscales that evaluate specific components of self-concept: personal, family, moral-ethical, social, and physical self. High scores on the entire 100-item scale are considered to indicate a high self-concept, whereas low scores are taken to indicate a low self-concept.

Information on the participants' demographic and socioeconomic characteristics was obtained from a questionnaire. The questionnaire included items on age, duration of RP, visual capabilities, educational background, employment background, current employment, and marital status.

Procedure

Members of two chapters of the Spanish Retinitis Pigmentosa Association in two Spanish towns (Oviedo and Granada) were recruited as potential participants. Those who expressed their willingness to participate and met the eligibility criteria were given copies of the questionnaire for demographic, socioeconomic, and educational information and copies of the TSCS. The layout of the printed scale was adapted to improve contrast, and a larger size of type (between 14 and 16 points) was used so that the participants could read comfortably.

RESULTS

The data for the study and control groups were compared with an appropriate *t*-test for differences of the means for independent groups depending on homoscedasticity (SPSS statistical package, v. 12.0). Mean scores and standard deviations were calculated for each self-concept subscale for the two groups (see [Table 1](#)). The participants with RP scored significantly lower on the family self-concept subscale, $t(43) = -2.278, p < .008$ (using the Bonferroni procedure: corrected alpha = desired alpha/number of independent test), but no significant differences were found in the moral-ethical self-concept, $t(43) = .18, p < .85$; physical self-concept, $t(43) = -1.08, p < .28$; personal self-concept, $t(43) = .61, p < .16$; or social self-concept, $t(43) = .54, p < .24$, subscales.

DISCUSSION

The lower scores for family self-concept indicated that the participants with RP rated themselves poorly as members of their families, were unsatisfied with their family members, or showed signs of not feeling well accepted or well loved by others in their immediate family circle (Fitts & Warren, 1996). This finding points to the need for measures to help people with RP modify their perceptions of their families, in light of the evidence that they feel less useful to their families or that they are a burden to their families. Because this situation is likely to generate conflicts that can affect family environment and functioning, intervention programs may be necessary for individuals with RP and their families to improve their personal well-being and the quality of their communication and relationships. With such a program, the family members will have a better understanding of the changes that are associated with RP and will know when and how to help (Cimarolli & Boerner, 2005). According to Reinhart (2001), this understanding is fundamental because instrumental help from family members is associated with better adaptation to vision

loss. The family members must also know the potential capabilities of their relative with RP and avoid protective attitudes that could cause family conflicts; reduce the relative's opportunities to learn various skills, including social interaction skills; restrict the relative's social contacts; and limit the relative's independence.

Support should also be oriented toward helping individuals with RP, so they understand that their current competencies are based on their own perceptions and that once they discover where their difficulties lie, their family self-concept can be reformulated (Fitts & Warren, 1996). This goal is important because high levels of self-concept are related to success in coping with the consequences of RP, a positive attitude toward life, and a greater degree of commitment and involvement, whereas low self-esteem has negative repercussions on physical and mental health and is related to low self-worth, depression, and isolation (Smith et al., 2003).

This study also found an absence of significant differences between the two groups in scores on the rest of the subscales. These findings coincide with those of other studies (Martinez & Sewell, 1996; Sherrill et al., 1990); however, differences in family self-concept were not found in these studies.

The most useful aspect of the study is that it documented the problems that adults with RP can have with family self-concept. Although this finding is interesting, it cannot be compared to the results of earlier studies of adults with RP because no similar studies appear to have been conducted.

We are aware that this study had limitations; for example, the method that was used in selecting the participants makes it difficult to generalize the results to the entire population of adults with RP. The results should also be considered with care because of the relatively small sample. Additional studies with larger samples are needed to confirm our findings.

REFERENCES

- Adler, R. (2002). La búsqueda de tratamiento para las enfermedades retinianas: Lecciones derivadas de la biología molecular y del desarrollo [Investigation of the treatment of retinal disorders: Lessons derived from molecular and developmental biology]. *Visión, 20*, 22-24.
- Beaty, L. A. (1992). Adolescent self-perception as a function of vision loss. *Adolescence, 27*(107), 707-714.
- Cimarolli, V., & Boerner, K. (2005). Social support and well-being in adults who are visually impaired. *Journal of Visual Impairment & Blindness, 99*, 521-534.
- Fitts, W. H. (1965). *Tennessee Self-Concept Scale: Manual*. Nashville: Counselor Recording and Tests.
- Fitts, W. H., & Warren, W. L. (1996). *Tennessee Self-Concept Scale: Manual*. Los Angeles: Western Psychological Services.
- Garanto, J. (1984). *Las actitudes hacia sí mismo y su medición* [Attitudes toward oneself and their measurement]. Barcelona: Ediciones Universitarias.
- Geruschat, D., & Turano, K. (2002). Connecting research on retinitis pigmentosa to the practice of orientation and mobility. *Journal of Visual Impairment & Blindness, 96*, 69-85.
- González, M. C., & Tourón, J. (1994). *Autoconcepto y rendimiento escolar* [Self-concept and school performance]. Pamplona, Spain: EUNSA.
- Gutiérrez, T. (1995). *Retinosis pigmentaria: Clasificación y tratamiento* [Retinitis pigmentosa: Classification and treatment]. Oviedo, Spain: Universidad de Oviedo, Servicio de Publicaciones.

- Harter, S. (1999). *The construction of self: A developmental perspective*. New York: Guilford Press.
- López-Justicia, M. D., Pichardo, M. C., Amezcua, J. A., & Fernández de Haro, D. (2001). Self-concept in Spanish low-vision children and adolescents and their normal-vision peers. *Journal of Visual Impairment & Blindness*, 95, 150-160.
- Machargo, S. J. (1997). *Programa de actividades para el desarrollo de la Autoestima* (Vol. 2) [Program of activities for the development of self-esteem]. Madrid: Escuela Española.
- Markus, H., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion and motivation. *Psychological Review*, 98, 224-253.
- Martinez, R., & Sewell, K. (1996). Self-concept of adults with visual impairments. *Journal of Rehabilitation* 62(2), 55-59.
- Reinhart, J. P. (2001). Effects of positive and negative support received and provided on adaptation to chronic visual impairment. *Applied Developmental Science*, 5, 76-85.
- Rundquist, J. (2004). Low vision rehabilitation of retinitis pigmentosa. *Journal of Visual Impairment & Blindness*, 98, 718-724.
- Sherrill, C., Hinson, M., Gench, G., Kennedy, S., & Low, L. (1990). Self-concepts of disabled youth athletes. *Perceptual and Motor Skills*, 70, 1093-1098.
- Smith, E., Nolen-Hoeksema, S., Fredrickson, B., & Loftus, G. (2003). *Introducción a la Psicología* [Introduction to psychology.] Madrid: Thomson.
- Tuttle, D. (1984). *Self-esteem and adjusting with blindness: The process of responding to life demands*. Springfield, IL: Charles C Thomas.

Wolffe, K. E. (1996). Career education for students with visual impairments. *RE:view* 28, 89-93.

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