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Functioning and Vision-Related Quality of Life in Severe Peripheral Field Loss due to Retinitis Pigmentosa: A Qualitative Study

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Title: Functioning and Vision-Related Quality of Life in Severe Peripheral Field Loss due to Retinitis Pigmentosa: A Qualitative Study

Abstract:

Vision impairment and blindness are associated with disability and decreased social participation and independence. While vision rehabilitation may improve patients' functional abilities, there is scarce data regarding the effectiveness of rehabilitation for patients with severe peripheral field loss (PFL). In order to evaluate rehabilitation strategies for individuals with severe PFL, a valid and reliable instrument to measure vision-dependent functioning and vision-related quality of life is needed. Accordingly, this qualitative study was the first phase in developing a patient-reported outcome (PRO) measure tailored to this population. Individuals with retinitis pigmentosa (RP) were recruited from the Kellogg Eye Center and the Association for the Blind and Visually Impaired. The study sample included 17 participants (53% female, mean age 48); median presenting visual acuity and Pelli-Robson contrast sensitivity were 20/40 and 1.2 log contrast sensitivity, respectively. The maximum horizontal extent of the Goldmann visual field was 11° in the better-seeing eye. Study participants completed a semi-structured qualitative interview, and two quality of life questionnaires. Interviews were recorded, transcribed and coded by two independent coders. Thematic analysis of the interview codes identified six vision-related quality of life themes across all RP participants: activity limitations, driving, emotional well-being, reading, mobility and social function. These themes will serve in the development of a PRO specific to severe PFL, which will facilitate evaluation and eventual evolution of low vision rehabilitation for patients with severe PFL.

Key Words:

Vision-related quality of life in retinitis pigmentosa peripheral field loss