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Cataract Surgery in People with a Severe Learning Disorder

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1. Introduction

In nature acquired blindness is a dangerous situation. Blind animals living in herds have difficulties associating with their group. For such animals it is often impossible to live alone. This can result in starvation and death. If intellectually competent humans are going blind they have the possibility to express to others what problems they face living in a society. They have difficulties in work and are, in many situations, dependent on other people. People with learning difficulties, especially the severely intellectually disabled are already care-dependent but they have additional difficulties expressing the problems associated with acquired blindness. Cataract is one of the leading causes of treatable blindness (Vision 2020, 2010). With an aging population the incidence of cataract is growing. Since life expectancy in severely intellectually disabled people has increased in western countries the incidence of cataract will also grow in this group (Bittles et al 2002, Bittles et al 2006).

The intellectually retarded represent a large group of individuals who require better eye and vision care than the general population but who do not always receive it, especially if the mental disability is severe (Bothe et al, 1991, Castane & Peris, 1993, Evenhuis & Nagtzaam, 1997, Goto et al 1995, Warburg, 2001, Van Isterdael et al 2006, Van Isterdael et al, 2008, Van Splunder et al 2004). The prevalence of cataract in intellectually retarded adults is higher than in the age-matched general population (Evenhuis, 1995, Klaver et al 1998, Limburg 2007). Ophthalmological abnormalities are often found in intellectually retarded people. In the last 15 years much research has been done on this topic. Many studies describe the frequency and cause of eye diseases in this group. However follow-up in these studies is often limited or absent. Little research has been done on the implementation of recommendations for treatment e.g. cataract surgery (Sjoukes, 2008). In this chapter an overview of different published studies is provided. Research has been done into the frequency of cataract in this population and how often the operation takes place as well as the indications for cataract treatment. The particular challenges and results of cataract operations in the severely intellectually retarded are also examined as well as how this population differs from a conventional one. Also described is who is involved in the decision-making after diagnosis for treatment. Special attention is given to the procedure before, during and after the operation. The significance of quality of life measures and cost-effectiveness will be discussed. The outcome data from operations will be provided. Recommendations for diagnosis, treatment and postoperative monitoring are also made.

What is the prevalence of severe intellectual handicap? In the Netherlands in 2008, 60,000 people had a severe mental handicap (Woittiez & Ras, 2010). This was out of a total population for the Netherlands of 16,445,593 (Woittiez & Ras, 2010). This means that the prevalence of severe mental handicap in the Netherlands is 3 per thousand.

This varies from 5 per thousand in younger people to 1 per thousand in people of about 70 years of age. In the period 1998 till 2008 the prevalence increased. This was not due to a greater incidence per se but due to longer life expectancy. Comparison with data from other European countries is difficult because of different methods of registration in these countries. All these people are dependent on care. In younger age groups they sometimes live at home with their parents. As the population of the severe mentally handicapped is becoming older it is usually not possible for their parents to care for them

2. A retrospective study of 5205 intellectually handicapped people

This study focussed on an institutionalised population of 5205 people with an intellectual disability who were referred for visual assessment between 1993 and 2003. The author tried to determine the prevalence of treatable visual impairment and how many times advice for treatment was implemented (van Isterdael et al 2006, 2008).

2.1 Materials and methods

The records of 5205 consecutive people examined by the Visual Advisory Centre of Bartimeus, Zeist, The Netherlands, from 1 January to 31 December 2003, were retrospectively reviewed. Bartimeus is a Dutch institution providing education, care and services to the blind and those with partial sight. The Visual Advisory Centre was started in 1991 to identify the visual problems of people living in institutions with intellectual disability, to provide information and to explore the possibilities for treatment. The Visual Advisory Centre now works at 7 establishments in the Netherlands. The centre works with 15 employers in 119 institutions. In a year around 3000 people are examined.

All subjects were people with an intellectual disability living in institutions and were referred to the Visual Advisory Centre by doctors specialising in their care. Doctors were responsible for selecting those people who could benefit from the centre, for example those who were difficult to assess or had a reduced visual performance.

Trained optometrists and an ophthalmologist examined the participants ophthalmologically according to a standard protocol. Full assessment required 90 minutes. Referring doctors provided personal data, data on limitation of overall physical mobility and the cause of intellectual disability, and a general medical history. Optometrists tested visual performance by assessing visual acuity and visual fields. Visual acuity was assessed with two tests - the Teller or Cardiff tests. The results were expressed in Snellen equivalents. Visual fields were assessed using the confrontation method. Ophthalmic assessment by the ophthalmologist included anterior segment examination, fundoscopy and retinoscopy with mydriasis.

Degree of intellectual disability was defined according to the Diagnostic and Statistical Manual, 4th edition TR classification: mild, IQ 55-70, moderate, IQ 35-55, severe IQ 25-35 and profound IQ<25 (American Psychiatric association, 2000). Visual performance was defined according to the World Health Organization (WHO) criteria: normal vision, visual acuity >0.8 and visual field >50degrees equating with mild vision loss, visual acuity >0.3 and <0.8

and/or visual fields >10 degrees and <30 degrees equating with profound vision loss to near blindness, light perception to visual acuity <0.05 and/or visual fields 10 degrees or less to, blindness, and no light perception. Statistical analyses, demographic data, visual assessment data and causes of intellectual disability, visual disorders and co-morbidity were analysed using SPSS V.10.1 and Microsoft Excel V.2002

2.2 Results

The percentage of men was 52.7 %. The mean age was 38.5 years. The percentage of participants >50 years was 23.5 %. Severe or profound intellectual disability was found in 93% of subjects. Immobility was found in 28.4% of subjects. Moderate vision loss to blindness was present in 43.8%. A specific cause of intellectual disability was reported in 58.4%. Down's syndrome was the most frequent cause of intellectual disability.

The prevalence of cataract in this population and patterns of referral are shown in Table 1. An unoperated cataract with a significant effect on vision was found in 10% of subjects. A visually significant cataract that had not previously been diagnosed before was found in 399 patients. The Visual Advice Centre advised referral to an ophthalmic surgeon unless it was contraindicated for medical reasons. 98% had cataract in both eyes. 219 of 399 (55%) patients were referred to the ophthalmic surgeon of whom 26% had cataract surgery.

No consent for the operation was obtained from the relatives in 14% of cases. In 74% of the referred patients the ophthalmologist performed no cataract surgery. The reason for treatment or non-treatment was not clear. The results of the 119 operated patients (119 out of 119 eyes) were satisfactory. In 117 patients vision improved and there was a very good improvement in living skills and behaviour commensurate with this afterwards. One patient moved to an unknown address so was not followed up and one patient suffered a retinal detachment. Although he received retinal detachment surgery vision was not better than before cataract surgery. After the unexpected hospitalisation for the retinal surgery his behaviour was difficult.

Self-mutilation of the eyes was present in 5% of the study population. This an important observation, because self-mutilation is a high risk factor for severe ocular morbidity. On the other hand is it possible that severe ocular morbidity can result in self-mutilation.

A specific cause of intellectual disability could be established in 58% of people who were studied, compared with 41-88.6 % in the literature (Arvio & Sillanpaa, 2003, Beange & Taplin, 1996, Haugen et al, 1995, Van Splunder, 2006, Warburg, 2001). Down's syndrome was reported in 21% of people, which is consistent with the literature (13.1-29%) (Arvio & Sillanpaa 2003, Haugen et al 1995, Hou et al 1998, Warburg 2001).

The prevalence of cataract in this group is difficult to compare with other studies because in many studies the age of patients is not comparable. Severe or profound intellectual disability was present in 93% of the study population, compared with 55% in the total Dutch institutionalised population with intellectual disability. Combined figures for visual impairment and blindness in institutionalised people with intellectual disability reported in the literature vary between 18.7% and 37% compared with 44% in the study's population (Arvio & Sillanpaa 2003, Van Splunder 2006).

2.3 Challenges in ophthalmic examination and treatment

Most severely intellectually retarded people are diagnosed with an intellectual disability from childhood. These people are more prone to common risk factors for poor health related

to diet, weight and physical inactivity as well as impaired vision and hearing, respiratory diseases and dental problems. Up to one third have an associated physical disability which puts them at risk of postural deformities, pulmonary infections, gastrointestinal problems and urinary incontinence (Cooper et al 2004). They are 20 times more likely to have epilepsy.

Determining factors for cataract operation*	No referral (n=180)	No surgery after referral (n=87)	Surgery after referral (n=57)
Other ophthalmic problems			
corneal	46 (26%)	23 (26%)	17 (30%)
retinal	61 (34%)	22 (25%)	14 (25%)
nystagmus	49 (27%)	25 (29%)	16 (29%)
optic nerve atrophy	15 (8%)	4 (5%)	2 (4%)
cerebral visual impairment	30 (17%)	11 (13%)	9 (16%)
total	137 (76%)	59 (68%)	41 (72%)
contra-indication			
bad medical condition	11 (6%)	7 (8%)	5 (9%)
behaviour problems	32 (18%)	16 (18%)	13 (23%)
ophthalmological	45 (25%)	14 (16%)	10 (18%)
total	78 (43%)	33 (38%)	19 (33%)
Very strong intellectually handicapped	68/92 (74%)	32/42 (76%)	20/27 (74%)
No permission	26 (14%) †	11 (13%) ‡	0 (0%) †‡
Bilateral cataract	34 (19%) †	24 (28%) ‡	39 (68%) †‡
* multiple determining factors possible			
† p < .05			
‡ p < .05			

Table 1. Survey of Referral and Operation, n=324.

	better	same	unknown	worse
Vision	98%	1%	1%	0%
Quality of life	98%	0%	1%	1%
Challenging behaviour	98%	0%	1%	1%

Table 2. Results of operated patients.

These health needs are often unrecognized or misdiagnosed. Their mental health problems have an even greater likelihood of going unrecognized. Another important issue is the challenging behaviour displayed by about 45% of people with a severe intellectual disorder, including aggressive, destructive, attention-seeking, self-injurious, noisy and hyperactive behaviour which in many cases can be treated by using correct healthcare.

Visual problems go frequently unrecognised. Identifying visual problems in this group is difficult and these people rarely mention them spontaneously. Clinicians need to think of visual problems as part of a differential diagnosis if there is a progressive uncertainty in the thought processes shown by these patients, especially when placed in new situations. Further in cases of self-mutilation and behavioural problems doctors must be alerted to the possibility of visual problems.

Eye examination has to be done in a special way. It can be time-consuming - 90 minutes on average for such patients. In addition it is of significant benefit if the examiner is familiar with this population.

It is not recommended to perform the examination alone. The patients are often very anxious because they do not understand what is being done. Explanation is difficult or impossible. Further they do not like irregular activities. It is very important to discover how near you can get to them before they stop co-operating or even start to hit, kick or bite. It is very important to display an attitude of professional calm. During the examination one has to encourage the patient in a positive way.

Most people in this group of severe intellectual handicapped people cannot read or understand pictures, many of them cannot even talk making communication even more difficult. Assessment of visual acuity in this group therefore requires special strategies. In most cases the vision can be only be measured by detection methods for example with Teller cards or Cardiff test (Clifford-Donaldson et al 2006) (Figure 1)

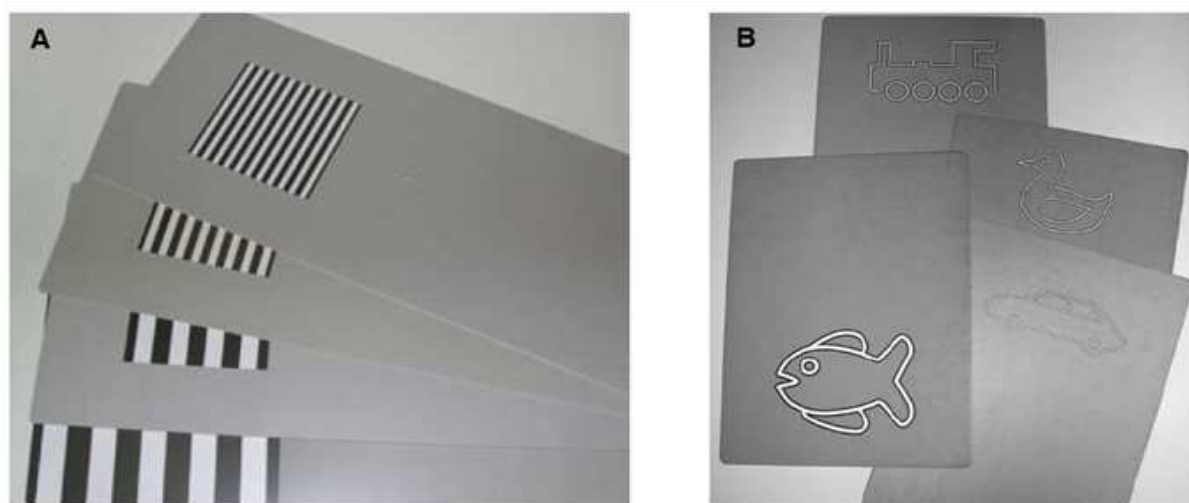


Fig. 1. A. Teller acuity cards, B. Cardiff acuity cards. Both are examples of resolution acuity.

The Teller acuity cards offer eye care practitioners a rapid and reliable method of assessing visual acuity in very young children and non-verbal adults. The set of seventeen cards allows clinicians to measure the ability to resolve black and white striped patterns on the cards. The eye care practitioner judges the patient's visual attention to each series of cards containing stripes of different widths (spatial frequencies). The Cardiff acuity test is also

designed for measuring visual acuity in young children and people with intellectual impairment. The test works by preferential looking - that is the patient simply looks towards the target and the examiner watches this eye movement response to determine whether the patient can see the target. If the patient reliably looks at the target, it is assumed in the test that he/she can see it. The principal of the target design is that of the vanishing optotype. The targets are pictures drawn with a white band bordered by two black bands, all on a neutral grey background. The average brightness of the picture is equal to that of the grey background. If the patients detail vision is good enough to resolve the white and black bands, the picture will be visible and the patient can look towards it. If the target lies beyond the acuity limit, the picture merges with the grey background and becomes invisible. The patient cannot look at the picture, because the grey card appears completely black. In the Cardiff test, each picture is located either in the top half or in the bottom half of the card. The examiner, watching the child's eye movements, can judge the position of the target from those eye movements. The pictures are all of the same size, but decrease in width of white and black bands. The visual acuity is scored as the narrowest white band for which the picture is visible. An important feature of the preferential looking technique is that the examiner should not know in advance the position of the target. The Cardiff test includes three cards at each acuity level. The three cards have the same picture, but two are at the top of the card and one at the bottom, or two are at the bottom and one at the top. This means that once one card has been presented the examiner cannot predict the position of the next card. Most of the time visual acuity even in persons with severe intellectual handicap can be measured. Because of physical restrictions and anxiety in the patients the anterior segment can only be examined by a portable handheld slit-lamp. Examination can be very demanding (figure 2).



Fig. 2. Eye examinations with severe intellectually disabled people can be very demanding

2.4 Decision-making when considering cataract surgery

If an operable cataract is diagnosed the therapeutic possibilities need to be evaluated. One has to be sure that there is no other ocular pathology responsible for vision loss. As operations in this group can only be performed under general anesthesia a decision has to be made as to whether this risk is acceptable. Cardiac, neurological and other systemic contraindications have to be excluded.

Extensive information is necessary for the decision-making process. Who is involved in the decision-making? The patient themselves, their family, in the Netherlands the curator of the institution, the doctors and nurses who care for the patient on a day to day basis and of course the specialist ophthalmic surgeon all need to decide. The group of patients is incompetent to understand information about the disease and to foresee the consequences of treatment. So other people have to decide and give consent on the part of the patient.

Many relatives are afraid of the impact of changes to their relative's vision and cannot foresee the problems that could arise during and after the operation. It is of great importance to explain the new methods of cataract surgery which allow faster rehabilitation. Examples include the use of smaller incisions than previously, the possibility of follow-up care in the community such as a polyclinic, and the use of new devices and medicines. Nurses and non-specialist doctors also need to be well-informed about the entire pre-, peri- and postoperative period since they are unlikely to be very familiar with care for the patient undergoing eye surgery. Many of them are afraid of the consequences of the visual deterioration in their patients' condition in the period building up to cataract surgery. Therefore it is important to stress that behavioural problems and uncertainty are often caused by visual disturbances and that the patient improves after the operation when his sight is better.

While the ophthalmic surgeon has the surgical experience of managing the patient with visual loss few ophthalmologists have more than basic medical familiarity in caring for people with a severe mental disorder. In the Netherlands there is comparatively little attention paid to these patients during general medical education of doctors. It is very important to inform the ophthalmologist about what to expect from the patient's behaviour in advance. Nowadays data and pictures of the patient can be sent by internet before consultation.

The Visual Advisory Centre developed a protocol for giving preoperative and postoperative instructions. If an ophthalmic surgeon preferred another protocol it was mentioned and included in the instructions. It is very important for intellectually disabled people to recapitulate the procedure several times. The Visual Advisory Centre conducted work using pictograms. Eyes, eye drops and doctors were reproduced on these pictograms.

In most of the operations prophylactic antibiotics were started one day before surgery. Depending on the patient a little sedation was given before surgery, on the day of the operation and afterwards. Cataract surgery was always performed under general anesthesia. Most of the surgeons liked to give a subconjunctival injection with corticosteroids and antibiotics after the operation. The postoperative period was in most patients less difficult than might have been expected. As soon as the patient noticed their better visual acuity they were much more co-operative than expected. Adjustment of eye drops was straightforward. Infections were not present and no patients touched their operated eye in a destructive way.

In the last few years it was noticed that some ophthalmic surgeons developed greater familiarity in operating on this group of patients. They became more eager to perform cataract surgery on these patients. This phenomenon is probably due to positive

reinforcement in this group. In spite of their limitations in expressing themselves this group of patients are satisfied and never complain about the results of surgery. Nurses and doctors are also content because giving care is easier to patients who do not complain.

It would be useful to perform a prospective study on this matter. Such a study has to determine the reason for treatment or no-treatment being decided in people with a severe intellectual handicap. The results of cataract surgery in this group should be compared with a conventional group of patients.

Complaints would need to be evaluated by anamnesis of patients, their families and care givers. Vision before and after operation would have to be compared. Ophthalmological examination of the anterior segment and fundus would be required before and after operations. Problems during anesthesia would also have to be evaluated. Beyond these core requirements trained staff would need to evaluate the quality of life score before and after the cataract operation. This can be done using instruments from the World Health Organisation (WHO) and the Visual Function Questionnaire of the National Eye Institute (National Eye Institute). A prospective study along these lines was organised in the Netherlands. Unfortunately the authors of the above study did not succeed in raising the monetary funds required for this project, partly due to the low priority given to this area by funding bodies and partly as the team split up.

2.5 Cases

Two patients from the group will be described in detail. The first patient AM was born in 1957. She had a severe intellectual handicap because of an inborn error of metabolism. Since the age of 30 she has been living in an institution. At that time her parents could not care for her anymore. In the beginning she was a relatively easy person to care for but in a few years she developed very difficult behaviour. She was aggressive and mutilated herself in a very destructive way. She even removed her right eye. Two persons were needed to cope with her 24 hours a day. The next most important aspect to her care was her regular treatment by a haptonomist. The Visual Advisory Centre was asked to assess her visual acuity. Eye examination revealed that she was blind because of severe cataract in her only eye. The Visual Advisory Centre advised referral to an ophthalmic surgeon. The family did not give permission. They blamed the institution for the change in behaviour. After 10 years of blindness and a lot of problems the curator of the institution gave permission. She was operated on. After the operation the vision improved up to 0.7.

She now lives in her own room, is happy with some simple activities and needs no extra care (Figure 3).

It was not possible to take photographs before the operation.

The second patient PB was a male, born in 1960 who had lived in an institution since the age of 35. His parents died and other family members were not able to care for him. He was an enthusiastic resident of the institution. His daily activity consisted of working in the garden. After some years he was becoming anxious in the morning and evenings when it was dark. He also could not find his chamber. He had bad vision in one eye because of congenital ptosis (Figure 4). The Visual Advisory Centre discovered a mature cataract in the other eye. He was referred to an ophthalmic surgeon with the permission of his curator. The ophthalmic surgeon performed cataract surgery in one eye and ptosis correction in the other eye. It is difficult for severe mentally handicapped people to understand the cause of change in their vision. He thought the eye caps (shield) with holes applied after the operation to protect the eye from damage caused the better vision. He did not want them removed as

would otherwise be routine. Two months later he was still living with the caps on. His vision improved to 0.8 in both eyes.



Fig. 3. Patient AM self-caring after the cataract operation. One eye was auto-enucleated.



Fig. 4. Patient PB before the cataract operation. Note additionally the squint, ptosis and consequent chin-up posture.

3. Costs of avoidable blindness

In Australia a study examined the costs of blindness for the whole population. The costs of eye diseases in 2004 which accrued in Australian dollars due to suffering and premature death were calculated – 1824 million Australian dollars were incurred in direct medical costs, 1781 million Australian dollars were incurred due to lost earnings for the visually impaired and costs for caregivers (family, friends) were 845 million Australian dollars (Abu Raihan, 2010).

In severely intellectually disabled people the situation is in some ways different. Loss of earnings from visual impairment are not relevant to consider as the sufferers are not considered part of the working population. However costs due to suffering and also from premature death may be incurred. Medical costs are another area. If a person is blind he needs more care especially if behaviour is also disturbed. On the other hand eye examinations in severely intellectual disabled people are time-consuming, as is the operation itself. In the Netherlands health care and health cure have different budgets. This means that if a person is treated because of avoidable blindness, institutions have to pay less but hospitals more. In many institutions dentists are paid for their work by the organisation. They even give general anesthesia to patients. While eye surgery is technically very demanding and intricate it therefore seems feasible in principle for a special (mobile) unit to perform eye operations on these intellectually disabled people, paid for by the care institution.

4. Conclusions

The group of subjects discussed in this chapter with a severe intellectual handicap lived in institutions. In the Netherlands many intellectual handicapped people live in small

protected units but for this group, most of them older than 30 years in age and severely handicapped, living in a specialised institution is unfortunately the most appropriate option. The Visual Advisory Centre examined these people in a novel way. A lot of eye diseases were found. Cataract was diagnosed frequently. Despite referral only a small percentage of the patients received cataract surgery. The patients who were operated upon showed good improvement in vision, quality of life and behaviour. Recommendations have been provided for future research and treatment.

5. Acknowledgment

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Consent was obtained for the photographs.

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