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focus

Cataract Surgery in patients with Learning Disability

Rostron E, Pilling R. Bradford Teaching Hospitals, Bradford, UK
rachel.pilling@bthft.nhs.uk

There are approximately 1.2 million people with Learning Disability (LD) in the UK. One in ten adults with LD have visual impairment [1]. There is a wide range of published prevalence of cataract in adults with LD, with an estimated 12% in those aged over 50 years and up to 16% in adults with Down's syndrome. A recent confidential inquiry found visual problems to be present in 50% of adults with LD who suffered a premature death[2]. Cataract represents a potentially reversible cause of visual impairment, but literature is sparse with relation to cataract outcomes in these patients.

Although people with LD have a shorter life expectancy compared to the general population, life expectancy is increasing with anticipated reciprocal increase in the numbers presenting for cataract surgery. Difficulties frequently encountered by the clinician when considering the risks and benefits of cataract surgery in this patient group include patient inability to communicate their symptoms, challenges in examination and assessment, surgical planning, and post-operative care.

It has been long acknowledged that a change in behaviour such as increasing frustration, anger, withdrawal or self-harming can be a sign of visual loss. However, diagnostic overshadowing, when symptoms of physical ill health are being mistakenly attributed to behavioural problems or as being inherent in the person's learning disabilities, can result in even close family and carers overlooking visual problems as the cause for a change in character. Carers report occasions where assumptions are made about a patient's quality of life based on their learning disability and how patients who cannot speak, read or walk are thought to not need vision. Anecdotally, there are many examples of patients with LD having cataract surgery declined because of concerns regarding eye rubbing, cooperation with post-operative drop regimes and post-operative infection (personal communication: Pilling RF, 2013).

There are many barriers to cataract surgery for patients with LD, chief among them being issues around asse ssing visual acuity, concern regarding increased perioperative complications and post operative care. The Equality Act of 2010 requires organisations to make "reasonable adjustments" in order for those with disabilities of any kind to access services[3]. There are several publications which make suggestions of reasonable adjustments to enable adults with LD to access eye outpatient services, but no guidance on adjustments in surgical intervention[4]. Here we offer a series of reasonable adjustments that can be adopted to improve patient experience and overcome some of the perceived barriers associated with patients with LD undergoing cataract surgery (Table 1).

Assessment of visual acuity is important in considering risk and benefits of surgery, but the absence of Snellen acuity should not preclude patients' eligibility for cataract surgery. We have developed a standardised functional visual assessment locally which is used to demonstrate visual function in patients with LD who are not able to cooperate with standard acuity tests **(Fig 1)**. Traditional measures of visual function to demonstrate cost effectiveness of cataract surgery (eg VF-14) refer to tasks which may not be relevant to adults with moderate and severe learning disability. We consider other factors such as ability to feed oneself, ability to recognise carers and a change in social interaction as measures of visual function which may improve following surgery.

Fig 1. Bradford Visual Function Box - standardised tool used to assess patients' vision based on ability to track or reach for object.

Case studies

Case 1: Patient H, age 53, was referred via the LD health centre with deterioration in vision. She had severe LD and no verbal communication. Her mobility had slowed significantly over 6 months such that she was almost completely wheelchair bound. When she transferred, she would feel with her feet for obstacles, and feel for food on her plate. She sat with her head bent and did not look at people. She had a long standing constant left exotropia. Distance visual assessment was not possible but she could track a 10mm bead at 33cm with both eyes open. It was not possible to instill drops in clinic, but on undilated examination she had dense cataract in both eyes.

A further appointment was arranged with the patient, her next of kin and a carer. Atropine was instilled at home prior to her next visit but no fundal view was possible in either eye due to poor cooperation. It was determined by the carer, next of kin and surgeon that H lacked capacity to consent for cataract surgery, but was in her best interests, so a consent form 4 was completed.

The patient was given a shield to wear periodically at home in the weeks leading up to surgery which she tolerated well. Attempts were made to desensitise the patient to drops but this was unsuccessful. Subconjunctival and intracameral steroid was given at the end of surgery and the wound was sutured. Because the patient had been intolerant of spectacles in the past, the decision was made to aim for -1.00 SE as a refractive outcome. There were no post-operative surgical complications. Visual acuity improved to tracking a 15mm ball at 3m. Patient's independence improved and she began to feed herself and mobilise freely without assistance.

Case 2: Patient D, age 47, was referred to clinic via the LD health facilitation team with deteriorating vision. D had moderate LD and was able to communicate well. She said she'd been finding it difficult to do her jigsaws and watch TV for a few months. She could feed herself but was becoming messier. Visual acuity was 3/24 unaided (Kay pictures) and on examination she had dense cataract in both eyes. D came to clinic accompanied by her sister and a member of the LD health facilitation team. Despite spending some time with D, it was felt by the sister, the LD team and the surgeon that although she was keen to improve her vision and understood this would require a general anaesthetic, she was unable to understand the risks and benefits of cataract surgery and a consent form 4 was signed.

D was able to tolerate post operative drops and a shield, but because of her age, additional post-operative subconjunctival steroid was administered, along with a 10/0 vicryl suture. There were no postoperative complications and visual acuity improved to 6/7.5 unaided. In the hours following surgery D noticed an improvement in

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her vision and was doing jigsaws the following day. Her sister reported that her caring needs had reduced as she was happier to be left alone in a room for periods of time than before her surgery.

Summary:

Cataract surgery can offer sight improvement for many people, including those with learning disabilities. Sight is the key to independence, and in many cases cataract surgery reduces the patients social care needs, improves their mobility, self care skills and communication. Many barriers to surgery are placed there by health care teams wishing to prevent causing distress for patients. However cooperative working with anaesthetists, carers and community health facilitation teams to pre-empt problems and where possible allow patients the opportunity to desensitise to new experiences and surroundings can minimise this risk. The majority of reasonable adjustments suggested do not require additional resources from within departments and the authors would encourage departments to build upon the examples to enable more patients to undergo successful cataract surgery. The perceived risk factors for complications can be managed perioperatively in conjunction with the Learning Disability community team and patient's carers with simple changes to surgical assessment and procedure. This will in turn reduce inequalities in availability of surgery to patients with LD.

Faruque Ghanchi, Editor Focus
Faruque.Ghanchi@bthft.nhs.uk

Stage in Pathway	Reasonable adjustment
Referral and appointment making	Identify learning disability on referral letter Offer pre appointment visit to the department Liaise with patient and carer to ensure appointment on a day and time carer is available to attend
On the day of the appointment	Offer a quiet area for patient to wait Alert staff to patient arrival to minimise wait Avoid patient joining system of queues for tests which may not be appropriate
Assessment in clinic	Visual assessment appropriate to patients ability eg with orthoptist, functional visual assessment Offer split visits – assess vision on one day, to see doctor on a separate visit
Communication and Discussion	Offer EasyRead leaflets [5] Copy letter to patient, carers, GP and community LD team

Pre-assessment

Pre- visit	Consider offering patient and carer a visit to the pre-assessment unit on the day of listing so they can experience the environment before any investigations are undertaken
Biometry	Consider allowing extra time or extra visits to complete biometry Consider allowing patient to watch while biometry measurements taken on (eg) carer so they understand what will happen Biometry can also be performed under GA
Involve anaesthetists	It is often helpful to arrange for the anaesthetist to meet the patient and carer before the day of surgery to anticipate issues such as posture, airway management and venous access
Pre operative investigations	In some cases, pre operative screening investigations may not be possible – this should also be discussed with the anaesthetist
Patient will not cooperate for dilating drops and/ or examination in clinic	Consider asking carers to instill longer acting dilating drops at home/before patient wakes Consider B-scan(ultrasound) in clinic Consider B-scan/fundal examination under GA prior to procedure
Venous Thromboembolism prophylaxis	Consider if omitting VTE is an appropriate reasonable adjustment
Choosing a bed	If the patient has adequate understanding, consider allowing them to choose the bed space to which they will be admitted on the day of surgery, and to meet the nurse who will be on duty if possible
Desensitisation to post operative treatment	Offering the patient a shield to explore and practice wearing at home avoids the distress of this being encountered on the first time after surgery. The patient and carer can also be issued with a bottle of artificial tears to practice drops instillation.

The Day of Surgery

Morning or afternoon list	Consider if patient will be able to tolerate fasting during day for pm list
Place on list	Often being first on list minimises delay Consider placing later in morning if arrival at hospital by 7.30am is problematic
Pre medication	Consider if patient would require sedation prior to anaesthetic and that this may alter placement on theatre list
Pre op drops	Consider if these can be instilled after anaesthetic induction
Concern regarding post operative infection/trauma to eye	Consider vicryl suture to wound

Post operative care

Recovery	Consider a quiet area Inform other patients that patient may sound in distress but is actually just in unfamiliar surroundings Allow carer to be present in recovery as patient wakes so they see a familiar face
Post operative drops	Consider a twice daily regime, which can be instilled while patient is asleep Avoid struggling to put in drops – pressure on the eye is more likely to cause harm than omitting drops
Post operative follow up	Offer an appointment the day following surgery should the carer have concerns, although if surgery is straight forward follow up can occur between 1 and 4 weeks as usual

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