Sir, Validation of VSLD questionnaire in patients with learning disabilities undergoing cataract surgery

There are ~ 1.2 million people with learning disability (LD) in the United Kingdom with one in ten people with LD estimated to have a visual impairment. Life expectancy in LD is increasing 1.2 with anticipated rise in the numbers presenting for cataract surgery. Assessing vision in this group of patients can be a challenge, which becomes a barrier to accessing surgery. We have developed Visual Symptoms in Learning Disability (VSLD) questionnaire as a novel tool to document vision-related signs and symptoms in patients with LD to establish visual function and facilitate decision making in patients who cannot perform traditional acuity methods. Here we share our prospective case series of 10 patients with LD undergoing cataract surgery, in which the questionnaire was applied and validated.

Methods

VSLD questionnaire was designed by pooling 50 questions from published visual function and social function tools, patient interest groups (RNIB, SeeAbility), patient advocates and learning disability facilitators. Statements were reviewed by health professionals and combined, reworded or omitted to leave 10 core statements (Table 1). The developed VSLD questionnaire was administered by specialists orthoptists, ophthalmologist or LD health facilitation nurse to 10 patients referred for cataract surgery. The responder was encouraged to report difficulty regardless whether they

consider that vision was a factor in their ability to perform the task, to avoid bias of diagnostic overshadowing.

Results

Nine out of 10 patients experienced an improvement in vision and VSLD score (Figure 1). VSLD improvement correlated with improvement in estimated visual acuity. The patient with a static VSLD score had undergone second eye surgery (pre-operative visual acuity 1.2 RE, 0.0 LE). Interestingly, even in those patients in whom problems with functioning were not thought to be directly related to vision, an improvement had been noted post-operatively, which gives us confidence in using the questionnaire as a way of avoiding diagnostic overshadowing bias.

Discussion

We have previously discussed methods of applying reasonable adjustments in order to facilitate cataract surgery in people with LD.^{3,4} Traditional measures of visual function to demonstrate cost effectiveness of cataract surgery such as VF-14 questionnaire⁵ refer to tasks which may not be relevant to adults with moderate and severe LD. In order to demonstrate utility of cataract surgery in patients with LD, one would strive to demonstrate improvement in functioning, but no assessment tool previously existed for this purpose. VSLD questionnaire will support the patient and healthcare team in decision-making process about cataract surgery in this challenging patient group, as well as providing an alternative way to audit cataract success in the absence of visual acuity.

Table 1 Visual Symptoms in Learning Disability questionnaire

1) Does the patient have problems with their mobility, finding it difficult to use steps or curbs, frequent trips or falls? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 2) Does the patient have problems with meals, cannot feed themselves, spills food, is disinterested in meal or leaves food on the plate? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 3) Does the patient have difficulty with eye contact or looking at people? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 4)Does the patient invade other people's private space or move their face close to objects to look at them NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 5) Does the patient use their hands to search for objects? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 6) Does the patient have problems with changes in lighting, dislike the dark or is sensitive to bright lights? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 7) Does the patient have problems with handicrafts, jigsaws, card games or other table top activities? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 8) Does the patient have problems when watching the TV? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 9) Does the patient have problems with being startled by someone approaching quietly or by unexpected sounds? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY 10) Does the patient have problems with rubbing or poking their eyes, or cover or close one eye at times? NO YES due to vision problems YES due to other reasons YES due to both vision and other reasons I CANNOT SAY

A score is derived as follows: 'zero' is scored for each task or behaviour that the patient is felt to be struggling with, or for those that are considered not to be applicable, or they are unable to answer. A score of 1 point is given for an answer of 'no difficulty', with resulting functional score result being high in patients with no or little difficulties, and low in those with marked functional difficulties, even when these were not thought related to vision.

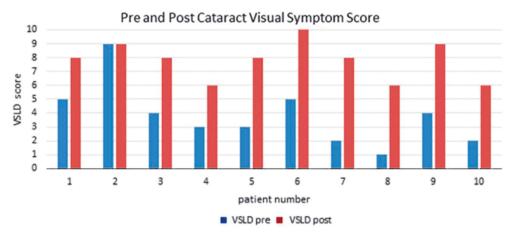


Figure 1 VSLD score comparing pre- and post-cataract surgery visual function for 10 patients with LD. VSLD, Visual Symptoms in Learning Disability.

Conflict of interest

The authors declare no conflict of interest.

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Sir, A novel record for patients with neovascular age-related macular degeneration: providing information and a personal treatment record

Education is key for health service users to facilitate understanding of complex health issues, such as risk factors and potential benefits of lifestyle and medical interventions. It is especially important in chronic conditions such as age-related macular degeneration (AMD).¹

Information leaflets are commonly used for patient education,² and personalised health records, where patient information is combined with a health record, have been successfully established in other specialties.³ This concept has yet to be translated into ophthalmic practice.

We have developed a novel personalised hand-held AMD record (PHAR) as a small booklet, combining 'easy to understand' information about AMD with a personalised health record, to increase patient education and engagement in the AMD service.

A PHAR (available online: http://www.ouh.nhs.uk/patient-guide/leaflets/files/13840Pmacular.pdf) was designed with information on various aspects about AMD, local support services and an intravitreal injection (IVI), and outpatient appointment record.

A self-reported questionnaire containing six questions rated from 0 to 10 (0 = no knowledge) was designed to evaluate our patients' knowledge in a number of domains related to AMD. The follow-up questionnaire also asked if patients had (1) read the information record; (2) found the IVI and outpatient appointment records useful; and (3) if they would recommend this resource to other AMD patients.

Over 7 weeks, 98 patients with neovascular AMD (nAMD) were approached to complete the baseline questionnaire prior to receiving a PHAR.

All 98 patients completed the baseline questionnaire. Of these, 93 patients (94.9%) completed the follow-up questionnaire after a mean of 40 days (SD: 15). All 93 patients indicated they had read the PHAR. There was a