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School Psychology International 2014 35: 357 originally published online 26 February 2013

DOI: 10.1177/0143034313476398

Article

School Psychology International

School Psychology International
2014, Vol. 35(4) 357–369

DOI: 10.1177/0143034313476398
spi.sagepub.com

Psychological and educational recommendations for working with young people with Retinitis Pigmentosa

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Abstract

This article reviews the consequences of Retinitis Pigmentosa, a retinal degenerative disease with progressive reduction of the visual field, visual acuity, contrast sensitivity, and night blindness. Retinitis Pigmentosa is addressed from both a psychological and an educational standpoint, focusing on the impact on learning, emotional well-being, and the social relationships of young people and adolescents. We examine problems affected people have to face and offer suggestions and strategies to professionals working with individuals and family members.

Keywords

Education, retinal degeneration, Retinitis Pigmentosa, psychology, Spain, young people

Many pathologies are identified as causes of visual restriction or visual loss, including those affecting the visual field (the area in space visible when an individual is looking directly ahead) (Cubbigge, 2006; López-Justicia, 2004).

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Diabetic Retinopathy, Retinitis Pigmentosa, or other retinal degenerations are examples of those pathologies. This article focuses on the effects of Retinitis Pigmentosa (RP) on education, development and well-being. RP onset is at an early age; but in most cases it is not until adolescence when it has a negative impact on psychoeducational, personal, and social terms. Affected individuals face changes during school years as a result of the limitations caused by the progressive character of this condition. These changes are challenging for teachers, parents and, also, for young people with RP.

RP as a retinal condition is not extensively widely known because of its etiology. The population of affected individuals is heterogeneous, making it necessary to address its study from different disciplines (e.g. clinical, psychological, social, educational, rehabilitation). This condition is characterized by a genetic alteration leading to retinal photoreceptor (cones and rods) degeneration, causing loss of function and affecting the quality of vision (Fernández, 2007). Clinical features include: Involvement of both eyes; loss of peripheral vision (i.e. the development of tunnel vision) and sometimes loss of central vision (decreased visual acuity) or the occurrence of scotomas (scattered visual field defects); weakened vision at night or under poor lighting conditions; problems adapting to changes in lighting; and changes in color discrimination (Agurtzane & Vecino, 2009; Rundquist, 2004). The disease affects approximately 1:3,000–5,000 individuals (Fernández, 2007; Velvet, Gasper, Eisenacher, & Wittinghofer, 2008). The low incidence might account for the scarcity of articles on related educational difficulties for young people with RP.

No medical or pharmacological treatment for RP is available. Progression is unpredictable and entails a loss of the ability to carry out earlier-acquired skills, leading affected individuals to perceive themselves negatively (Kiser & Dagnelie, 2008) due to a perception of the loss of ability to carry out daily living tasks or to move freely around in space—two skill-sets where people with RP normally experience difficulties (Fuhr, Liu, & Kuyk, 2007; Rundquist, 2004). The onset, primarily night-blindness, is usually noted between 6–12 years. While the rate of visual loss for some is high during primary and secondary education (Parmeggiani et al., 2011), in most cases visual incapacitation becomes notable at about 20 years. Such changes make it necessary for individuals to face the consequences of a progressive illness characterized by features that have a considerable influence on education, mobility, socialization, and employment. As a result, different psychological, educational, and social problems are frequently reported once RP has been diagnosed and the person has been informed of its consequences (Strougo, Badoux, & Duchanel, 1997).

Since the final prognosis is unpredictable and does not only depend on genetic or medical variables, it is essential to consider the impact of different factors as the condition progresses (Parmeggiani et al., 2011). This article focuses on those factors with two main aims: (1) To review the history of functional repercussions of this condition in terms of education, affective and emotional state, and family relationships of adolescents and young people with RP; and (2) to suggest psychological and educational actions aimed at making work with young people and adolescents with RP easier.

Retinitis Pigmentosa and education

The main aim of educational actions for students with RP is to monitor its development and make it possible for them to be fully integrated, autonomous, and independent individuals in personal, family, educational, social, and labor terms (López-Justicia, 2004). We must start by appropriately evaluating the difficulties and potential of intended actions in order to have a basis to design actions.

Psychological and educational evaluation

Evaluation discloses the capabilities and potential of adolescents and young people with RP, which is, in turn, valuable for determining which aids and support are necessary (López-Justicia, 2004). This involves a collaborative process of data collection and analysis from all stakeholders (e.g. parents, teachers, siblings, classmates) in order to make decisions aimed at improving the conditions.

As a general rule, the psychological and educational evaluation of the needs of students with visual impairment starts with an ophthalmological and optometric assessment (Hall-Lueck, 2004). The report should contain data relevant to the patient's near and distant visual acuity, visual field, and contrast sensitivity. Apart from visual tests, hearing capacity must be examined by a specialist, since hearing impairments are frequently co-occurring with RP. (Batista, Diaz, Sera, Milian, & Borrego, 2008). Usher syndrome is an example of the relationship between RP and hearing loss.

Upon completion of the initial assessment, evaluation focuses on assessing the performance of students in specific visual tasks in natural settings, such as instructional classrooms. The aim is to make decisions relevant to the adequacy of the educational response and consider which personnel and/or material support is necessary (Hall-Lueck, 2004). The psychological and educational aspects to be assessed are:

1. Cognitive development is assessed in order to identify conditions related to visual impairment; also, it is necessary to assess academic achievement in each study/subject area;
2. Visual-perception and functional vision;
3. Affective and emotional development (e.g. self-concept, anxiety and depression);
4. Family and social environment.

Visual-perception and functional vision

The study of visual functioning, that is, how a person uses visual abilities to perform the usual tasks of daily life, is relevant regardless of pathology (Hall-Lueck, 2004; López-Justicia, 2004). Many studies have described variations in visual functioning as significant for those with RP (Hahm et al., 2008; Szlyk et al., 2001;

Trudeau, Overbury, & Conrod, 1990); so, knowing only that a child has an eye disease is necessary but by itself insufficient for crafting an appropriate intervention.

Visual functioning is assessed by a professional qualified for assessing and treating visual disabilities (e.g. ophthalmologists, optometrists or qualified psychologists, or others with training in visual impairment). The main goal is to determine the individual's vision function (Hall-Lueck, 2004). The outcomes of this assessment are as valuable as the data provided by ophthalmological tests that determine whether vision exists and to what extent (Hahm et al., 2008; Szlyk et al., 2001). Lists or self-report tools are used in the tasks in order to record observable behaviors. These actions help interpret visual functioning in daily living. Some of the tests of proven use for young people are *Look and Think* (Chapman, Tobin, Tooze, & Moss, 1989), the *Sonksen Picture Guide to Visual Function* (Sonksen & Macrae, 1987; Vervloed, Ormel, & Schiphorst, 2001); *Visual Function Self-report* (Steinberg et al., 1994); *Visual Activities Questionnaire* (Sloane, Ball, Owsley, Bruni, & Roenker, 1992); and the National Eye Institute Visual Function Questionnaire-25 (VFQ-25) (2000).

Very few studies have analysed the deficiencies and visual perception potential in children and young people with RP, yet these aspects require attention. Visual perception plays an important role in reading and writing, spatial mobility, driving, as well as in situations requiring measurement of distance and speed, or for discriminating objects oriented in different directions (Martin, 2006). As a result, visual perception is connected with educational, social, and recreational activities (Brown, Rodger, & Davis, 2003), as well as with daily living. Recently Chacón-López (2011) showed visual-perception difficulties in young people with RP, mainly with regard to form-constancy and figure-ground discrimination, and suggested the need to draw attention to the limitations they face when carrying out tasks related to their education.

Emotional development

Visual impairment has been identified as a potential cause of feelings of inferiority and incapacity, affecting a person's social relationships and leading to reduced academic achievement and poor social adjustment (Beaty, 1992) and negative self-concept (Garaigordobil & Bernarás, 2009; López-Justicia & Nieto, 2006); gender-based differences have been found for self-concept (Calek, 1980; López-Justicia & Pichardo, 2001; Rasonabe, 1995). In the study carried out by López-Justicia and Pichardo (2001), young women with low vision perceived themselves in a more positive manner than did young men in terms of physical self-concept, suggesting a better acceptance of their own body and their visual impairment.

The progressive nature of RP has consequences for emotional development. Both depression and anxiety seem frequent conditions among people with RP (Hahm et al., 2008; López-Justicia et al., 2011), although the period of greatest crisis or stress occurs during or immediately following diagnosis

(Nemshick, Vernon, & Ludman, 1986). The progression of visual loss is slow and is a threat to the adolescent's growing independence. This might explain why people with RP, who are generally young children when the condition is initially diagnosed, are at a high risk for reacting with stress and anxiety (Bittner, Edwards, & George, 2010). Reactions to the diagnosis of RP differ depend on a person's psychological make-up, the way they perceive the condition, their personal and social coping resources, and the amount of control they can exert over the course of events. The following are reactions frequently observed in people with RP: Social isolation; dropping out of school or leaving their employment; symptoms of depression or changes in self-concept (López-Justicia & Nieto, 2006; Strougo et al., 1997). Such reactions are understandable, in so far as the condition has a negative impact on functional skills such as reading, mobility, and driving (Runquist, 2004). Difficulties in adapting to visual loss have been observed among people with RP with relation to health-care, academic and professional environment, social environment, and family relationships (Jangra et al., 2007).

Adolescents with RP find additional problems interacting with peers, particularly concerning their degree of autonomy in social/personal functioning. This is generally assessed by looking at how effective they are in carrying out various daily living tasks; they often fail to perform such tasks adequately, especially those related to orientation and mobility, and this could harm their feelings of personal and social well-being (Black et al., 1997). Orientation and mobility become the primary problem for young people with RP; they walk more slowly and are at five-times greater risk for bumping into objects, especially when light conditions are inadequate (Brilliant, 1999; Haddad, Sampaio, Oltrogge, Kara-José, & Betinjane, 2009). As a result, achieving autonomy in mobility must be an essential curriculum goal. Relative to that, Kef (2002, 2004) and Huurre & Aro (1998) highlighted that adolescents with visual impairment often have a very small circle of friends (generally fewer than five) and socialization problems with their peer-group. This is contrary to their preference since they feel the need to have a larger social network and do more activities with their friends; they participate in fewer spare time activities and spend less time with their peers (Pfeiffer, Pinquart, & Münchow, 2012). Friends' support, rather than that provided by the family, affects well-being, and adolescents with visual impairment feel less supported by their peers than unaffected adolescents. As a result, social skills training for RP students and their friendship groups enhances integration (Kef, 2004).

Educational support

As a general rule no adaptations need to be implemented in the curriculum to achieve full inclusion; yet adaptations may be necessary regarding access to the curriculum and didactic methods. They may require the use of optical, non-optical, and technological aids (López-Justicia, 2004). Two main types of curriculum adaptations might be necessary: (a) Adaptations of *access* to the

curriculum (personal-, material- and organization-elements; (b) Adaptations in the basic *elements* of the curriculum: (objectives, contents, methodology, and resources). The following key actions may be found to be of use by educators when trying to minimize the effects RP:

1. Removing as many video/film screenings and slide/transparency projections as possible from classroom practice. They are difficult to watch and people with RP often struggle when trying to take notes during projections. If visual images must be used, then students with visual impairment should be provided with support notes/materials;
2. Using larger font in photocopies;
3. Remove materials with poor color quality, limited contrast, or blurred color. Black print on a white background, or vice versa, is ideal (Berubé, 1991). Color quality is noted here because loss of contrast sensitivity is one of the main difficulties faced by affected individuals (Spellman, Alexander, Fishman, & Derlacki, 1989), and with a significant impact on their ability to carry out daily living tasks (Szlyk et al., 2001);
4. Improving ambient lighting, since low-light-levels translate into a reduction of individuals' contrast sensitivity (Spellman et al., 1989).

In relation to the social and educational inclusion, educators play a fundamental role; they must promote an environment where all the students can work together; and where there are appropriate conditions for learning to take place and students' well-being to be maximized. They should seek guidance in the use of optical, non-optical, or technological aids to enhance the vision and to improve the visual functioning of people with RP (Alves, Monteiro, Rabello, Gasparetto, & Carvalho, 2009).

Resources to access the curriculum

Visual loss causes difficulties in different process such as reading and writing activities, access to information technologies, or limitations in independence and autonomy in daily life (Alves et al., 2009; Caparrós, 1994). A series of optical, non-optical, and technological resources are outlined in this section. They are aimed at facilitating students with RP access to information and education, and at improving their efficiency in daily living (Haddad et al., 2009).

Using *optical aids* in education and during visual training is very useful for image recognition, scanning, visual memory, and mobility (De Castro, Berezovsky, De Castro, & Salomão, 2006). The use of optical aids in RP is especially recommended because it helps people enhance their remaining visual acuity (Laderman, Szlyk, Kelsch, & Seiple, 2000; Laitinen et al., 2007); this aspect should not be discounted for many with RP maintain some remaining visual acuity until the end of their life (Grover et al., 1999).

Most individuals with RP request visual and mobility aids (Nemshick et al., 1986; Parmeggiani et al., 2011) especially for compensating for visual field restrictions. Fortunately, a wide variety of optical aids are available to suit the needs of affected people. Table 1 shows a summary of the optical and electronic aids most commonly used, classified by *near vision* (tasks that are performed between 25–30 cm) and *distance vision* (task performed at 5 m of distance or further away).

Fresnel prisms are recommended for visual field restriction; they consist of a set of prisms that cause object images to move towards the center of the visual field. They are beneficial for people with RP, who cannot move their head and eyes quickly enough while moving about. Other aids include:

Non-optical aids (Aids used for improving vision performance, posture, contrast, or working distance.) Some examples of these aids: (1) *Solar filters* are yellow-polarized glasses that eliminate light reflection; they can be incorporated into either eyeglasses or contact lenses (Parmeggiani et al., 2011); (2) *Page filters* are plastic sheets placed over the text for reading; colored paper (yellow and orange shades are most common) and felt-tip pens (Brilliant, 1999; Trauzettel-Klosinski, 2010); (3) *Bookstands and drop-leaf tables* are useful aids for avoiding the incorrect posture and fatigue that usually result from working excessively close to materials (Brilliant, 1999). (4) *Light control*: When light quality is adequate, the need for magnification may be notably lower; (5) We find the following recommendations useful—avoid glare, dazzle or reflections onto the text; ensure that light comes from above and from the side opposite the writing hand, and use both artificial light and natural light (Bérubé, 1991; Brilliant, 1999; Haddad et al., 2009); (6) Use mobility canes to avoid obstacles, and improve night mobility.

Technological aids (products designed to improve autonomy and mitigate hindrances resulting from visual impairment, especially when facing contrast sensitivity problems such as color and brightness; Schurink, Cox, Cillessen, van Rens, & Boonstra, 2011). Technological aids facilitate the access to the digital environment, in which the students have to develop themselves, promote their lives, and improve educational and social inclusion (Alves et al., 2009). TV-magnifiers are the best

Table 1. Optical and electronic low vision supports classified by near vision and distance vision.

	Distance vision	Near vision
Optical aids	Eyeglass-mounted telescopes	Stand magnifier
	Hand-held binocular telescope	Dome magnifier
	Hand-held monocular telescope	Hand held magnifier
	Fresnel prisms	
Electronic aids	Head-mounted Electronic Vision Enhancement Systems	Head-mounted/Hand-held/Stand-mounted and Mouse-operated Electronic Vision Enhancement Systems

known technological aids. They consist of a closed-circuit television system projecting a magnified image of a text onto a screen (Caparrós, 1994). Their use is adequate for both ordinary reading and writing and for use with a personal-computer.

Other aids which facilitate access to the internet include character amplifiers and screen readers. Additional aids include Braille lines, electronic talking note-takers, talking watches and purses featuring compartments for reducing the difficulties for locating coins (Caparrós, 1994; Parmeggiani et al., 2011).

Psychological and educational support

Visual degenerative disease can impact the quality of life and affect individuals psychologically, academically, and socially. Affected adolescents experience anxiety and fear in dark places, which are common features of social environments for young people. As a result, their opportunities to develop social and relationship skills are limited (Nemshick et al., 1986).

Understandably, RP adolescents feel embarrassed when tripping over obstacles or falling as a result of their reduced visual field. Others do not understand their impairment since falls are considered to be a result of clumsiness or failure to pay attention (Nemshick et al., 1986). Progressive loss of vision concerns the RP adolescent since they are afraid of losing independence and they hope their vision will not worsen (Nemshick et al., 1986). Other related fears are limitations in social life, feelings of non-adaptation, shame, and the feeling of 'being different'. As a result, assistance and psychological and educational counseling are often needed for young people with RP. This is important for two reasons: It is a means for them to accept their condition and it helps them to adjust properly to society, receive adequate training, achieve personal fulfillment, and build their life plan (Nemshick et al., 1986).

Support and assessment for students with visual impairment has particular importance when they approach entry to the competitive employment market; with improvements in their social, emotional and personal competency, and personal attitudes, there is an increased probability of locating employment (Bell, 2012; Fleming & Fairweather, 2012). A study carried out by Cameto and Levine (2005), showed that two years after finishing high school education, only 46% of visually impaired students were working; in the case of students without visual impairment, the proportion was 59%. Other authors (Bell, 2012; Fleming & Fairweather, 2012) insist on the importance of mentoring, vocational rehabilitation, or special education services to help new-workers in their incorporation into the employment market.

Family and Retinitis Pigmentosa

Chronic diseases have repercussions not only on the well-being and quality of life of those affected, but also on their families (Agudelo, Casadiegos, & Sánchez, 2009). Anxiety levels among relatives of individuals with RP are very close to those registered among adults with RP themselves (Chacón-López,

López-Justicia, Fernández, Chacón, & Polo, in press; López-Justicia et al., 2011). This might be due to the degenerative nature of the condition and to the feeling of unease when thinking about the extent of their suffering at that moment and in the future (Agudelo, Casadiegos, & Sánchez, 2009; Hahm et al., 2008).

Nemshick et al. (1986) note that a high percentage of impaired individuals find family support to be valuable, whereas others perceived it as overprotection or complained about the lack of understanding of their condition or that family members even denied their problem. Other studies stress the difficulties related to self-concept in adolescents with RP (López-Justicia & Pichardo, 2001) and place special emphasis on the negative repercussions of RP for interactions between affected adolescents and their families.

Collaboration between schools, families, and medical/psychological services, can help support visually impaired people and their families (Alves et al., 2009). The following suggestions are addressed to professionals working with families: Provide families with sufficient information to understand the changes associated with the degenerative nature of the illness so that together they can face the consequences of this pathology; provide for parents' educational and psychological needs (Woods, Parkinson, & Lewis, 2010); give guidance related to what abilities their adolescent still has; encourage parents to facilitate independence by avoiding overprotection (Cimarolli & Boerner, 2005; López-Justicia & Nieto, 2006); and recommend that families become active with associations supporting families of people with RP or other visual impairments (Tröster, 2001).

Conclusions

We offer basic steps to approach educational, functional, and social problems related to the degenerative retinal condition RP, with the intention of identifying potential objectives for intervention (Turner & Erchul, 1987). Adolescence is a complex period for any individual, especially for someone with a degenerative disease. Understanding how they feel and how they face their condition, as well as the strategies they might need to better understand their situation and to develop more control over their situation, should translate into a higher quality of life (Bittner et al., 2010). The simplest of interventions may prove highly effective in enhancing their quality of life and personal well-being. For all these reasons, professionals should cooperate both with families and teachers, explain to them the characteristics of RP, and offer them expert psychological counseling. Doing so will help students with RP access the school curriculum (Haddad et al., 2009), promote greater educational and social inclusion, and lead to better integration into society.

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