Living With Nystagmus – The Patient’s Perspective

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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. Increasingly however, the patient’s perspective and description of their visual function is being recognised as important in nystagmus.

Aim

To present patient reported information about living with nystagmus.

Methods

Ten Orthoptic students and three Lecturers in Orthoptics, who are also practising 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. monocular) 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 employment.

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’s 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

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 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 nystagmus. 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