

Introduction

A clinical measure of visual acuity is the most common method of assessment of a patient with nystagmus. Despite this, visual acuity measured at one point in time during an eye hospital visit is recognised as a poor indicator of a patient’s visual function in daily life. Other more detailed measures of visual function tend to rely on eye movement recording equipment and are often undertaken as part of laboratory based studies of nystagmus^{1,2,3}. Increasingly however, the patient’s perspective and description of their visual function is being recognised as important in nystagmus⁴.

Aim

To present patient reported information about living with nystagmus.

Methods

Ten Orthoptic students and three Lecturers in Orthoptics, who are also practicing Orthoptists, attended the Nystagmus Network Open Day, 2015. Students and staff interacted with parents, families and people with nystagmus of a range of ages and discussed the issues they experienced relating to aspects of daily living. Information from the patient’s perspective was collated immediately afterwards and analysed for common themes.

Results

When describing living with nystagmus and the difficulties they experienced with aspects of daily living, common themes were described by both people with nystagmus and their families.

Mobility and navigation

- More difficult in stressful and busy environments like train stations and supermarkets - causes anxiety, making nystagmus worse
- Crossing roads - need time to look each way and this is difficult in fast moving traffic
- Low vision aids (i.e. monoculars) can be life changing and can lead to increased independence
- Distinctive landmarks and well lit environments make navigation easier - maps and street names not helpful

Employment

- Always given list of careers can’t do, but would prefer information on what can do
- Usually best to be totally open with potential employers about visual disability but be careful as it could hinder

Social interactions

- Looking at people - need time to look at things and work out who people are, which is particularly difficult in crowded, busy environments
- Social problems associated with walking past people and not recognising them
- Hobbies and sports - participation and progression made more difficult due to visual impairment
- It is an invisible disability therefore people just think you are odd

Other people’s knowledge and understanding of nystagmus

- Difficulties associated with other people’s lack of knowledge about nystagmus and lack of understanding of the difficulties they face
- People try to help, but have no understanding of nystagmus. They often ask if you’ve tried glasses

Technology

- Importance of access to technology and being able to use technology in different environments
- Smart and mobile technology - one of the most positive impacts on daily life to occur recently
- Availability of audio information can significantly improve accessibility (i.e. on public transport)
- Different viewing positions needed for different devices in different environments
- Some screens are too big - preference for smaller screens with user manipulation of the zoom

Changes over time

- Recognition that needs and the type of support needed will change over time
- Recognition that vision varies with tiredness and hunger
- Visual demands change over time - making access to visual material harder and making access to lighting more important
- Educational needs of the child - parents feeling that they were fighting for their child’s needs

Confidence

- Nystagmus and visual impairment can affect confidence - difficult to know what to say to people and difficult to ask for help
- Confidence needed to use low vision and mobility aids in public

Quotes from children with nystagmus:

“When my eyes get tired, my teacher tells me to take a sensory break”

“Nystagmus is a strange invisible feeling in your eyes”

“I find it easier to play interactive computer games on the Wii as the remote is better than the controller on the PlayStation”

“I couldn’t do some of the things I can do without my smartphone”

Quotes from adults with nystagmus

“I think of my nystagmus and my visual impairment as separate issues”

“I couldn’t do things on my left and I didn’t know why”

“People don’t know about nystagmus, they don’t understand it.... they just don’t get it”

“I always ask people what they will be wearing when I meet them to make it easier for me to spot them”

“I have sometimes have trouble seeing whether my gas cooker flame is lit”

Quotes from parents of children with nystagmus

“I find it useful to keep a diary of my child’s symptoms, difficulties and adaptations, as they vary day by day”

“I try to ask my child where they would like to sit”

“I want to know what the vision measurements mean for my child in practice, what do they mean for their everyday life?”

“Even though the teachers have been told about the nystagmus, they don’t understand it and they forget”

“Nystagmus doesn’t mean my child is stupid, they are actually quite intelligent”

“We were immediately told that he wouldn’t ride a bike... seven years later he can!”

Discussion

Patient reported descriptions of the impact of nystagmus on daily life was collated following discussions with children and adults with nystagmus and the families of children with nystagmus. Common areas of difficulty were identified as mobility and navigation, employment, social interactions, confidence, recognition that needs will change over time and other people’s knowledge and understanding of nystagmus. Social interactions have also been identified as particularly important in other qualitative studies of nystagmus⁴. Access to technology and developments in available technology were both reported as leading to recent significant improvements in aspects of daily living for people with nystagmus.

Conclusion

Information from patients with nystagmus and from their families about how their daily life is affected by nystagmus can be helpful in identifying specific areas that may benefit from intervention and support. Issues that affect daily life are likely to change over time. Using technology can significantly improve the daily lives of patients with nystagmus.

References

1. Felius J, Fu VLN, Birch EE et al. (2011) Quantifying Nystagmus in Infants and Young Children: Relation between Foveation and Visual Acuity Deficit. Invest Ophthalmol Vis Sci. 52: 8724-8731.
2. Felius J, Muhanna ZA. (2013) Visual Deprivation and Foveation Characteristics Both Underlie Visual Acuity Deficits in Idiopathic Infantile Nystagmus. 54: 3520-3525.
3. Jones PH, Harris CM, Woodhouse JM, et al. (2013) Stress and Visual Function in Infantile Nystagmus Syndrome. Invest Ophthalmol Vis Sci. 54: 7943-7951.
4. McLean RJ, Windridge KC, Gottlob I. (2012) Living with nystagmus: a qualitative study. Br J Ophthalmol. 96: 981-986.

