Article ▸ Vision and Driving Difficulties with Nystagmus: Finding New Pathways

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ABSTRACT

Background: Nystagmus is an involuntary movement of the eyes in a rhythmic manner. Many individuals with this condition are visually impaired, some are registered blind, and very few can drive vehicles. It can severely disrupt quality of life, especially deteriorating confidence and self-esteem. The impact of nystagmus on driving performance can be severe and can disrupt visual sampling of the driving environment, interfere with driving behavior, and affect traffic safety. This can lead to fatal accidents both to an individual with nystagmus and to people on the road. Nystagmus reduces the overall quality of life, making it challenging and increasing dependence on others for routine activities. Despite this condition being one of the major causes of visual impairment globally, its impact on quality of life and driving difficulties has not been studied. The present study intended to assess these aspects of vision and driving difficulties and to codify rehabilitation measures in order to provide some relief to people with nystagmus and improve their daily living.

Methods: The research was completed in two countries, India and the United Kingdom (UK), better to represent the wider population with nystagmus. A total of 79 Indian participants were included in the study: 42 with infantile nystagmus and 37 with acquired nystagmus. Quality of life was assessed through a standardized Health Related Quality of Life (HRQOL) Questionnaire, and vision-related quality of life (VR-QOL) was assessed through the Indian Vision Function Questionnaire. Twenty-four UK participants were recruited, and quality of life was assessed via questionnaire. Driving performance was assessed on 27 Indian participants (19 infantile, 8 acquired).

Results: Quality-of-life assessment revealed that the major visual difficulties faced by both Indian and UK participants with nystagmus included difficulty with both distance and near vision, recognizing faces, focusing, oscillopsia, visual discomfort, and an overall reduction in near work. Driving was a major problem; forty-one percent (n=27) of overall participants could drive. Out of 27 participants assessed for driving, forty-one percent (n=11) passed, and fifty-two percent (n=14) failed. A negative correlation was found between visual acuity (logMAR) and VR-QOL, which was statistically significant (r_s=-0.398, p=0.0001).

Conclusion: Forty-one percent of our participants on whom a driving assessment was performed exhibited proficient on-road driving skills and passed the driving test. Hence, people with this condition can drive if they possess potential vision, and further training can improve their driving skills. Counseling sessions, yoked prisms, vision therapy, and occupational therapy training were effective in relieving the visual discomfort and providing an overall boost in self-esteem and confidence level for people with nystagmus.

Keywords: driving, nystagmus, oscillopsia, quality of life, vision therapy

Introduction

Nystagmus is an involuntary eye movement in a 'to-and-fro' manner that can be either infantile or acquired later in life. The prevalence of nystagmus in the general population is not well documented due to a limited number of studies in this area. A cohort study was conducted on partially sighted or blind children older than 15 years in Denmark to estimate the prevalence.[1] In the Netherlands, a study was conducted among 220,802 army recruits who were excluded from service because of deteriorated vision.[2] This study concluded that among 220,802 recruits, 117 were discharged because of nystagmus. Out of 117 discharged recruits, 56 were examined further, and 29 were found to have congenital type nystagmus. A study was performed on elementary school children in first grade in Malmö, Sweden between 1941 and 1959. It was further extended to family members of affected children.[3] This study reported a total frequency of 1 in 1500 children, with boys showing 1 in 1000 and girls showing 1 in 2800. This study examined only children with nystagmus and their affected family members but excluded adults with non-familial forms of nystagmus. In the United Kingdom, a study examined 10-year-old children in a representative sample of 15,000 with

visual acuities ranging from 20/20 to poorer than 20/200.[4] This study concluded that congenital nystagmus was the second most common cause of partial sight or blindness after congenital cataract. However, none of these studies provided data on adults or children with acquired nystagmus specifically. Savananthan[5] et al. established the prevalence of nystagmus in the general population to be 24 per 10,000. This study further reported that the most common form of nystagmus was neurologic, which accounted for 6.8 per 10,000, followed by nystagmus associated with low vision (4.2 per 10,000) and nystagmus with retinal disease association (3.4 per 10,000).

Many people with this condition are visually impaired, some are registered blind, and very few can drive vehicles. Nystagmus can severely disrupt lifestyle, especially deteriorating confidence and self-esteem.[6] Driving is one of the most common necessities for daily life. Nystagmus can disrupt visual sampling of the driving environment, interfere with driving behavior, and affect traffic safety. The impact of nystagmus on driving performance can be severe, and only a few individuals can drive with such a condition.[6] This directly or indirectly affects their daily living and hampers routine activities. Individuals with nystagmus either have to use the public transport system or need to be dependent upon somebody for routine transportation because of their inability to drive and poor handling of the vehicle. Despite these concerns about the potential effects of nystagmus on driving performance and overall quality of life, there has been no research on the effect of nystagmus in the driving context.

Supported by a World Council of Optometry (WCO) Fellowship award, this study had two main aims: to understand the difficulties in daily living faced by those with nystagmus and to find appropriate rehabilitation measures. The study aimed to plan specific rehabilitative modalities and protocols to be followed by people with nystagmus so as to have preventive measures. It also explained conditions that are preferable or detrimental for driving, such as fog, daylight, night, highways, etc. The study also looked into the quality of life for people with nystagmus and highlighted the issues that appear to be the most problematic and affect their daily living the most. The research was completed in two countries, India and the United Kingdom (UK), to cover a wider population with nystagmus. There is a paucity of data to estimate the prevalence of nystagmus in the Indian population; no population-based study was located. Also, no information is available regarding the quality of life of people with nystagmus in the Indian population. A few studies have been conducted in the UK that address these concerns of driving difficulty and quality of life with nystagmus;[6,7] however, no study has looked into this aspect of nystagmus in the Indian population. This study intended to assess these aspects of vision and driving difficulty and codify rehabilitation measures. This study also tried to understand the difficulties faced by people with nystagmus in different countries and to answer the question of whether these difficulties are the same in both locations.

The study focused on the following broad aims:

- To evaluate vision and driving difficulties and to assess the quality of life of people with nystagmus (both Indian and UK participants)
- To assess driving performance on highways and busy traffic roads and in different environmental conditions such as a bright sunny day, dim light, or a rainy/cloudy day
- To investigate driving performance as determined by on-road driving assessments in Indian participants
- To investigate the driving performance of UK subjects as determined by standardized questionnaires and online meetings
- To explore the common difficulties faced by people with nystagmus in different locations (India and the UK)

Methods

Seventy-nine Indian participants were included in the study: 42 with infantile nystagmus and 37 with acquired nystagmus. Participants were recruited from several tertiary eye hospitals and eye care and research centers across New Delhi and the National Capital Region (NCR), which included the Centre for Sight Super Speciality Eye Hospital, Dr. Shroff's Charity Eye Hospital, Jyoti Institute of Paramedical Sciences, Dayal Institute of Allied Health Sciences, Divya Jyoti Eye Care Centre, Sitaram Bhartia Institute of Science and Research, and the National Institute of Medical Sciences. The Indian Optometric Association played a significant role in the referral of subjects and collaboration with the eye care centers to provide their support and resources throughout the study. This research adhered to the tenets of the declaration of Helsinki. Ethical approval was obtained from the National Institute of Medical Sciences, Dr. Shroff's Charity Eye Hospital, Centre for Sight Super Speciality Eye Hospital, and Jyoti Eye Care Centre & Paramedical Institute. Informed consent was obtained from all participants.

A complete eye examination was performed, which included tests of visual function (visual acuity on the ETDRS chart), contrast sensitivity (Bailey-Lovie chart), colour vision (Ishihara plates), and visual field (confrontation and Humphrey visual field analyzer). Binocular vision assessment consisted of cover test, stereopsis, near point of convergence, near point of accommodation, positive and negative fusional vergence, and vergence and accommodative facility. Semi-structured interviews were conducted with participants at four eye care centers including patients with both acquired and infantile nystagmus. Quality of life was assessed through a standardized Health Related Quality of Life (HRQOL) Questionnaire (Appendix 1; http://bit.ly/2cwaUsF), and vision-related quality of life was assessed using the Indian Vision Function Questionnaire (IND-VFQ) (Appendix 2, http://bit.ly/2c8lC9F).

The IND-VFQ has three scales: a 21-item section for general function, a five-item section for psychosocial impact,

and a seven-item section for visual symptoms. The items in the general function section cover mobility, household performance, economic activity, and activities of daily living. The psychosocial scale has items concerning social, family, and personal wellbeing. The visual symptoms section has items addressing vision, photophobia, and glare. A four-point response scale assesses visual symptoms and psychosocial impact: 1 (best score) to 4 (worst score). The questions in the general function section have a five-point scale from 1 (best score) to 5 (worst score). For each scale, a composite score was calculated as the cumulative total of individual responses expressed as a percentage of the maximum score possible and then transformed such that 100 represented the best possible score (no difficulty with any of the items in that scale) and 0 the worst score (maximum difficulty in that scale).

The UK participants were recruited with the help of the UK Nystagmus Network and social media sites. A standardized questionnaire was sent via email to 41 participants; 24 were returned with answers and analyzed. Hence, a total of 24 participants were considered for analysis. An online meeting was arranged with participants, and the major issues pertaining to their daily activities and driving difficulties were discussed via open discussion and a questionnaire. Statistical analyses were performed using the SPSS Inc. V.17.0 and Microsoft XL 2007.

Assessing Driving Performance

Driving performance was assessed on 27 Indian participants (19 infantile and 8 acquired) who had a valid driving license and attested that they drove regularly. The on-road driving assessment consisted of observations while driving in the area surrounding the eye center. The outcome was based on the performance of a number of actions (maintaining speed, applying brakes, maintaining steady steering, and lane position) commonly encountered in daily driving. A driving instructor with twenty years of driving experience in the Delhi Transport Corporation (Government of Delhi) was included in the study to assist in the evaluation. Information pertaining to the driving ability of each participant was recorded in a standardized format. An occupational therapist (OT) from the National Institute of Medical Sciences was also involved to assist in the study, having good experience in driving rehabilitation. The OT and the author (NS) interviewed the participants using questionnaires which included review and history of health, medication, alcohol, physical evaluation, driving and accident history, vision assessment, and the knowledge of traffic rules. The examination of visual function focused on visual acuity, depth perception, peripheral vision, night vision, and glare. A confrontation field test was performed to evaluate the peripheral vision, in which the participant had to report the presence of the target when it was brought from the periphery to the centre. After all the assessments were completed, a meeting was held among the author, the OT, and the driving instructor. The driving instructor was informed to take special care of 5 participants having constricted peripheral fields and poor stereopsis. Out of these 5 participants, 1 participant reported that he had not driven a vehicle for the past 2 years because of unavailability of his car, but he was confident enough to drive.

The assessment of on-road driving performance was performed at three different times during a day: morning 8:00 AM to 8:30 AM, afternoon 1:00 PM to 1:30 PM, and evening 6:30 PM to 7:00 PM. The participants had to drive for 30 minutes continuously at one time, which covered driving on clear roads, busy traffic, bright light (during afternoon), and dim light (evening). The car used for assessing driving performance in the study was arranged by the driving instructor himself, and the location of the driving assessment was kept as close as possible to the study centres. The driving assessment started on the nearby streets, crossing the red-light intersection points, covering an area having schools and markets, and lastly covering a four-lane road. The participant drove the car on roads with varying speed limits. The driving instructor was monitoring each and every action of the participant and writing comments on the performances, which included handling of the steering, use of gear and accelerator, use of brakes and signals, speed, lane changes, and intersections. If the driving instructor felt that there was anything wrong or unsafe in the driving that could lead to serious injuries, he was authorized to stop the evaluation. Based on the performance of the participants, the driving instructor made a decision of either 'pass' or 'fail.'

Results

The mean age of the Indian participants (n=79) on whom the IND-QOL was performed was 33±10 years. The number of male participants was almost the double the females. The mean binocular visual acuity and contrast sensitivity were 0.20±0.13 logMAR (95% Confidence Interval (CI), 0.16-0.22) and 1.65±0.20 log units (95% CI, 1.63-1.68), respectively. The demographic data of all participants (n=79), Indian participants on whom a driving assessment was performed (n=27), and UK participants (n=24) has been summarized in Table 1.

The major visual difficulties faced by Indian participants included difficulty with both distance and near vision, difficulty in recognizing faces, difficulty in focusing, oscillopsia, visual discomfort, and an overall reduction in near work. The visual difficulties are summarized in Table 2.

The driving assessment and open discussion with the 27 Indian participants revealed the common difficulties that they faced. The most common difficulty reported was a problem in making judgments about an object on the road. Difficulty in driving during the afternoon in the bright sunlight was the second major issue. Some of the other reported difficulties were problems in maintaining speed, applying brakes, maintaining steady steering and lane position, loss of concentration, coloured halos, glare, and difficulty in dim

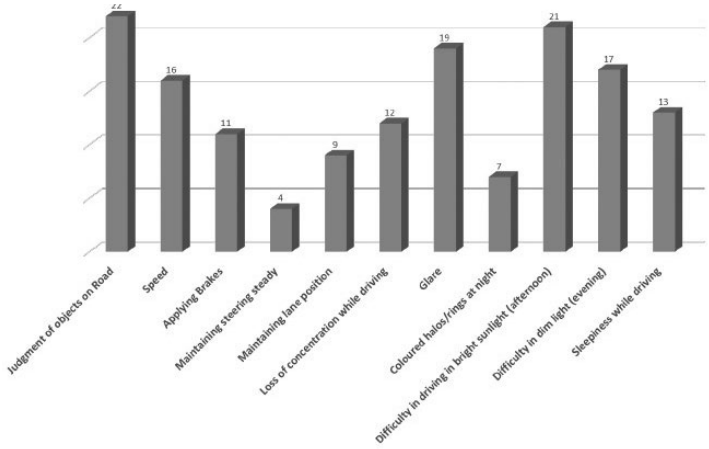

Figure 1. *Major driving difficulties in Indian participants (n=27)*

Table 1. Demographic Data

Category 1: n=79	
Age: Mean (SD)	33 (10) Years
Male: n, %	52, 66%
Female: n, %	27, 34%
Binocular Visual Acuity (logMAR): Mean (SD), 95% CI	0.20 (0.13), (95% CI, 0.16-0.22)
Contrast Sensitivity (log units): Mean (SD), 95% CI	1.65 (0.20), (95% XI, 1.63-1.68)
Category 2: n=27	
Age: Mean (SD)	31 (9)
Male: n, %	17, 63%
Female: n, %	10, 37%
Category 3: n=24 (UK Participants)	
Age: Mean (SD)	27, (10)

Table 2. Major visual difficulties in Indian participants, n=79

Major Visual Difficulties	**n (%)**
Distance vision	62 (78%)
Near vision	42 (53%)
Difficulty in recognizing faces	9 (11%)
Difficulty in focusing	59 (79%)
Oscillopsia	47 (59%)
Visual discomfort	71 (90%)
Reduced near work	68 (86%)

light (Figure 1). Out of 27 participants, only 11 participants passed the driving assessment test. A clear decision of 'pass' or 'fail' could not be made on the driving performance of two participants as the driving instructor wanted to investigate their driving abilities further.

Out of the 24 UK participants, only 15 used to drive or had prior driving experience. Driving performance was not accessed on UK participants. They were interviewed and their difficulties were discussed. Hence, only 15 participants were interviewed for driving difficulties. Visual discomfort was reported by a majority of UK participants (n=21), followed by reduced near work. The visual and driving difficulties of UK participants are summarized in Tables 3 and 4, respectively.

A Spearman's correlation was performed in order to determine the relationship between visual acuity and IND-VFQ scores. A statistically significant negative correlation was found between visual acuity (logMAR) and VR-QOL(r_s = -0.398, p=0.0001, n=79; Figure 2).

Table 3. Major visual difficulties reported by UK participants, n=24

Major Driving Difficulties (UK participants)	**n (%)**
Distance vision	13 (54%)
Near vision	7 (29%)
Recognizing faces	6 (25%)
Difficulty in focusing	15 (63%)
Oscillopsia	17 (71%)
Visual discomfort	21 (88%)
Reduced near work	19 (79%)

Table 4. Driving difficulties reported by UK participants, n=15

Major Driving Difficulties (UK participants)	**n (%)**
Judgment of objects on road	11 (73%)
Speed	9 (60%)
Applying brakes	12 (80%)
Maintaining steady steering	6 (40%)
Maintaining lane position	2 (13%)
Loss of concentration while driving	2 (13%)
Glare	11 (73%)
Coloured halos/rings during night	7 (47%)
Difficulty in driving in bright sunlight (afternoon)	10 (67%)
Difficulty in dim light (evening)	8 (53%)
Sleepiness while driving	7 (47%)

Discussion

This is the first study investigating on-road driving performance and evaluating the major visual and driving difficulties of people with nystagmus. The findings demonstrate that the majority of people with nystagmus have visual difficulties while driving and performing day-to-day activities. The major issues reported were difficulty with distance and near vision, recognizing faces, difficulty while focusing, oscillopsia, visual discomfort, and an overall reduction in near work. Driving was a major issue; only forty-one percent (n=11) of overall participants could drive or had a valid driving license. Most of the participants reported using the public transport system for their daily transportation. The visual and driving difficulties reported by UK participants were lesser as compared to the Indian participants, as determined by the standardized questionnaire. Fifty-two percent (n=14) of the Indian participants failed the driving performance assessment. The driving instructor reported common difficulties, including

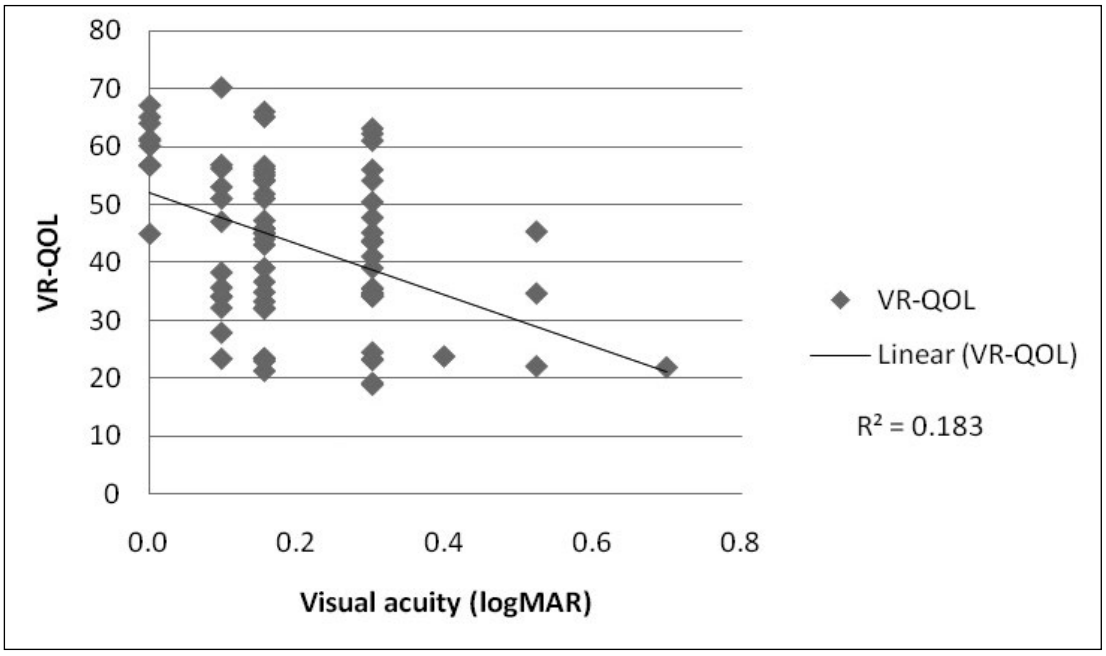

Figure 2. *Correlation between visual acuity and IND-VFQ (n=79)*

maintaining lane position and steering steadiness, particularly on highways, and applying the brakes properly, especially in busy traffic and areas surrounding colonies and schools. The majority (81%, n=22) of participants reported difficulty in judging an object on the road, because of which they were unable to apply the brakes on time. The participants who failed the driving performance test were advised to go for further training to improve their driving skills; however, we have not reported the effect of training on the driving performance of these participants. The OT was instructed to provide proper therapy to subjects who needed mobility training. In the future, we plan to study the improvement in driving performance of these participants as a result of training.

Our interviews and discussions with participants revealed problems with low self-esteem, a lower confidence level, and a tendency towards keeping to themselves. The similar problems of standing out/not fitting in and poor self-confidence have been reported by McLean et al.[7] Cosmetic appearance and personal look was found to be one of the major concerns; the participants were quite anxious about their future and career. Studies concerning strabismus have reported poor cosmesis due to eye deviations as one of the major causes of reduced self-confidence and difficulty with interpersonal relationships.[8] An effective treatment modality for nystagmus should consider cosmetic appearance as one of the major factors. Hence, in the future, we plan to study the impact of cosmetic appearance of nystagmus.

Participants with lower self-esteem and confidence were referred for counseling sessions to help them increase their motivation and gain confidence about their remaining visual capability. The purpose of the counseling sessions was to make participants aware of their capabilities and boost their confidence so that they could use their skills in the best possible manner. We stumbled across seven participants who were extremely talented and who had good academic records and excellent communicative skills. They however had a lack of confidence and lower self-esteem, which became obvious during the time of interview. They accepted that nystagmus had severely deteriorated their will-power, and hence, their overall performance was lower when compared to normal subjects. Some of the participants broke down to tears while narrating their past experiences and stories of life. All of these participants were helped through counseling sessions, and they felt that their self-esteem and confidence level improved. This change was quite obvious when they were interviewed again by the author. The author delivered public presentations and visited the offices of these participants regarding the awareness of nystagmus. Further research should focus on the role of counseling in improving quality of life with nystagmus.

Vision is one of the major factors influencing quality of life, and a reduction in vision directly hampers daily living activities. In our study, we found a negative correlation between visual acuity and quality of life assessed through the IND-VFQ. This indicates that visual acuity alone may not be the major factor that affects daily living and quality of life in nystagmus. We found that other factors like glare, driving difficulties, visual discomfort, and an overall reduction in near tasks also contributed to deteriorating the quality of life of a person with nystagmus. Other difficulties that were commonly present in both UK and Indian participants included dizziness, fatigue, oscillopsia, and overall restriction in their movement. The findings in our study correspond well with the affected domains of living raised by McLean et al.[7]

We would like to highlight some of the treatment modalities that we recommended for our participants, which helped in their day-to-day activities and improved their overall

performance. Our first priority was to correct for refractive error, which was present in seventy-two percent (n=57) of the participants. We encountered 11 participants (14%) with an abnormal head posture (AHP) used to dampen the amplitude of nystagmus. These participants had the usual complaints of neck pain and headache. For such participants, we dispensed yoked prism, which enabled them to have a normal head posture, and it also dampened the nystagmus. We also stumbled across participants with poor accommodative and vergence parameters that were causing visual discomfort and reduced near work. A complete binocular vision assessment revealed that 19 participants (24%) had vergence dysfunction, 17 (22%) had accommodative dysfunction, and 23 (29%) presented with a combination of both vergence and accommodative dysfunction. All of these participants were non-strabismic in nature. Vision therapy was given to these participants to improve their vergence-accommodative parameters. We have not quoted the exact data on the binocular vision anomalies and the effect of our treatment modalities (such as yoked prisms for AHP and the role of vision therapy in relieving symptoms for nystagmus) as further focused research is underway to address these aspects. Some of the participants with refractive error were treated with contact lenses.

The limitations of our study included the small sample size for driving performance assessment; however, there are very few people who drive with such a condition. A previous study is lacking against which to compare our findings concerning a driving assessment. The driving performance of UK subjects could not be assessed (so as to have a better comparison of the driving performances), which is one of the limitations of our study. The sample size of participants based on nationality was not equal, making the comparison difficult.

Conclusion

Our study, for the first time, investigated on-road driving performance in those with nystagmus in different environmental conditions and assessed the vision and driving difficulties faced by these people in day-to-day life. The study also highlighted some of the effective means of treatment, as well as rehabilitation measures to improve quality of living. Nystagmus being a universal concern, the study has highlighted the major issues of daily living and driving difficulties in India and the UK. We have demonstrated that 41% of our participants on whom driving assessment was performed exhibited proficient on-road driving skills and passed the driving test. This shows that individuals with this condition can drive if they possess potential vision, and further training can improve their driving skills. We have also revealed the role of counseling sessions, vision therapy, and OT in relieving visual discomfort and providing an overall boost in self-esteem and confidence level of those with nystagmus. Rehabilitation and training can prove to be effective in improving driving skills and alleviating the visual difficulties of daily living.

Declaration

The study was facilitated and supported by the World Council of Optometry (WCO) with a fellowship grant award to the first author.

Acknowledgment

The authors would like to thank all the participants in India and the UK, the fellowship grant committee of the World Council of Optometry, and all the reviewers for their comments and suggestions on the paper. The authors deeply thank Prof. Carly Lam, Chair, Fellowship Committee WCO and Ms. Maria Arce, International Policy and Strategy Director WCO for the constant support and guidance throughout the study. The authors also express their sincere thanks to Marc Taub, OD, MS for his valuable inputs in the paper.

References

1. Norn M. Congenital idiopathic nystagmus. Acta Ophthalmol 1964;42:889-96.
2. Hemmes GD. Hereditary nystagmus. Am J Ophthalmol 1924;10:149-50.
3. Forssman B, Ringnér B. Prevalence and inheritance of congenital nystagmus in a Swedish population. Ann Hum Genet 1971;35:139-47.
4. Stewart-Brown SL, Haslum MN. Partial sight and blindness in children of the 1970 birth cohort at 10 years of age. J Epidemiol Community Health 1988;42:17-23.
5. Sarvananthan N, Surendran M, et al. The prevalence of nystagmus: the Leicestershire nystagmus survey. Invest Ophthalmol Vis Sci 2009;50:5201-6.
6. Pilling RF, Thompson JR, Gottlob I. Social and visual function in nystagmus. Br J Ophthalmol 2005;89:1278-81.
7. Mclean RJ, Windridge KC, Gottlob I, Infirmary LR. Living with nystagmus: a qualitative study. Br J Ophthalmol 2012;96(7):981-6.
8. Archer SM, Musch DC, Wren PA, et al. Social and Emotional Impact of Strabismus Surgery on Quality of Life in Children. J AAPOS 2005;9(2):148-51.

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Singh NK, James R, Yadav A. Vision and driving difficulties with nystagmus: finding new pathways. Optom Vis Perf 2016;4(4):146-51.

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