

The Pediatric Cataract Register (PECARE): Challenges in scientific evaluation of visual development

Jenny Gyllén,^{1,2*} Birgitte Haargaard³ Alf Nyström,^{1,2} Arzu Karatepe Hashas,^{1,2} Anna Linnarsson Wiklund,⁴ Eric Trocmé,⁴ Annika Rosensvärd,⁴ Ulrika Kjellström,^{5,6} Jenny Wallander,⁷ Kristina Tornqvist,^{5,6} Gunilla Magnusson^{1,2}

¹ Department of Ophthalmology, Sahlgrenska University Hospital, Mölndal, Sweden

² Department of Clinical Neuroscience, Institute of Neuroscience and Physiology, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

³ Private ophthalmologist, Copenhagen, Denmark

⁴ St Erik Eye Hospital, Stockholm, Sweden

⁵ Department of Ophthalmology, Skåne University Hospital, Lund, Sweden

⁶ Department of Clinical Sciences, Ophthalmology, Skåne University Hospital, Lund University, Lund, Sweden

⁷ Jönköping Ryhov County Hospital, Jönköping, Sweden

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* Correspondence: jenny.gyllen@vgregion.se

Abstract

The purpose of this study was to analyse visual acuity tests and methods used in children who have undergone cataract surgery in Sweden as well as the success rate of visual acuity testing, in order to improve current treatment.

Children registered in PECARE who underwent cataract surgery between 1st January 2007 and 31st July 2016 were included. Visual acuity test methods were analysed at the follow-up ages of 1, 2, 5 and 10 years.

A total of 424 children were operated, 209 girls (49%) and 215 boys (51%). The number of operated eyes was 584, of which 320 (55%) were bilateral cataracts and 264 (45%) unilateral. A total of 660 follow-up visits took place, and successful visual acuity measurements were achieved in 416 of these cases: 106/228 (46%) at 1 year of age, 128/226 (57%) at 2 years of age, 169/193 (88%) at 5 years of age, and 13/13 (100%) at 10 years of age.

Visual acuity test methods differed among the follow-up clinics, making comparisons challenging. The Kasper test was widely used before the age of 2, and has been validated, but not been published scientifically. The success rate was higher for Kasper than for other tests.

A challenging diversity of methods for testing visual acuity are used in Swedish paediatric cataract care. Age-related national guidelines regarding visual acuity tests methods are needed for the development and improvement of current treatment. Scientific evaluation of visual development is an important outcome in order to reach equal care. Furthermore, the Kasper test needs to be scientifically re-validated.

Keywords: paediatric cataract, congenital, visual acuity tests

Introduction

The aim of the Swedish National Quality Registries is to improve health care by continuously evaluating treatment results as well as patient reported outcome measures. Furthermore, they are tools in the national work for securing equal care between genders and age, independently of where you live in Sweden. The registries are funded by the Swedish Association of Local Authorities and Regions (SALAR), and regular reports of health care improvements are requested. The Pediatric Cataract Registry (PECARE) highlights several challenges when scientifically evaluating visual acuity among Swedish children in general. Therefore, it can be used as a scientific example of the challenge shared by other child-related quality registries and may be shared worldwide. For instance, there is no national, Scandinavian or European, agreement regarding age-related visual acuity tests. Another challenge is that for the youngest children, there is an acceptance of not achieving a result from visual acuity testing, justified by the lack of cooperation of the child due to their young age. However, the visual acuity result is always dependent on the interaction between three parties: the child, the parent and the professional.

Childhood cataract can be congenital or acquired, unilateral or bilateral, dense or partial. It is a very rare condition, but still one of the most common causes of blindness in children worldwide (Gilbert & Foster, 2001). In Sweden, about 40 children per year are born with congenital cataract (Haargaard et al., 2015). Newborns have an immature visual system and normal visual development requires, among other things, clear ocular media. If untreated, an eye with dense cataract will become severely visually impaired due to amblyopia and often requires surgery (within the first three months), followed by numerous visits to an ophthalmology clinic for several years during childhood to enable proper visual development. Early detection and surgery is essential (Gilbert & Foster, 2001). Unlike cataract surgery for adults, cataract surgery performed on children is associated with a significantly higher rate of complications in the form of glaucoma, inflammation, secondary visual axis opacification (VAO) and retinal detachment (Chan et al., 2012). Childhood cataract surgery is centralised by the Swedish National Board of Health and Welfare, and at present St Erik Eye Hospital (St Erik), Stockholm, and Sahlgrenska University Hospital (SU), Gothenburg, hold licences for National Specialised Medical Care for children under 3 years of age. They are called regions 1 and 2 in this study. One treatment goal for cataract surgery in children is visual acuity compatible with driving licence requirements where best corrected binocular visual acuity must be at least decimal 0.5 binocularly.

PECARE is a subdivision of the Swedish National Cataract Registry and collects data on aspects of cataract surgery and outcomes from all ophthalmology units in Sweden (Lundström et al., 2002; PECARE, 2025). One goal of PECARE is to strive for equality of care among children and adults, between children in different regions of Sweden, and to ensure early detection of paediatric cataract in new-borns by continuously evaluating and optimising

current screening strategies. Other goals are to reduce surgical complications, analyse unusual treatment outcomes on a national level, and to facilitate analysis of the underlying causes of childhood cataracts (PECARE, 2025). PECARE also works to evaluate and optimise collaboration with families as co-caregivers in the treatment of children with cataracts and to disseminate new knowledge on improving care.

At present, there is no general agreement as to which visual acuity test to use in paediatric ophthalmology (Anstice & Thompson, 2014). Choices are instead guided by knowledge and tradition. In the EU, a project called Euroscreen was carried out to collect data on vision and hearing screening programmes for children in all EU countries (*"Euroscreen vision & hearing"*, 2023). In Sweden, various forms of preferential looking tests (PL tests) such as the Teller Acuity Cards (TAC) and the Cardiff Acuity Test (Cardiff) are mainly used from 0 to 2.5 years of age, and thereafter, the Lea Hyvärinen test (LH), the Hooper Visual Organization test (HVOT) and the Konstantin Moutakis visual acuity chart (KM chart) (Adoh & Woodhouse, 1994; Moutakis et al., 2004; Rydberg, 2013; Teller et al., 1986). As a complement to TAC and Cardiff, a new variant of PL has been developed in Sweden: the Kasper PL vision test (Kasper), consisting of test cards with stylised faces in decreasing size, which are shown until the child no longer maintains fixation (*"Kasper visual test chart"*, 2023). See Figure 1. In addition to visual acuity measurement, electrophysiology in the form of visual evoked potential (VEP) is also used for the youngest, non-verbal children (Lyons & Lambert, 2022).

Visual acuity measured with one test cannot be compared to a value measured with another method for the same age. Since visual acuity outcome is one of many important measures of success rates in paediatric cataract surgery, there is a need for agreement on visual acuity testing within the PECARE quality register, but also in our nation. Thus, the aim of the study was to analyse visual acuity tests used in children operated for cataract in Sweden as well as the success rate of visual acuity testing, in order to improve current treatment.

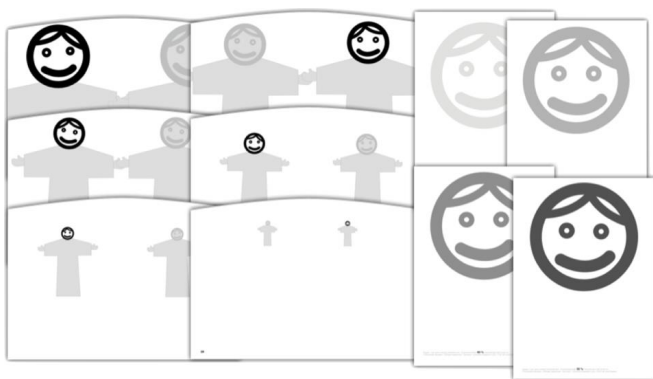


Figure 1: Kasper PL visual test for children under 2 years of age.

Methods

The PECARE registry was initiated in 2007 to gather data on post-operative outcome and aggravating factors among children undergoing cataract surgery before 8 years of age and has a coverage of 95% (PECARE). Demographic data, such as patient age and sex, age at time of diagnosis and surgery, surgical variables and

reasons for patient referral, as well as who initiated primary contact, are reported to PECARE. Treatment outcomes as represented by visual development and occurrence of complications at 1, 2, 5 and 10 years of age are entered for each child. All measured visual acuity values are monocularly tested with glasses or contact lens correction for best corrected visual acuity (BCVA).

Children registered in PECARE who underwent cataract surgery between 1st January 2007 and 31st July 2016 were included in this study. During this period, 424 children were operated, 215 boys (51%) and 209 girls (49%), giving a M/F ratio of 1.03. Of these 160 had bilateral surgery, however, not all children with bilateral cataracts had both eyes operated. The number of operated eyes was 584 in which a total of 660 follow-up examinations were performed at the ages of 1, 2, 5 and 10 years. Of the total 584 operated eyes, 320 (55%) were bilateral cataracts and 264 (45%) unilateral. Please see Magnusson et al. (2018) for more detail.

The study was performed in accordance with the tenets of the Declaration of Helsinki as well as the General Data Protection Regulation (GDPR) and was approved by the Swedish Ethical Review Authority (reference numbers 2023-07821-02).

Results

Visual acuity tests were attempted for all children and results were achieved for 228 eyes (46%) at 1 year of age, 226 (57%) at 2 years of age, 193 (88%) at 5 years of age and 13 (100%) at 10 years of age, see Figure 2.

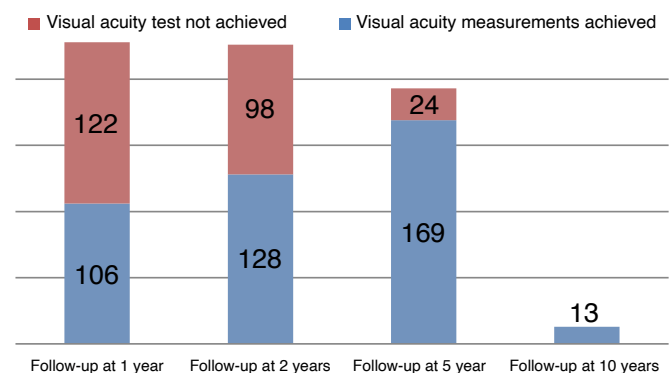


Figure 2: Overview of the total number of visual acuity measurements achieved (blue) and not achieved (red) distributed over follow-up visits at 1, 2, 5 and 10 years of age $n = 660$.

Table 1 shows the predominant visual acuity test methods at each follow-up age. At 1 and 2 years of age, the predominant methods in PECARE were TAC and what is referred to as an "other method". The "other method" is explained in free text when registering in PECARE, e.g. Cardiff, Kasper or Kay Picture tests. At the age of 5 years, the predominantly used methods were LH, HVOT and KM boards, and at the age of 10 years, KM and letter charts.

In the catchment areas of Region 1 and Region 2, i.e. the two operating clinics in Sweden, the choice of visual acuity test methods differed for the different follow-up ages. The proportion of successful visual acuity measurements at 1 year of age was slightly lower for Region 2 (38.0%) than for Region 1 (47.1%). For 1-year-olds TAC dominated in Region 1 and "other method" in Region 2. In Region 1 "other method" was in some cases described as "per-

ception”, in others non-existent, i.e. “amaurosis”, and for one eye the visual acuity method was not described. In Region 2 “other method” was described as Cardiff and Kasper tests, “perception”, or non-existent, i.e. “amaurosis”. The method was unexplained for four eyes.

Table 1: Visual acuity tests used at different ages during follow-up visits registered in PECARE.

Test	Age			
	1 year (%)	2 years (%)	5 years (%)	10 years (%)
Other	43.4	54.7	9.1	0
TAC	56.6	39	1.7	0
HVOT	0	0.8	32	0
LH	0	4.7	40	0
KM	0	0.8	16.6	30.8
VA letter chart	0	0	0.6	69.2

Note: VA = Visual acuity, LH = Lea Hyvärinen, HVOT = HVOT acuity chart, TAC = Teller Acuity Cards, KM = Konstantin Moutakis.

For 51.2% of the total number of eyes tested in 1-year-olds, the “other method” of the Kasper test was used.

In contrast to the follow-up at 1 year, for the 2-year-olds, the proportion of successful visual acuity measurements was higher in Region 2 (63.3%) than Region 1 (48.3%). Also, for following up the 2-year-olds TAC was predominant in Region 1 and “other method” in Region 2. The Kasper test was only used in clinics in Region 2. The total percentage of eyes in 2-year-olds measured with the Kasper test was 35.7%. In Region 1 four eyes were measured with LH, and in Region 2 one eye was measured with HVOT, two eyes with LH and one eye with KM. The “other method” was described in Region 1 as seven eyes that had “perception” or non-existent visual acuity, i.e. “amaurosis”, as well as five eyes for which the method was left unexplained. In Region 2, in addition to Cardiff and Kasper, the “other method” was explained by eight eyes measured with Kay Pictures, three with KM symbols/charts, and four eyes were labelled amaurotic.

For the 5-year-olds, HVOT, LH and KM dominated with some differences between the clinics. In Region 2, HVOT dominated with 58.2%, followed by KM at 19.4%, and LH at 9.0%. In Region 1, the distribution was LH 63.4%, HVOT 12.9%, and KM 11.8%.

For follow-up of the 10-year-olds, KM and letter charts were the predominant tests. Too few follow-ups were recorded for this age group to detect possible differences between clinics.

The proportion of children with recorded developmental delay at the time of follow-up was 15.4% for 1-year-olds and 16.4% of all registered eyes at 2 years of age. In the group with unsuccessful visual acuity measurements, 22.1% had developmental delay at 1 year of age and 23.5% at 2 years of age.

No significant difference between girls and boys could be seen in this study, either in terms of the proportion of girls and boys with cataracts or in terms of the proportion that could or could not perform a visual acuity test.

Discussion

This study highlights the challenges of measuring, evaluating and comparing visual acuity in children when using a variety of dif-

ferent methods, especially during the first years of life. Our findings illustrate the problem that there are no European or Swedish guidelines for visual testing of children.

The strength of this study is that it is a geographically based cohort. Furthermore, the data represent all parts of ophthalmic healthcare for children in Sweden, which makes the study unique. Also, the success rate of visual testing of children under the age of 2 years in Sweden has not been investigated before, making this study an important contribution to the literature. One should bear in mind that one third of the children with cataract have a congenital syndrome or intellectual disability, which potentially could decrease the success rate.

In the PECARE register, visual acuity was successfully measured in 88% of eyes at the follow-ups of 5-year-olds, and in 100% of eyes at the follow-ups of 10-year-olds. The register only used scientifically evaluated tests at these follow-ups, which was not the case for the younger children. Visual acuity was successfully measured in fewer than 50% of the children under 2 years of age. Visual acuity measurement in children depends largely on the cooperation of the child, the skill of the examiner and the test method (Adoh & Woodhouse, 1994; Rydberg, 2013). To some extent, developmental delay can explain why visual acuity measurement was not possible in the younger children in this study, but not entirely. Nor does gender provide any explanation for the absence of visual acuity measurements. It can therefore sometimes be assumed that the age of the child determines how much visual acuity data can be collected. At the ages of 1 and 2 years, the general opinion is that children often will not accept occlusion of one eye and therefore do not cooperate in monocular visual acuity testing, which is shown in our analysis. Moreover, visual acuity testing is largely dependent on the child’s ability to concentrate, which varies depending on factors such as stress, hunger and lack of sleep. It can also be speculated about whether examiners’ experience and confidence in visual acuity testing of young children also vary in different parts of the country. The choice of visual acuity testing method is also likely to have an impact. Many attest to the difficulty of performing visual acuity testing on children aged 1 to 3 years, as they are easily distracted and grow tired of the examination (Adoh & Woodhouse, 1994; Rydberg, 2013). However, children with visual impairments have been found to be better at cooperating at this age than children with normal vision, probably due to the limited “visual attention area” of children with visual impairment (Rydberg, 2013). The difficulties of visual acuity testing in children under 2 years of age are reflected by the results of this study, where visual acuity was successfully measured in 46% of eyes at the 1-year-old follow-ups and 57% of eyes at the 2-year-old follow-ups.

Our study indicates that the Kasper test provides more successful visual acuity measurements in children at 1 and 2 years of age, possibly because it is more appealing for children. The test was designed with a face since newborns are better able to fixate on round shapes than straight ones and because children fixate on faces and stylised figures at an early stage (Maurer & Barrera, 1981; Morton & Johnson, 1991). Unlike many other PL tests, the test card does not have a grey half but instead has a grey low contrast face with a grey body of the same size as the black high contrast “test face”. See Figure 1. The test is designed in this way to help the tester un-

derstand if the child has better visual acuity than the current card. Like the Cardiff test and the Harris stylised face test, the Kasper test is based on a stylised image, a more complex stimulus, and is thus a kind of hybrid of the striped pattern test and the single optotype test. This could possibly give more accurate visual acuity values than TAC and be better at detecting a lateral difference in visual acuity in a child with e.g. strabismic amblyopia (Harris et al., 1984; 1986).

At the eye clinic at Skåne University Hospital, the Kasper test was compared with VEP and was found to be equally sensitive in detecting as VEP. Several professionals at the clinic used the Kasper test and each detected the difference in visual acuity between the eyes. They also conducted a study comparing Kasper and TAC and found that, in general, visual acuity results were better by a line or two with TAC. However, none of these studies have been published. Furthermore, the Kasper test needs to be compared with other standardised tests and validated.

A national agreement on visual acuity testing is important for equal care, since the present study has mapped the differences found in PECARE in the choices of visual acuity measurement methods in the Swedish eye care system. The PECARE steering committee reached consensus in 2017 and has recommended the following choices of methods for visual acuity testing for different age groups: Kasper, TAC or another PL test method at < 2.5 years of age, LH at 2.5–3.5 (4) years of age, HVOT at 4–5 years of age and KM at 5–6 years of age. These recommendations are formulated in the instructions for performing the follow-up. Visual acuity is an important variable for evaluating cataract surgery in children as well as for vision rehabilitation, amblyopia treatment and evaluating the treatment of surgical complications. It is therefore of the utmost importance that there is agreement on the choice of visual acuity test method for these children. Since the present study represents all paediatric eye clinics in the country, it is likely that divergent methods are also used for children with other causes of visual impairment. The Swedish Health and Medical Care Act requires that the quality of healthcare provision must be systematically and continuously improved and assured (SFS 2017:30, 2017). To be able to conduct retrospective journal-based studies of good quality for diseases in addition to paediatric cataracts, it is desirable to have national agreement. It is likely that our findings will apply to visual acuity measurements in conditions other than paediatric cataract.

Clinical implications

Discussions should be had about which new strategies would be beneficial in minimising failures in visual acuity testing of the youngest ages. Optimising cooperation with parents is naturally of paramount importance. One strategy could be to send instructions to parents ahead of their first visit to the medical centre, asking them to prepare the child for the visual acuity test by referring to an instructional film. It is important to provide information to parents on how to minimise stress factors that reduce concentration in children during an eye clinic visit. For example, optimal food intake, leaving in good time for the visit, and preferably even having already played a game with one eye covered, as well as having played with the optotypes that will be presented during the visual acuity test, can make the situation one that is char-

acterised by pleasure and recognition for the child. Cooperation within the healthcare team should also be optimised and should include standardised training in visual testing. Good interdisciplinary team spirit in combination with a test that is familiar to the examiner is certainly an important factor for successfully measuring visual acuity in children.

Conclusion

A challenging diversity of methods for testing visual acuity are used in Swedish paediatric cataract care. Age-related national guidelines regarding visual acuity tests methods are needed for the development and improvement of current treatment. Scientific evaluation of visual development is an important outcome in order to reach equal care. Furthermore, the Kasper test needs to be scientifically re-validated.

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Pediatric Cataract Register (PECARE): Utfordringer ved vitenskapelig evaluering av synsutvikling

Sammendrag

Formålet med denne studien var å analysere tester og metoder for måling av visus hos barn som har gjennomgått kataraktkirurgi i Sverige, samt å undersøke suksessraten for synsskarphetstesting for å forbedre dagens behandling.

Barn registrert i PECARE som ble operert for katarakt mellom 1. januar 2007 og 31. juli 2016 ble inkludert. Metoder for visustesting ble analysert ved oppfølgingsalder 1, 2, 5 og 10 år.

Totalt ble 424 barn operert, 209 jenter (49%) og 215 gutter (51%). Antall opererte øyne var 584, hvorav 320 (55%) hadde bilateral katarakt og 264 (45%) unilateral. Totalt fant det sted 660 oppfølgingsbesøk, og vellykkede visusmålinger ble oppnådd i 416 av disse tilfellene: 106/228 (46%) ved 1 års alder, 128/226 (57%) ved 2 års alder, 169/193 (88%) ved 5 års alder og 13/13 (100%) ved 10 års alder.

Metodene for visustesting varierte mellom de ulike oppfølgingsklinikkene, noe som gjorde sammenligninger utfordrende. Kasper-testen ble mye brukt før 2-årsalderen. Den er validert, men ikke vitenskapelig publisert. Suksessraten var høyere for Kasper-testen sammenliknet med andre tester.

Variasjonen i metoder for visustesting innen svensk pediatrik kataraktomsorg er utfordrende. Alderstilpassede nasjonale retningslinjer for tester og metoder for måling av visus er nødvendig for å utvikle og forbedre dagens behandling. Vitenskapelig evaluering av synsutvikling er et viktig mål for å oppnå lik behandling. Videre må Kasper-testen vitenskapelig re-valideres.

Nøkkelord: pediatrik katarakt, medfødt, visustester

Il Registro della Cataratta Pediatrica (PECARE): Sfide nella valutazione scientifica dello sviluppo visivo

Riassunto

Lo scopo di questo studio è stato analizzare i test di acuità visiva e i metodi utilizzati nei bambini sottoposti a chirurgia della cataratta in Svezia, così come il tasso di successo delle misurazioni dell'acuità visiva, al fine di migliorare il trattamento attuale.

Sono stati inclusi i bambini sottoposti a chirurgia della cataratta tra il 1° gennaio 2007 e il 31 luglio 2016 registrati in PECARE. I metodi di misura dell'acuità visiva sono stati analizzati alle età di follow-up di 1, 2, 5 e 10 anni.

In totale, 424 bambini sono stati operati, 209 femmine (49%) e 215 maschi (51%). Il numero di occhi operati è stato 584, di cui 320 (55%) cataratte bilaterali e 264 (45%) unilaterali. Complessivamente si sono svolte 660 visite di follow-up, e l'acuità visiva è stata misurata con successo in 416 di questi casi: 106/228 (46%) a 1 anno di età, 128/226 (57%) a 2 anni di età, 169/193 (88%) a 5 anni di età e 13/13 (100%) a 10 anni di età.

I metodi di test dell'acuità visiva differivano tra le cliniche di follow-up, rendendo le comparazioni difficili. Il test di Kasper è stato ampiamente utilizzato prima dei 2 anni di età, ed è stato validato ma non pubblicato scientificamente. Il tasso di successo è risultato più elevato per il test di Kasper rispetto ad altri test.

La gestione della cataratta pediatrica in Svezia è caratterizzata da un'ampia eterogeneità nei metodi impiegati per la valutazione dell'acuità visiva, elemento che rende complessa la comparazione dei risultati. L'elaborazione di linee guida nazionali, differenziate per fasce d'età, appare necessaria per favorire lo sviluppo e l'ottimizzazione dei protocolli terapeutici attuali. La valutazione scientifica dello sviluppo visivo rappresenta infatti un esito fondamentale per garantire uniformità ed equità di trattamento. Inoltre, il test di Kasper richiede una rinnovata validazione scientifica.

Parole chiave: cataratta pediatrica, congenita, test di acuità visiva