TRENDS IN REGISTERED BLINDNESS IN EASTERN BULGARIA

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ABSTRACT

PURPOSE: The purpose of the study was to evaluate the incidence and causes of registered blindness and low vision in Eastern Bulgaria.

METHODS: Documentation per each included patient based on archives of the Expert Disability committee was evaluated and divided in two intervals. The cumulative incidence per 100 000 was calculated in 3 severity groups for bilateral and monocular blindness and by residence.

RESULTS: The incidence of binocular blindness decreased from 63.79 to 41.61 for males and from 64.21 to 41.14 for females during the second period. Meanwhile, monocular blindness increased from 41.14 to 65.14 for males and from 33.01 to 48.83 for females. It rapidly increases after 60 years of age and is the highest for those over 80. Patients with visual acuity (VA) below 0.05 comprise 40-35%, between 0.06 and 0.1 – 22-35%, and 0.15 to 0.3 – 38-34%. The proportion and incidence of patients with VA below 0.05 have decreased two times during the second period among residents of cities and remained high – 42–48% in the rural population. Severe monocular blindness was significantly higher among males across the whole population. In the age group below 19 years, the leading causes of binocular blindness were retinopathy of prematurity (ROP), congenital glaucoma, microphthalmos and congenital cataract and for monocular impairment – trauma and amblyopia. For those above 20, the main causes were glaucoma, end-stage diabetic retinopathy, cataract – both with significant reduction in the incidence, AMD and trauma.

CONCLUSIONS: Systematic evaluation of the deteriorated quality of life and estimation of the cost of vision loss and eye diseases to individuals and their families as well as extended family caregivers and third-party payers, the health care system and Bulgarian society is essential in the development of evidence-based interventions that translate research into enhanced clinical and community practice and prevention of unnecessary visual impairment.

Keywords: binocular blindness, monocular blindness, incidence, Eastern Bulgaria

INTRODUCTION

Analysis of the dynamics in the magnitude and cause of blindness and low vision reveals both the measurable positive effect of introducing new treatment modalities (1,2,3) and the disparities in the quality and access to ophthalmic care (4). A recent review of the Vision Loss expert Group found that age-standardized prevalence of blindness and vision impairment has decreased globally in the last 20 years, however the demographic trends towards older adults growing in relative and absolute num-

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Assisted Members in every country and region of the world have led to an increase in the number of people with vision loss since 1990, indicating that measures to reduce blindness were successful but were insufficient to counteract the aging of the population in the past decades (5).

Bulgaria has faced considerable challenges for the last 20 years. The country shares the specific demographic structure of the European region with a significant rise in the proportion of people over 60 years of age; it had a difficult transition from free universal health services to private and government care within an insurance scheme and still struggles with the impacts of economic crisis and political instability. Meanwhile, ophthalmic diagnostic and therapeutic practices have changed fundamentally involving the routine use of effective and cost-ly equipment and interventions. How have Bulgarian patients been affected?

The registration of Bulgarian citizens with blindness and low vision was established by a legal act in 1968 as a part of their social welfare assessment. The patients are evaluated by their treating ophthalmologist, then presented to a regional senior committee and if found eligible, they are referred for further clinical assessment by a specialized ophthalmic expert board – four for the country – and the level of their disability is estimated in percentage. The benefits for the handicapped are substantial, including a monthly pension according to the severity of vision loss, reduced fees for transport, medications and rehabilitation, thus the patients with deteriorated vision are strongly motivated to seek registration. For each individual applicant the committee issues a document with the passport data, a summary of relevant history and clinical findings, best-corrected visual acuity, visual fields outlines when constricted, and the full diagnosis which is defined and coded according to the ICD-10 (6).

In this study we examined the trends in the incidence and causes of registered blindness and low vision in Eastern Bulgaria – a territory of 30 000 sq.km with a population of almost 1.8 million people – for the period from 2005 to 2012 as recorded in the archive of the ophthalmic expert board in Varna, Bulgaria.

MATERIALS AND METHODS

The certificates of all newly registered patients with best-corrected visual acuity (BCVA) of 0.3 and less or visual field constriction to 10 degrees or less in one or both eyes certified by the ophthalmic expert board in Varna, Bulgaria from January 1st 2005 to December 31st 2012 were extracted for this report.

The patients were aggregated in three severity categories according to their best-corrected visual acuity (BCVA) and visual field loss – visual acuity from no light perception to BCVA 0.05, from 0.06 to 0.1 or visual field constriction within 5 degrees from the fixation point, and from BCVA 0.15 to 0.3 or visual field constriction between 6 and 10 degrees. The full diagnosis of each eye and the leading cause of monocular or binocular blindness and low vision were reviewed and finalized for each individual case and summarized in broader diagnostic groups for further analysis.

The annual population datasets of the seven administrative districts whose patients had been referred to the ophthalmic expert board and certified as visually impaired within the above criteria during this period were obtained from the population database as published by the Bulgarian National Statistical Institute, including the latest census results from 2011 and the updates for 2012 (© 2013 National Statistical Institute, www.nsi.bg).

The cumulative incidence was calculated in 20-years age strata for both genders per 100 000 persons of the population. Initially, data were analyzed for the period from 2006 to 2011 in two time intervals, each consisting of three years. The resulting incidence rates had unacceptably broad confidence intervals as the number of cases was low and fluctuated significantly through the years. Patient information was collected for two more years – 2005 and 2012 and added to the initial database for further analysis of two intervals of four years each. Rates were calculated for the inhabitants of district cities, smaller towns and villages, administrative districts totally and the whole region by age and gender.

RESULTS

For the period 1 January 2005 to 31 December 2012, a total of 1846 patients with binocular blindness and low vision were newly registered, 911 males
and 935 females, as well as 1631 patients with monocular vision impairment, 915 males and 716 females.

The average age of male patients was 58.59 years and of female ones – 61.63 years. There was a drop of around ten years in the average age of female patients with binocular vision loss during the second period due to decrease in the number in the group over 80 years of age – from 250 to 82.

The cumulative incidence of binocular vision loss was in the same range for both genders during the first period. After the age of 59 years it increased exponentially reaching the highest levels for the group over the age of 80. The incidence reduced significantly during the second period by approximately 30% [confidence level (CL) 99.5%] and the largest decline was among the eldest – by 43% for males and 73% for females (Table 1).

Meanwhile, the cumulative incidence of monocular impairment increased significantly by 38% for males and 42% for females during the second interval (CL 99.5%). The cumulative incidence was rising gradually with age and was higher for the males throughout the whole period (Table 2).

The age-standardized incidence was increasing by 60% for males and 50% for females, and again, the rates for males were significantly higher.

Male patients were more severely disabled – for both binocular and monocular blindness, the cumulative incidence of the most profound vision loss – from no light perception to 0.05 – was significantly higher among them (CL 99.5%). It decreased from 25.96 to 14.38 for males with binocular vision loss during the second period and almost doubled for those with monocular involvement – from 28.39 to 44.67. There was a marked decline in the cumulative incidence of female patients with severe binocular blindness during the second period – from 23.47 to 9.67, whereas it increased from 16.68 to 25.91 for monocular impairment (Table 3).
The cumulative incidence of binocular blindness and low vision among the residents of district cities and other towns was significantly less during the second period of observation, especially for females in the most severe vision loss category. The population of rural areas had significantly higher incidence rates in this category even though it has decreased twice for the last four years.

There were no significant differences in the cumulative incidence of monocular blindness between the residents of cities and rural areas. The largest incidence rise was among males in the most severe disability category.

The cumulative incidence of binocular blindness and low vision among children and adolescents below the age of 20 years has remained stable for the whole period and is significantly higher among the boys – 30.10–26.34 compared to the girls – 19.59–15.47. The number of patient with visual acuity below 0.05 has reduced by 12% and the cumulative incidence decreased from 12.73 to 11.91. Leading cause of binocular blindness and low vision in normal-term children and adolescents below the age of 20 is congenital glaucoma, followed by congenital cataract, microphthalmos and optic atrophy (Table 4). The incidence of monocular blindness and low vision has almost doubled from 8.13 to 13.41 for boys and tripled from 3.71 to 10.89 for girls during the second period, with marked rise in the group with BCVA 0.05 and below. The leading causes of monocular impairment are trauma and amblyopia. There were no significant differences in the incidence rates and leading causes for children living in the cities in comparison to those from villages (Table 5).

The cumulative incidence of retinopathy of prematurity has remained stable – 6.09–6.23 throughout the whole period of observation – 21 cases certified from 2005 to 2008 and 22 cases – from 2009 to 2012, with significant fluctuations for boys and girls from urban and rural areas. Of these patients, only 14(32%) were born after 2005.

Glaucoma was the leading cause of both binocular and monocular blindness and low vision in the group over the age of 20 years and was significantly higher among males (Table 6). The incidence of binocular blindness for the rural population was almost twice higher compared to that of city residents. While the incidence for women from the cities has dramatically decreased from 13.74 to 6.84 during the second period, it has remained unchanged for the village residents and increased among men from the cities. There was a marked rise in the incidence of monocular blindness among men from cities and women from villages during the second period (Table 7).

End-stage ophthalmic complications of diabetes were the second most frequent cause of binocular blindness with significant differences between urban and rural residents. In the course of the second interval the cumulative incidence for the whole population has decreased by about 30–40% and among city women – by 65%. The incidence of monocular blind-
<table>
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<tr>
<th>Year</th>
<th>Condition</th>
<th>Number</th>
<th>Incidence</th>
<th>Gender</th>
</tr>
</thead>
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<tr>
<td>2009-2012</td>
<td>Congenital glaucoma</td>
<td>77,692</td>
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<td>Males 25, Females 24.35</td>
</tr>
<tr>
<td>2009-2012</td>
<td>Congenital cataract</td>
<td>33,171</td>
<td>1</td>
<td>Males 1, Females 32.17</td>
</tr>
<tr>
<td>2009-2012</td>
<td>Optic atrophy</td>
<td>44,251</td>
<td>1</td>
<td>Males 23, Females 21.25</td>
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<tr>
<td>2009-2012</td>
<td>Macular hypoplasia</td>
<td>35,27</td>
<td>31.61</td>
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</table>

**Table 4. Leading causes of binocular blindness and low vision in the group from 0 to 19 years of age by residence, gender and period of observation**
Trends in registered blindness in Eastern Bulgaria

The cumulative incidence of age-related macular degeneration followed close. It was higher for the urban population during the first period and decreased for the rural population by 15% for the males and 35% for the females.

Cataracts were the next cause of binocular blindness and low vision, with much higher incidence for the rural population compared to city residents. The rates of monocular blindness and low vision due to macular degeneration increased significantly, especially among village residents, and have become the leading cause for the whole female population from both cities and villages.

Consequences of trauma to the eye and brain were the most important cause of monocular blindness and low vision for men and their incidence has increased significantly – from 8.89 to 13.45, mainly due to the rise in the rates for the urban population – from 6.68 to 10.79.

The patients with the most advanced vision loss with BCVA from no light perception to 0.05 in the better eye were 40% of the males and 27% of the females during the first interval. Their incidence rates have reduced significantly during the second interval to 14.38 and 9.67 and comprised 43% and 16% of the whole group for this period.

Although the incidence of these patients from villages was less during the period 2009-2012 – from 37.26 to 23.73 for men and from 38.11 to 17.93 for women, it was two to three times higher compared to that of city residents and comprised 43–41% of the whole group for this interval.

Although the incidence of these patients during the second interval was much lower and in the same range for the whole population, but it increased during the second period, especially among village dwellers. The cumulative incidence of age-related macular degeneration followed close. It was higher for the rural population during the first period and decreased for the second period by 15% for the males and 35% for the females.

Table 5. Leading causes of monocular blindness and low vision in the group from 0 to 19 years of age by residence, gender and period of observation

<table>
<thead>
<tr>
<th>District cities</th>
<th>Other towns</th>
<th>Villages</th>
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<td>Females</td>
<td>Males</td>
</tr>
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<td>Cumulative incidence</td>
<td>Number</td>
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<tr>
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<td>---------</td>
</tr>
<tr>
<td>2005 - 2008</td>
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<td></td>
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<tr>
<td>Amblyopia</td>
<td>4</td>
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<td>Trauma</td>
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<tr>
<td>Corneal opacity</td>
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<tr>
<td>Amblyopia</td>
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<tr>
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Table 6. Leading causes of binocular blindness and low vision in the group over the age of 20 years of age by residence, gender and period of observation.

<table>
<thead>
<tr>
<th>Year</th>
<th>Glaucoma</th>
<th>Diabetic retinopathy</th>
<th>AMD</th>
<th>Optic atrophy</th>
<th>Cataract</th>
<th>Pseudo-phakia</th>
<th>Myopia</th>
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<td>27</td>
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<td>143</td>
<td>61</td>
<td>51</td>
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Table 7. Leading causes of monocular blindness and low vision in the group over the age of 20 years of age by residence, gender and period of observation

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<th>District cities</th>
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<th>Females</th>
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<td>Cumulative incidence</td>
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<tr>
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<tr>
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<td>5.82</td>
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<tr>
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End-stage diabetic complications in the eyes were the second most important cause of severe visual impairment for the 2005-2008 interval with higher incidence for the rural population, especially women. For the years 2009 to 2012 the total incidence decreases three times from 4.59 to 1.64 for men and 4.11 to 1.93 for women, mainly due to a significant drop among women from the cities – there are no female patients with this BCVA for the second period.

Cataracts were the third most frequent cause of severe disability with rates three to four fold higher among people from the villages and females were more severely affected. There was a marked reduction in the incidence from 2.37 to 1.34 for males and from 4.96 to 1.24 for females for the period 2009–2012, and again, there were no city women for 2009–2012 in this group.

**DISCUSSION**

The registers of the blind have been an important source in the research of prevalence and time trends in vision loss in Australia, Germany, UK, Ireland, Italy, Israel, Kuwait and Oman (2, 3, 8-26). The Information on diagnoses and legal blindness status is proven to be of superior precision and allows for useful linkages to other databases (8) thus revealing the influence of demographic shifts and the progress in accessibility and quality of ophthalmic care.

This is the first analysis of registered blindness of such scope and duration in Bulgaria. The database of the regional expert board is a reliable source of accurate demographic and clinical information collected by experienced ophthalmologists over a long period of time in a consistent manner covering a population of almost 1.8 million nationals. The study stratifies the patients into severity categories and includes groups of borderline to legal blindness as they have greater potential for rehabilitation. It presents for first time the incidence, dynamics and main causes of monocular blindness in parallel to binocular vision loss considered to be disability by law.

As mentioned above, registration of vision loss in Bulgaria is voluntary and may not encompass all patients if they did not apply for social support, a shortcoming demonstrated in the UK by Barry RJ et al (17), Malik et al (18) and Liew G et al (19). Still, considering the incentives for patients to be certified on one hand, and the lack of stigmatization for being blind in Bulgarian society on the other, it can be argued that the number of unregistered patients with legal blindness is probably very small. The database of the archive does not provide information on the marital status, level of education and personal or household income of the patient. The certificates of the disabled follow the format of all legal documents in Bulgaria and out of concerns for political correctness do not reveal data on the ethnic origin of the patients. All these limitations restrict the review into the social background of blindness within the available records of age and residence. The purpose of the evaluation by the Expert board is to verify the level of impaired vision and main cause of the disabling condition and there are no collected details on the time of diagnosis, medical treatment or surgeries done prior to the permanent loss of vision, a limitation that precludes assessment of the quality and promptness of specialized management.

The outcome demonstrates a characteristic increase of blindness and low vision after 60 years, reflecting the progressive ageing of Bulgarian population. There is a marked decrease in the incidence of binocular blindness and low vision in Eastern Bulgaria for the period after 2009, especially among patients with profound impairment. Vision loss below 0.05, which is close to the levels of legal blindness in Israel, had cumulative incidence per 100 000 residents of 14.38 for males and 9.67 for females in Eastern Bulgaria for the period 2009-2012, compared to an annual rate of 16.6 in Israel for the year 2008 (3). For the same disability category the cumulative incidence per 100 000 people during the years of observation decreased from 6.26 to 3.53 for males and from 5.80 to 2.92 compared to 14.82 for females and 7.16 for males in Northrhine, Germany for 2000–2008 (12). Meanwhile, monocular blindness and low vision has increased sharply in all age groups and severity categories in proportion to the decline of binocular impairment, especially among males. Unlike the findings in most contemporary research, this study reveals that Bulgarian men are at higher risk of vision loss. Rural population in this territory has higher incidence of blindness but the differences compared with the urban residents are decreasing after 2009.

Glaucoma is the leading cause of binocular blindness throughout the whole period with fairly
constant certification of male patients and a rapid decrease of the incidence among females, coupled with a simultaneous rise in the monocular impairment after 2009. Downward trends in blindness secondary to glaucoma has been reported in cohorts in Olmsted, USA (28) and Fife, Scotland (29) comparing patients under observation for more than 20 years; certification in the course of the last decade has been in the same range in the UK (18, 28) and the proportion of glaucoma cases has decreased in Israel from 1999 to 2008 (3). Population-based studies in Europe indicate wide variations in the prevalence of glaucoma and loss of vision due to glaucoma (30), but the common observation is that age over 60 years is the key risk factor for both ocular hypertension and glaucoma, and progressive deterioration of the visual field. Considering the demographic structure of Eastern Bulgaria with even distribution of the elderly in urban and rural areas, the decline in the incidence of blindness due to glaucoma among city women could be attributed to earlier diagnosis, availability of appropriate medications and better compliance.

Over the last four years the incidence of binocular blindness and impaired vision from end-stage diabetic complications in Eastern Bulgaria has declined significantly, especially among female residents of district cities. A similar situation has been reported in the USA (31), UK (18) and Scotland (32), whereas the proportion of diabetic retinopathy/maculopathy patients has increased in Germany (11) and Israel (3) and reaches 8.31% in Italy (24). This review is not designed to identify the reasons behind these significant shifts in the incidence of blindness from diabetes. The prevalence of diabetes in Bulgaria was estimated at approximately 9% of the population in 2007 and additional 3% with diabetes are yet to be diagnosed (33). Available data from Bulgaria and other countries in Eastern Europe suggest that the prevalence of diabetes is increasing over the last 10 years (34) which would be expected to result in higher incidence of retinopathy and loss of vision. It can be speculated that the drop in binocular blindness and rise of monocular impairment could be associated with improvements in the screening and quality of retinopathy treatment, including the wide use of anti-VEGF agents for macular edema, as well as better glycemic control and management of cardio-vascular complications in diabetic patients.

Pediatric blindness has lower prevalence compared with adult blindness and has been reported to account for 4% of the total blindness globally (1, 35). Each source of information on the burden of childhood visual impairment has significant limitations. High-income countries report mainly reviews on children enrolled in the schools for blind, however, the data are not comprehensive, admission criteria vary between institutions and often diagnoses are not formulated according to WHO definitions. Population-based studies are far more costly and rarely have a pediatric sample sufficient to reveal the actual prevalence and causes of childhood blindness. As pointed out by Kong L et al (35), the prediction of incidence is even more difficult because it requires longitudinal studies or efficient data entry systems. Several countries maintain national registries of the blind and visually impaired, including Canada, the UK, Finland, Germany, Kuwait, and Australia, that have different levels of legal blindness and varying coverage depending on whether registration is a mandatory prerequisite in order to receive social benefits. Changes in the national certification criteria and procedures may interrupt the homogeneity of the data and hence preclude comparisons. Still, in Kuwait, where a population-based blindness study of the total population was done in parallel to analysis of data on applicants for blindness certification collected for ten consecutive years, the register provided far more accurate information on the magnitude and causes of vision impairment among children (25). There is a trend towards increasing incidence of new pediatric blind registration in the UK from 0.17 per 10 000 in 1982 to 0.41 per 10 000 in 2011 (36,37) and in Australia the number of registered blind children has doubled in the last 7 years (38). In Eastern Bulgaria, the incidence of low vision and blindness below the age of 19 has remained in the same range for the whole period with a decrease for those with profound vision loss below 0.05. The proportion of patients with retinal conditions was 27-28%, similar to that in the UK registry; however 16–17% of our patients had glaucoma and 9% - cataract, both considerably higher in comparison with the British population. The leading cause of certification was ROP and its proportion was 21% and 28% during the observation period similar to the estimates for the former socialist countries (39), Eastern Europe and Central
Asia (40), however, only 32% of these patients were born after 2005, and since 2011 there are no new cases with loss of vision less than 0.05. This development parallels the stable decrease of neonatal mortality rate per 1000 live births (NMR) in Eastern Bulgaria from 5.99 for 2008 to 4.95 for 2012 and in the country as a whole – from 5.00 for 2008 to 4.48 for 2012. Still, the proportion of preventable and treatable childhood blindness is significant and probably related to regional differences in the standards of neonatal care and variations in the implementation of the national screening and treatment guidelines for ROP, congenital cataract and glaucoma. The rise in the incidence of monocular blindness due to amblyopia and especially eye injuries during the period 2009-2012 indicates problems and disparities in the early childhood vision screening and treatment of refractive errors and strabismus and the need for public health strategies to enhance awareness of prevention of eye trauma, to promote education and to increase access to qualified ophthalmic care.

CONCLUSIONS

The trends in the incidence of avoidable and preventable registered blindness in Eastern Bulgaria demonstrate that current practice policies and guidelines for screening and treatment of major eye disorders have to be updated in order to raise the professional standards and achieve further reduction of monocular and binocular vision loss. Research is necessary to elucidate the effect of regional, educational, ethnic and economic risk factors contributing to disparities in eye care and clinical outcome. Assessment of the barriers to ophthalmic services covering the access attributes of availability, accessibility, acceptability and affordability can provide useful information on the location and magnitude of vulnerable communities and their specific pathology and needs. Systematic evaluation of the deteriorated quality of life and estimation of the cost of vision loss and eye diseases to individuals and their families as well as extended family caregivers and third-party payers, the health care system, and Bulgarian society is essential in the development of evidence-based interventions that translate research into enhanced clinical and community practice and prevention of unnecessary visual impairment.

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