

Introduction

Providing appropriate standardised care and support for nystagmus patients is challenging. It is such a heterogeneous group of patients with a diverse range of functional vision and visual symptoms. McLean et al (2012) showed that nystagmus negatively affects quality of life and this was in part due to the general lack of understanding of the condition and how it affects everything they do.

A step to improve their quality of life is to ensure information and support provided by the eye care team is available, easily accessible and suits their needs. Further awareness of the condition amongst health professionals would also be beneficial. Only by asking individuals with nystagmus, and families, of their patient experience of eye clinics will it be possible to develop appropriate resources and improve the patient experience.

Purpose

To determine methods of improving care for nystagmus patients based on recommendations from individuals with nystagmus and their families.

Method

Ten undergraduate orthoptic students and three lecturers from the University of Sheffield attended the 2015 Nystagmus Network (NN) Open Day (figure 1). This was funded by The University of Sheffield, Faculty of Medicine, Dentistry and Health, Curriculum Development Fund. The aim was to enhance student knowledge of the condition, awareness of the impact of nystagmus on daily living and collate suggestions from attendees (individuals with nystagmus, families, clinicians and educationalists) how current care and support available could be improved.

In preparation for the open day a list of questions focussing on the nystagmus patient experience and how this could be improved had been devised and discussed. At the NN open day students led informal discussions with individuals with nystagmus and their families to determine the patient and family perspective on the current care of nystagmus patients in the UK and Ireland. The value of orthoptic input was also explored. Suggestions on how care, advice and support for nystagmus patients and their families could be improved was noted. Key areas were identified.



Figure 1. Orthoptic students from the University of Sheffield attending the NN open day. They all enthusiastically discussed how to improve the patient experience with people with nystagmus and their families.

Results

A general consensus of lack of standardised service, information and support for patients with nystagmus was found. Some individuals with nystagmus and their families reported a positive patient experience when attending the eye clinic and that the eye care team understand their condition. However there were many comments highlighting the need for further awareness of how the condition impacts on their daily lives, more details about the condition in the form of leaflets and where to seek further personal, emotional, educational, social and financial support. It was felt that different information and support is needed at different ages and stages of the condition. Recommendations where service, information and support could be improved are shown in Figure 2.

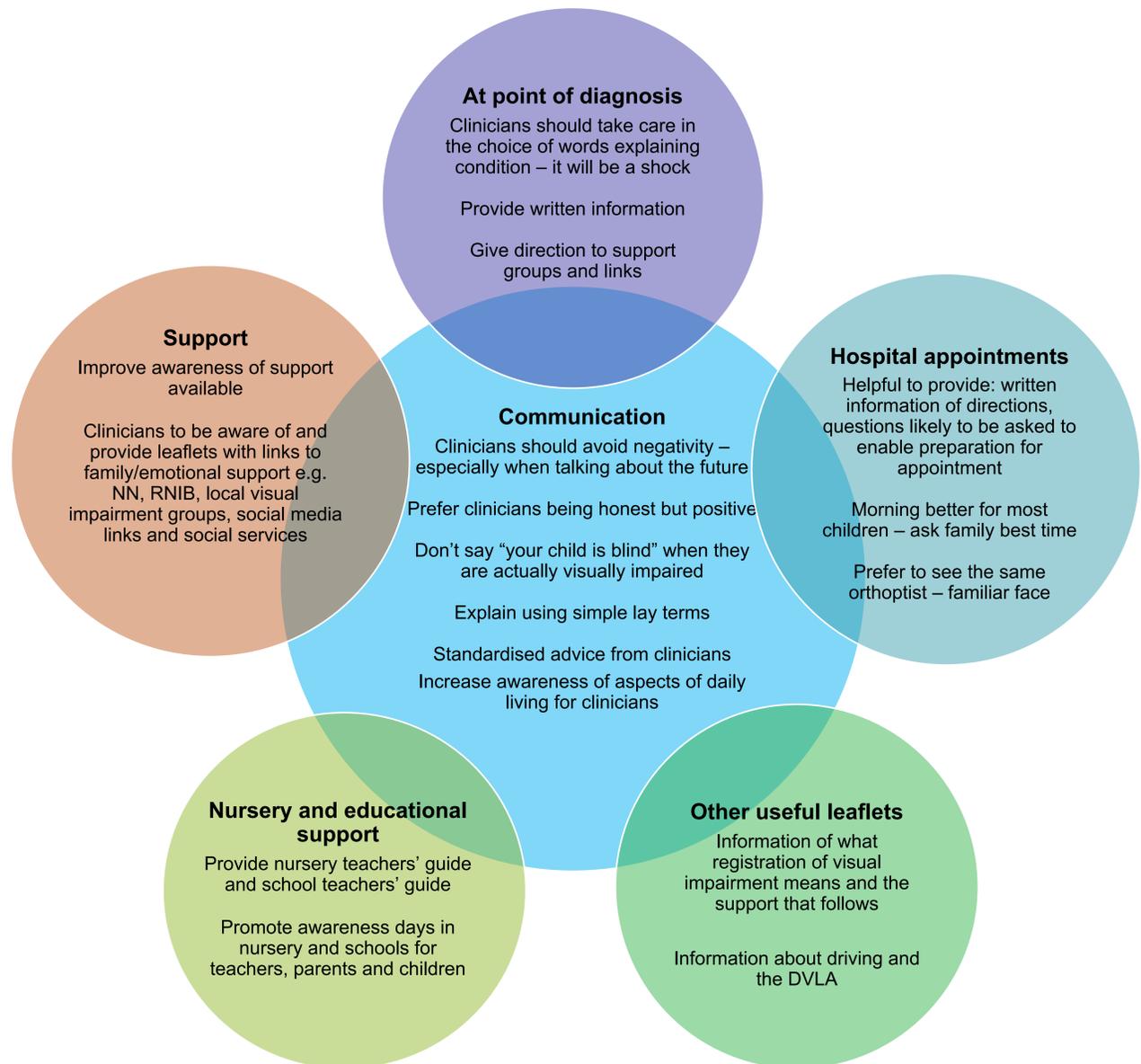


Figure 2. Recommendations from individuals with nystagmus and their families on how to improve the patient experience .

Discussion

Discussion with individuals with nystagmus and their families from across the UK and Ireland who attended the NN open day highlighted the need for improved and standardised care. A suggested method of implementing this is to produce a standardised nystagmus information pack which can be made available for all orthoptists and eye care clinics in the UK and Ireland to use. This pack should include information leaflets about:

- The condition nystagmus and how it can affect daily living
- Emotional and family support including NN, RNIB, local visual impairment groups, relevant social media groups etc.
- What to expect when attending an eye clinic or low vision appointment and questions that may be asked
- What registration of visual impairment will mean and the support that will become available as a result of this
- Educational and social support available
- Nursery teacher's guide
- School teacher's guide
- Driving and the DVLA

Limited understanding regarding the impact of nystagmus on daily living was a recurrent theme. Designing an awareness leaflet for eye care professionals with details of aspects of daily living that is a particular struggle for nystagmus patients and how certain advice and support can improve the patient experience could enhance understanding and awareness.

Conclusion

Awareness, care and support of nystagmus patients can be improved by producing a standardised nystagmus information pack for eye care professionals containing a range of information leaflets relevant for different ages and stages of the condition. Distribution of the appropriate leaflets to nystagmus patients, families and any who support these patients will enhance the patient experience.

Reference:

McLean RJ, Windridge KC, Gottlob I (2012). Living with nystagmus a qualitative study. Br J Ophthalmol. 96:981-6.