

Visual impairment in children and adolescents in Norway

BACKGROUND The Norwegian Register of Visual Impairment and Blindness (Blindekartoteket) was discontinued in 1995 owing to inadequate reporting and poor data security. Since then, no registration of visual impairment has taken place in Norway. All the other Nordic countries have registers for children and adolescents with visual impairment. The purpose of the present study was to survey visual impairments and their causes in children and adolescents, and to assess the need for an ophthalmic register.

MATERIAL AND METHOD Data on children and adolescents aged less than 20 years with impaired vision ($n = 628$) were collected via the county special needs education centres for the visually impaired in the period 2005–2010. This took the form of a point prevalence study as of 1 January 2004. Visual function, ophthalmic diagnosis, systemic diagnosis and additional functional disabilities were recorded.

RESULTS Approximately two-thirds of children and adolescents with visual impairment had low vision, while one-third were blind. The three largest diagnostic groups were neuro-ophthalmological diseases (37 %), retinal diseases (19 %) and conditions affecting the eyeball in general (14 %). The prevalence of additional functional impairments was high, at 53 %, most often in the form of motor or cognitive impairments.

INTERPRETATION The results of the study correspond well with similar investigations in the other Nordic countries. Our study shows that the registers of special needs education for the visually impaired are inadequate with respect to medical data, and this underlines the need for an ophthalmic register of children and adolescents with visual impairment.

Visual impairment creates major challenges in many areas of life – schooling, work and leisure, family relations and society in general. The consequences of visual impairment for children are particularly serious, because vision is so fundamental to early development in many different areas, such as motor skills and social adaptation. To ensure the optimal development of children with visual impairment, it is crucial that they are closely followed up, by the medical profession and by special needs and visual impairment specialist educators alike.

It is important for the community to gather information about the prevalence and extent of different functional impairments, so that the necessary help and resources can be made available and distributed optimally. We were relatively early in procuring visual impairment data in Norway. In the early 1950s, Dr Johan C. Holst, an ophthalmologist, published a pioneering work on the prevalence of blindness in Norway, with detailed information about medical diagnoses (1). Another important Norwegian work in this field is Dr Magnus Odland's medical and socio-medical study of blind and partially sighted patients in Hordaland County in the 1970s (2). A separate section of Odland's work was devoted to the prevalence of blindness and visual impairment in children (< 20 years old).

Johan C. Holst was the driving force

behind the establishment of the Norwegian Register of Visual Impairment and Blindness (Det norske blindekartotek), a national register of persons with visual impairment to which all ophthalmologists were required to report. The register was established as early as 1968, and was thus one of the earliest health registers in Norway. Owing to more stringent requirements for data security and protection of privacy, and dwindling reporting, the register was discontinued in 1995. Since then there has been no national overview of persons with visual impairment in Norway.

Special needs educational services for the visually impaired

Children with visual impairment are not only dependent on good ophthalmic assessment, treatment and follow-up; habilitation and rehabilitation, which are largely provided by special needs teachers specialising in visual impairment, are equally important (3). The Norwegian Education Act and Kindergartens Act stipulate that each child's level of functioning must be taken into account, and that they have the right to receive adapted teaching. This means that visually impaired children have a right to qualified persons who can assist teachers and pre-school teachers by providing expertise on visual impairment. In principle, this is the responsibility of the municipal edu-

Olav H. Haugen

olav.haugen@helse-bergen.no

Cecilie Bredrup

Eyvind Rødahl

Department of Ophthalmology
Haukeland University Hospital
and

Department of Clinical Medicine
Faculty of Medicine and Dentistry
University of Bergen

MAIN POINTS

Since the discontinuation of the Norwegian Register of Visual Impairment and Blindness (Blindekartoteket) in 1995, there has been no medical registration of children and adolescents with visual impairment in Norway – the only Nordic country where this is the case

The most frequent cause of visual impairment in children and adolescents in Norway is neuro-ophthalmic diseases, followed by retinal diseases and diseases that affect the eyeball in general

More than half of children and adolescents with visual impairment have additional functional impairments

There is a need for a Norwegian ophthalmological register of children and adolescents with visual impairment

cational and psychological counselling service (PPT). Very few municipalities have their own teachers for the visually impaired, and they are therefore dependent on receiving this expertise from outside.

The organisation of the public special educational service for the visually impaired has been under construction, but this service is now organised within the Statped system – the governmental special needs education service, which in addition to visual impairment covers areas such as deafblindness, hearing, language/speech, acquired brain damage and complex learning difficulties. Statped is divided into four regions (South-East, West, Central, North), each of which provides services for its particular municipal and county council in the form of individual and system-based services.

Visual impairment registers in the other Nordic countries

There are currently national registers for persons with visual impairment in all the other Nordic countries. Denmark has had a register since the 1930s, but only for children (aged 0–17). Registration is mandatory, and is a prerequisite for receiving rehabilitation for visual impairment (4). Finland has had mandatory registration of all those with visual impairment, irrespective of age, since the mid-1980s (5). A visual impairment register was established in Sweden in the mid-1960s, but was inactive for many years before being re-established in 1990. Today it covers only children aged 0–19 years. The Icelandic register covers the entire age range, and has been operating since the late 1980s (6).

In about 1990, a project group called NORDSYN, consisting of Nordic eye specialists, was established. The group wanted to collect data on visually impaired children in the Nordic countries. The work was based on the national registers, with the exception of Sweden, since this register had been inactive for many years. The project resulted in several articles that dealt with prevalence data, aetiological factors, diagnoses and gender distribution (7–10).

In Sweden, the re-establishment of a visual impairment register for children led to a doctoral thesis (11) with part publications following the same pattern as the NORDSYN study (12–14). This thesis found an age-specific prevalence of visual impairment of 11 per 10 000 (0–19 years) and an age-specific prevalence of blindness of 29 per 100 000 (0–15 years).

The situation in Norway

The current situation is that there are active, updated registers of visually impaired children in all the Nordic countries except Nor-

Table 1 Classification of visual impairment according to ICD-10 (WHO)

Group	Visual acuity (x) ¹	Visual field
Moderate visual impairment, category 1	$0.1 \leq x < 0.33$	
Severe visual impairment, category 2	$0.05 \leq x < 0.1$	
Blindness, category 3	$0.02 \leq x < 0.05$	Visual field $\leq 10^\circ$ radius around central fixation (irrespective of visual acuity)
Blindness, category 4	Light perception $\leq x < 0.02$	
Blindness, category 5	No light perception	
Category 9	Undetermined	

¹ Best possible correction of visual acuity of the best eye

way. Following the discontinuation of the Blindekartoteket in 1995, a working group was appointed to consider the possibility of further activity. The report from this working group was presented in 1997. It was concluded that a central, country-wide register of visually impaired persons should be established, initially restricted to children and adolescents aged up to 20.

The report was broadly endorsed when it was circulated for comments. However, the matter was put on hold (letter from the Norwegian Government Inspectorate of Health, October 1998) because a Health Register Act was in the offing. After this law was adopted in 2002, the matter of the register was taken up again, by ophthalmologists who work mainly with children, the Norwegian Association of Ophthalmologists, and the Norwegian Association of the Blind and Partially Sighted. So far, however, it has not led to the establishment of a visual impairment register.

As a consequence of this situation, a research project was started in 2004. The aim was to gather data on children and adolescents with impaired vision, with the emphasis on degree of impairment, diagnostic groups, aetiology and the prevalence of additional impairments. The project was also intended to function as a pilot study for the establishment of a register.

The purpose of this article is to present data from this survey, shed light on some of the special factors that apply to this patient group, and stress the importance and necessity of having a medical register of children and adolescents with visual impairment.

Material and method

All persons with visual impairment according to WHO's ICD-10 criteria (15) (Table 1) and who are covered by the Norwegian Education Act have a right to special needs edu-

cational assistance. Since 1996, the special needs educational service for the visually impaired has been authorised to maintain a register of its users. Thus, it was decided that the project should apply to work with the special needs education centres for the visually impaired. With the consent of the users or parents, the special needs teachers also obtain ophthalmic information from the patient's ophthalmologist or ophthalmological department.

The survey was conducted in the form of a point prevalence study as at 1 January 2004 (coinciding with the start of the project) of registered users under the age of 20 of the special needs educational service for the visually impaired, which at the time was organised with one centre in each county. For reasons of personal privacy, the invitation letter to the patients or parents was sent out by the individual centre on behalf of the

Table 2 Visual function in 628 Norwegian children and adolescents aged < 20 with impaired vision, classified according to WHO categories

Group	Number	(%)
Visual acuity 0.33	75	(11.9)
Moderate visual impairment, category 1	267	(42.5)
Severe visual impairment, category 2	71	(11.3)
Blindness, category 3	106	(16.9)
Blindness, category 4	44	(7.0)
Blindness, category 5	47	(7.5)
Category 9	18	(2.9)
Total	628	(100)

Table 3 Distribution of ophthalmologic diagnostic group among 628 visually impaired children and adolescents aged < 20

Group	Example	Number	(%)
Conditions located in the eye as a whole	Albinism, excessive myopia	87	[13.9]
Congenital conditions anterior segment	Congenital cataract, aniridia	63	[10.0]
Congenital conditions posterior segment	Hypoplasia of the optic nerve, coloboma	56	[8.9]
Congenital dysfunctions	Congenital nystagmus	25	[4.0]
Retinal diseases	Retinitis pigmentosa, retinopathy of prematurity	120	[19.1]
Neuro-ophthalmological diseases	Cerebral visual impairment, atrophy of the optic nerve	234	[37.3]
Miscellaneous	Retinoblastoma, chronic uveitis	25	[4.0]
Uncertain		18	[2.9]
Total		628	[100]

Table 4 Distribution of systemic principal diagnosis (ICD-10 group) among 628 visually impaired children and adolescents aged < 20

Group (ICD-10)	Total dataset		Neuro-ophthalmological diseases	
	Number	(%)	Number	(%)
C+D Neoplasms	22	[3.5]	18	[7.7]
E Metabolic disorders	100	[15.9]	7	[3.0]
G Diseases of the nervous system	50	[8.0]	44	[18.8]
H Diseases of the eye	71	[11.3]	5	[2.1]
I Sequelae of cerebrovascular disease	5	[0.8]	5	[2.1]
P Conditions originating in the perinatal period	93	[14.8]	60	[25.7]
Q Congenital malformations and chromosomal abnormalities	216	[34.4]	62	[26.5]
Other/unknown	71	[11.3]	33	[14.1]
Total	628	[100]	234	[100]

research project, together with the statement of informed consent, which the parents were to return to the project management. Subsequently, the register data from the centres on those users who had given their consent were made available to the project.

Data collection took place through project members going to each individual centre, manually reviewing the register journals, and entering the relevant variables in a database: gender, ophthalmological principal and secondary diagnosis, systemic principal and secondary diagnosis, corrected visual acuity of the best eye or binocularly, visual field and additional disabilities. Many jour-

nals contained visual function data from several different examination dates. We chose to use data from the examination closest in time to 1.1.2004.

The informed consent statements received provided access to 845 register records for children and adolescents under the age of 20, and data were extracted from these at the special needs education centres in the period 2005–2010. In 23 of the cases, the data on visual function in the records were so deficient or unclear that they were excluded from further analysis.

Of the remaining 822 patients, 269 (32.7 %) by definition did not have impaired

vision (corrected vision of the best eye ≥ 0.33 and no serious visual field loss). Seventy-five members of this group (8.9 %) had visual acuity 0.33. Because this latter category was regarded as visually impaired in some previous studies (including Odland's study in Hordaland county) (2), we have chosen to do the same in our further presentation, despite the fact that WHO defines impaired vision as visual acuity < 0.33 . The dataset therefore encompassed 628 persons (346 boys) with visual acuity of ≤ 0.33 .

The diagnoses were registered with ICD-10 code, both ophthalmological and systemic. The diagnoses were also grouped according to anatomical location, applying the same system as in the NORDSYN study: conditions located in the eye as a whole, congenital conditions of the anterior segment, congenital malformations of the posterior segment, congenital dysfunctions, retinal diseases, neuro-ophthalmological diseases and miscellaneous conditions.

As in the NORDSYN study, the following additional functional impairments were registered: motor dysfunctions (cerebral palsy etc.), cognitive impairment, impaired hearing and epilepsy.

The study was approved by the Regional Committee for Medical and Health Research Ethics West (no. 116.03) and the Norwegian Centre for Research Data (no. 10118).

Results

Visual function

Table 2 shows the distribution of the various degrees of visual impairment among the patients. Of those who had impaired vision according to the definition ($n = 628$), 413 (66 %) had low vision (WHO categories 1–2) and 197 (31 %) were blind (WHO categories 3–5). A large majority (83 %) of the former had moderately impaired vision (category 1).

There were visual field data for 229 of the 628 included patients. Of these, 132 had documented visual field loss, in 17 of them due to hemianopsia.

Diagnosis

The distribution by diagnostic group is presented in Table 3. The three largest diagnostic groups were neuro-ophthalmological diseases ($n = 234$, 37.3 %), retinal disorders ($n = 120$, 19.1 %) and conditions that affect the eyeball in general ($n = 87$, 13.9 %).

In the group neuro-ophthalmological diseases, cerebral visual impairment (81 %) and atrophy of the optic nerve (11 %) predominated, while the majority of the retinal disorders were hereditary retinal dystrophies (70 %) and retinopathy of prematurity (22 %). Table 4 shows systemic principal

diagnosis according to the ICD classification for both the total dataset and the largest ophthalmic diagnostic group, neuro-ophthalmological diseases.

Additional disabilities

A total of 334 patients (53 %) had at least one additional disability. The most frequent were motor disabilities ($n = 260$, 41 %) and cognitive disabilities ($n = 241$, 38 %). Hearing impairment was registered for 46 persons, the dominant diagnostic groups being malformations of the posterior segment (e.g. CHARGE syndrome), retinal diseases and neuro-ophthalmological diseases. Epilepsy was reported in 141 patients (22 %).

Neuro-ophthalmological diseases

Because neuro-ophthalmological diseases constituted by far the largest diagnostic group, we wanted to study this group of patients more closely. The dominant diagnosis was cerebral visual impairment. Usually, cerebral visual impairment is defined on the basis of the following criteria: structurally normal eye examination, impaired visual function and detected injury in the posterior part of the visual system, i.e. behind the optic chiasm.

There was a higher percentage of blind compared with partially sighted individuals in the group neuro-ophthalmological diseases compared with the total dataset (proportion of blind persons 46 % versus 31 % in the total dataset). There was also a substantially higher prevalence of additional disabilities in this group – 85 % had at least one additional disability, 74 % had two or more.

Discussion

Our survey shows that of Norwegian children registered as visually impaired, 66 % were partly sighted (defined by us as visual acuity 0.33 plus WHO category 1 and 2) and 31 % blind (WHO category 3, 4 or 5). This distribution between partial sightedness and blindness corresponds well with the distribution in the similar Swedish study from the 1990s (12) and in the NORDSYN study (7).

Interesting in itself is the finding that almost a third of the registered children had visual acuity > 0.33 , and thus are not visually impaired according to the WHO definition. This may indicate that the special needs service does not focus solely on visual acuity as a referral criterion, but considers the patient's overall situation. If this is the case, we regard this as a good assessment, as we know that a number of children with multiple disabilities have visual problems that may not necessarily affect their visual acuity, but tend more to affect their visuo-cognitive functions. Our data are not detailed enough to show with any certainty

whether this is the reason for the large number of children with visual acuity > 0.33 .

There is a preponderance of boys in most studies of visual impairment in children, as was also the case for our dataset. In the NORDSYN study, a boy/girl ratio of 1.39 was found (7). In our study this ratio was $346/282 = 1.22$, in practice the same as the ratio of 1.20 in Blohmé and Tornqvist's study from Sweden (12).

Two main findings emerge from our study. One is that neuro-ophthalmological diseases, particularly cerebral visual impairment, are the predominant diagnoses. Similar findings were made by the NORDSYN group (9) and Blohmé and Tornqvist in Sweden (14). Aetiologically, this is a heterogeneous group – some have known brain damage from the perinatal period (including birth asphyxia and prematurity), while others have genetic conditions.

There are recently published studies in which whole genome sequencing has been able to verify the genetic cause in a large percentage of children with cerebral visual impairment and cognitive impairments (16). These are diagnostics that are increasingly used in ordinary clinical assessments and which may be able to provide a specific diagnosis for more of these children in the future.

The second main finding is that more than half of the visually impaired children had additional impairments, particularly motor (cerebral palsy) and cognitive impairments. This finding corresponds well with the Swedish study, in which 60 % of all children with visual impairment had additional disabilities (13). The highest prevalence of additional impairments (85 %) was found in the group with neuro-ophthalmological diseases, which is consistent with the findings of the Swedish study (88 %) (14).

This means that the ophthalmic health service for visually impaired children in many cases has to be a cross-disciplinary collaboration involving paediatricians, special needs teachers for the visually impaired, psychologists, neuropsychologists, physiotherapists and social workers. Close cooperation with patient associations and the Norwegian Association of the Blind and Partially Sighted is also crucial to an optimal result.

A special group that it is important to be aware of consists of those who have both visual and hearing impairment. Deafblindness is defined as a separate specialist area in the Statped system, and covers all those who have combined visual and hearing impairment. In our dataset there were 46 such patients (7.3 %).

Our study has some manifest weaknesses. For various reasons, the logistics of sending

out the invitations to participate, the reminder letters, the receipt of statements of consent, and the organisation and collection of the data turned out to be far more time-consuming than initially assumed, and hence the study has extended over a period of very many years. Similarly, the analysis of the database with quality assurance of the data has taken considerably more time than expected.

Because we had to recruit patients to this study via the special needs education service, and because we were dependent on written consent, the patient data in the study are incomplete and may be selective. This means that the data must be interpreted with caution in an epidemiological context. The medical data available are of variable quality. Nonetheless, the material provides a picture of the group of children with visual impairment who are being monitored in the special needs education system for the visually impaired.

The similarities between our data, the NORDSYN study and Blohmé and Tornqvist's data indicate that the distribution among the various diagnostic groups and the distribution between partial sightedness and blindness are roughly the same in Norway as in the other Nordic countries.

If we assume that the Swedish age-specific prevalence data from the 1990s (12) are correct, we should have about 1 450 blind and partially sighted children and adolescents here in Norway. A recent study from the UK indicates that while the percentage of adults with visual impairment is declining, the percentage of children with such disabilities is rising (17). It is assumed that there are various reasons for this, but that the increased survival of small pretermatures and increasing immigration are two contributory factors. Because we do not have a Norwegian register, we do not know whether there is a similar trend in Norway.

We found during our registration work that the archived medical information in the special needs education register cannot function as a complete register for ophthalmological data, nor can this be expected. Subsequent to the conclusion of the data collection in this research project, the special needs education service for the visually impaired has also been reorganized, as mentioned initially.

The Statped system is now required to deal with the municipal authorities and not the specialist health service. This presents a regrettable bureaucratic obstacle to the important cooperation between ophthalmologists and special needs educators, which makes it even more necessary to establish a special ophthalmological register for children and adolescents with visual impairment.

Conclusion

Our study indicates that the prevalence of visual impairment among children and adolescents, the distribution between partially sighted and blind, and the distribution among different medical diagnostic groups is relatively similar to that found in similar studies in the other Nordic countries. At present, visually impaired Norwegian children and adolescents are only registered by the special needs education service, and this register is not designed to be a medical register.

Norway is the only Nordic country that does not have an ophthalmological register, and it is recommended that this should be established urgently. Such a register could provide valuable information about the causes of visual impairment in children and adolescents, make it possible to identify changes in the disease panorama for children and adolescents, improve possibilities for optimal cross-disciplinary treatment and follow-up, habilitation and rehabilitation, and increase the opportunities for research in this field.

The register, which should preferably be an online register, should contain data on the age at the onset of disease, various aspects of visual function (visual acuity, visual field), ophthalmic and systemic diagnosis and data on secondary diagnoses and additional impairments. The register should be prospective, with data collection every fifth year, for example, as some eye diseases in children are progressive. We hope that the establishment of such a register can take place in the near future.

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Olav H. Haugen (born 1955)

Specialist in eye diseases, professor and head of the Section for Paediatric Ophthalmology and Strabismus.

The author has completed the ICMJE form and reports no conflicts of interest.

Cecilie Bredrup (born 1973)

Specialist in eye diseases and researcher. She has specialist expertise in paediatric ophthalmology and hereditary eye diseases.

The author has completed the ICMJE form and reports no conflicts of interest.

Eyvind Rødahl (born 1957)

Specialist in eye diseases and professor. He has specialist expertise in hereditary eye diseases and orbital disorders.

The author has completed the ICMJE form and reports no conflicts of interest.

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