National Register for the Blind: a tool for health programme management

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السجل الوطني لفاقدي البصر: وسيلة من وسائل إدارة البرامج الصحية

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الخلاصة: أجرى الباحثان دراسة تحليلية استعادية شملت 3525 من فاقدي البصر في العينين، المسجلين في عُمان حتى نهاية عام ألفَيْن، وأوضَحا طريقة الفحص، والمحافظة على السِّجلاّت، وتحليل المعطيات. وتم توزيع قوائم بمختلف فئات فاقدي البصر على عدة منظمات، بقصد المعالجة والتأهيل. كما تم تقصي دور السجل الوطني في تسجيل سادِّ (الكاتاركت) المسبب للعمى، والعمى الناجم عن علّة القرنية، واستئصال متلازمة الحصبة الألمانية الخِلْقية، ورعاية فاقدي البصر في عُمان. وتبيَّن أن للسجل الوطني دوراً مفيداً في تحديد الأفراد المرشحين للتأهيل، وكذلك في رصد الجهود الإقليمية لمعالجة حالات العمى القابل للشفاء. وخلصت الدراسة إلى أن الاستخدام المتعدد للسجل الوطني، يمكن أن يجعله أداة مهمة في إدارة البرامج الصحية في عُمان.

ABSTRACT We carried out a retrospective analytical study of 3525 bilaterally blind people registered in Oman to the end of 2000. We described the examination method, maintenance of the register and analysis of data. Lists of different categories of blind people were distributed to various organizations for management and rehabilitation purposes. The role of the national register in addressing blinding cataract, corneal blindness, eradication of congenital rubella syndrome and care of blind people in Oman was also examined. The register was useful in identifying candidates for rehabilitation and also for monitoring regional efforts to manage curable blindness. This multiple use of the register could make it an important tool for health programme management in Oman.

Registre national des personnes aveugles : un outil pour la gestion des programmes de santé

RÉSUMÉ Nous avons réalisé une étude analytique rétrospective de 3525 personnes atteintes de cécité bilatérale enregistrées à Oman à la fin de l'année 2000. Nous avons décrit la méthode d'examen, le maintien du registre et l'analyse des données. Les listes des différentes catégories de personnes aveugles ont été distribuées à diverses organisations s'occupant de prise en charge et de réadaptation. Le rôle du registre national dans le recensement des cas de cataracte cécitante et de cécité cornéenne, dans l'éradication du syndrome de rubéole congénitale et pour les soins des personnes aveugles à Oman a également été examiné. Le registre a été utile pour identifier les cas pouvant bénéficier d'une réadaptation ainsi que pour surveiller les efforts régionaux de prise en charge de la cécité curable. Cette utilisation multiple du registre pourrait en faire un outil important pour la gestion des programmes de santé à Oman.

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Received: 09/12/03; accepted 17/02/04

Introduction

It has been estimated that there were 40 million blind people worldwide at the beginning of the 21st century, and that this will double by 2025 [*1*]. The World Health Organization, in its efforts to reduce the prevalence of visual disability, promotes national health programmes to address this problem. Detection and management of curable blindness is one of the strategies which can help a country to reduce the prevalence of visual disability in a short time. In countries with high rates of visual disability and a small population, identification of blind people through the existing health system is possible.

Oman is located in the Arabian Peninsula and has a population of 2.3 million [*2*]. The prevalence of bilateral blindness was reported to be 1.08% in 1997, around 17 000 blind people (visual acuity < 3/60 in the better eye) [*3*]. The activities of the eye health programme have been managed on a regional basis since 1995. Twenty-five ophthalmic units, with nearly 60 qualified cataract surgeons, provide eye care in Oman. A national register was introduced in 1998 [*4*]. The aim was to identify all cases of curable blindness, set targets for operating on curable patients and register all young people with non-curable blindness for the purposes of rehabilitation. Since 1999, around 12 centres have been established in different regions of Oman where blind children can be rehabilitated.

After 2 years, the National Register for the Blind was evaluated and the information used to monitor the Eye Health Care Programme at regional and national levels. We undertook this study to explain the methodology used in the National Register for the Blind in Oman and to recommend the employment of such registers at national and regional levels to manage national health programmes.

Methods

We carried out a retrospective analytical study of the National Register for the Blind. All bilateral blind people registered between January 1999 and December 2000 at all ophthalmic units of Oman were included in the study.

All the patients who visited ophthalmic units were examined by a qualified ophthalmologist. If visual acuity was < 3/60 in the better eye or the person had a correspondingly compromised field of vision, he/she was declared bilaterally blind and registered on the National Register for the Blind. The ophthalmologist recorded details of the patient's personal profile on a standard form, including type of visual disability and principal and underlying causes of blindness. If the eye condition was curable and facilities were available within the institution, management was undertaken to cure the blindness and improve the quality of life. The patient was referred to the nearest ophthalmic unit for further management if facilities were not available in the registering institution. Health education for the specific eye disease was given by health staff to improve surgical compliance. If postoperative vision had improved after 8 weeks and the patient was no longer blind, e.g. patients having cataract operations, this information was forwarded on a standard form to update the register.

A national report was prepared annually and was given to all the regions for further action. The report summarized the epidemiological profile, achievements of the register, constraints and results; it also included an inventory of curable and non-curable blind patients in each region.

A number of quality assurance procedures were incorporated. The conditions to be reported in the Register were clearly defined in the information collection form. This was routinely used as a reference by

the ophthalmologists for case records and the health information system. A standard form was used to collect the information in all regions. The ophthalmologists in each region were briefed about the inclusion criteria, the method of maintaining the register and the flow of information. A computer format was prepared at central level and then distributed to the regions for computing the data periodically. The forms and methods had been tested in 2 regions for 3 months. Required modifications were carried out and then the register was launched nationally. The data were audited before analysis to ensure uniformity.

The information was computed by qualified statisticians in each region using *Epi-Info,* version 6, data entry format. The data from all regions were checked then pooled and the national register data were analysed using *SPSS,* version 9. A univariate analysis model was used. The frequencies and ratios of the number of registered blind people in different sub-groups were estimated for comparison.

Results

Between January 1999 and December 2000, 3525 bilaterally blind people were registered, 1975 (56%) females and 1950 (44%) males. Analysing by age group, 1570 (44.5%) were ≥ 60 years of age; 1655 (47%) were 40–59 years, 205 (5.8%) were 20–39 years and 45 (1.3%) were < 20 years. Information on age was missing for 50 people.

The regional distribution of the study sample was compared with the number of blind people in each region recorded in the national survey conducted in 1997 [*5*]. The prevalence and frequency for each region is given in Table 1.

Table 1 **Regional distribution of people registered blind**

Region	People registered blind		
	2001		1997[a]
	No.	%	%
South Batinah	840	23.8	15.2
North Batinah	649	18.4	24.8
Dhakhiliya	520	14.8	20.9
South Sharqiya	515	14.6	9.0
Muscat	319	9.0	6.9
Dhahira	280	7.9	11.4
Dhofar	180	5.1	3.8
North Sharqiya	148	4.2	3.9
Musandam	74	2.1	4.2
Total	3525	100	100

[a]*Regional proportion for 1997 was based on the National blindness survey [5].*

The study sample was classified by cause: curable, preventable and non-curable. If the principal cause was reported to be cataract or non-trachomatous corneal opacity, it was classified as curable cause of blindness. Trachomatous corneal opacity, glaucoma and aphakia were classified as preventable causes of blindness. The causes related to the posterior segment were classified as non-curable causes of blindness. According to these classifications, there were 995 bilateral blind people in the curable group, 1507 in the preventable group and 995 in the non-curable group. Information on cause was missing for 28 people.

Sixteen children under 15 years of age and with non-traumatic cataract, microphthalmos, anophthalmos, congenital glaucoma and unexplained pigmentary retinopathy as the principal causes of bilateral blindness were classified as having

clinical congenital rubella syndrome as the underlying cause and were listed on the register of those with congenital rubella syndrome.

Twenty-nine children (16 males and 13 females) under 15 years of age were identified as bilateral blind.

Those who were bilateral blind with principal cause as cataract but still having residual vision were identified from the register and added to the list for curable blinding cataract. The regional distribution of the sample is shown in Table 2.

If the principal cause of visual disability per eye was non-trachomatous corneal opacity for a patient under 40 years of age and having residual vision, he/she was included on the list for managing corneal opacity by keratoplasty: 13 such cases were identified from the register as immediate targets for corneal surgery.

After the ophthalmologists had operated on blinding cataract, information on the patient's post-operative visual status was supplied to update the national register. If visual acuity had improved to better than 3/60 in the eye operated on at the end of 6 weeks, he/she was classified "not blind" and the national register was updated by deleting the name.

There were 214 visually handicapped people 15–40 years of age who could be enrolled for vocational training.

Discussion

The National Register for the Blind has been maintained in Oman since 1999. The aim was to guide the national programme for identifying people with curable blindness in each region and arranging for them to be operated on. A further aim was to list those with non-curable blindness to rehabilitate them. In countries like the United Kingdom, Canada and Sweden similar registers are maintained to provide social security and periodically review the profile of visual handicap.

In the first 2 years, despite some teething problems, the register has helped the national programme to improve its ef-

Table 2 **Distribution of blinding cataract by region**

Region	Persons with cataract in ≥ 1 eye		Operated on and subsequently classified not blind	
	No.	%	No.	%
South Batinah	304	23.3	116	38.2
North Batinah	282	21.7	51	18.1
South Sharqiya	222	17.1	56	25.2
Dhakhiliya	137	10.5	34	24.8
Muscat	127	9.8	34	26.8
Dhahira	111	8.5	48	43.2
Dhofar	85	6.5	54	63.5
North Sharqiya	17	1.3	10	58.8
Musundam	17	1.3	1	5.9
Total	1302	100	404	31.0

forts in reducing the prevalence of curable blindness and as a guide for the rehabilitative services.

Over the 2 years of the study period, 3525 registered cases represents only around 20% of the 17 000 (14 000–20 000) projected bilaterally blind people in Oman [*6*]. This suggests a wide gap between the actual numbers and those on the register. Health services are free in Oman and within accessible distance [*2*]; therefore, inability to visit the ophthalmic units is not likely to be the cause of this gap. The annual morbidity report suggests that around 1800 people with bilateral blindness had visited ophthalmic units in 1999 and 1030 in 2000 [*2,3*]. This almost matches the number of registered cases. Thus, morbidity figures and the register differ from the projected figures for blindness, which seem to be on the high side.

In Oman, the male:female ratio in the general population is 52:48 [*3*]. The male: female ratio for blind people is 35:65 [*6*]. The National Register for the Blind records a male:female ratio of 56:44. This could be because fewer females than males with visual disability attend ophthalmic units. Thus, gender may be a barrier among blind people to visiting ophthalmic units.

According to the register, the elderly population constituted a large proportion of visually handicapped people in Oman. This was found in the national blindness survey also: prevalence of childhood blindness was 7/10 000, in agreement with the low number of children under 15 years of age registered blind [*5*].

The regional distribution of registered blind people differed from that for bilateral blindness estimated through a community-based survey carried out in 1997 [*5*]. For instance, the number of people registered blind in South Batinah was 8.6% more that in the 1997 survey. In contrast, registration in North Batinah was lower, 6.1% less than in 1997. Regional differences in the registration process may account for this.

The trend of registered blind in Oman differs from Israel [*7*], the United Kingdom [*8*] and Denmark [*9*]. Most of these countries keep records of those who are permanently blind and they cite glaucoma, age-related macular degeneration and diabetic retinopathy as the leading causes of blindness. This is in contrast to the leading causes of blindness found in our study. Complications of trachoma in the form of corneal opacity and phthisis bulbi were the leading causes among people registered blind in Oman.

Global data on childhood blindness [*10*] as well as data from a study done in Canada [*11*] suggest that in the developing countries preventable causes of childhood blindness were mainly due to corneal opacification caused by a combination of measles, xerophthalmia and the use of traditional eye medicine. In industrialized countries in the early 1970s, the leading causes of childhood blindness were cataract, optic atrophy, nystagmus and retrolental fibroplasia [*10*]. Our findings suggest that even though the magnitude is low, avoidable causes and congenital causes both contribute to childhood blindness in Oman.

In our study the proportion of cases of blindness due to non-curable causes and those due to lens-related causes was consistent with the results of the 1997 survey [*5*]. Diabetes and age-related macular degeneration cause blindness due to involvement of the posterior segment. The large proportion of trachomatous and non-trachomatous corneal opacities and cataracts prevented us from reviewing the diseases causing posterior segment blindness. This might be the reason for the low proportion of diabetic- and age-related retinal causes of blindness recorded.

Oman is aiming to eliminate congenital rubella syndrome by 2005 [*12*]. Ophthalmic complications are the most important manifestations of this syndrome and ophthalmologists have always played an important role in the epidemiological investigation [*14*]. Children visually handicapped owing to conditions such as congenital cataract, congenital glaucoma, microphthalmos and anophthalmos should be investigated for possible congenital rubella syndrome [*15*]. A list of these children from the National Register was forwarded to the Department of Disease Surveillance and Disease Control for further investigation and updating of the register.

Oman initiated rehabilitative services for blind people in 1999. In about 12 centres throughout the country services for blind children are managed by the Ministry of Social Affairs. A list of 13 children from the register was forwarded to them to ensure that volunteers from these centres approached the parents and enrolled the children in the centres for rehabilitation and training.

The national health care programme can achieve the goal of reducing blindness in the short-term if incident blinding cataract cases are operated on through the existing eye care services. A national register of visually handicapped people could locate those with blinding cataract. We prepared regional lists and distributed them to the mid-level managers of the eye health care programme so they could approach those on the register and counsel them and arrange surgery.

The updating of registers is not done as promptly as the initial notification. The low coverage of reporting of operations on blinding cataract is a matter of concern as it suggests a backlog of nearly 70% in the 2 years previous to our study. However, evaluation of cataract cases which have been operated on in the ophthalmic units suggests that 85% were at the blinding stage and only 15% were non-blinding. Thus, nearly 2500 eyes with blinding cataract were operated on in the previous 2 years. This indicates there is a wide gap between the reported number of cataract cases and reports of operations on blinding cataract cases to update the register. This could be due to under-reporting of cataract operations. The regional authorities should investigate the low coverage of the system for updating the register. Cases operated on outside the Ministry of Health, such as the private sector within and outside Oman, are not reported. They could be identified and subsequently reported by periodically following up people who are registered blind.

A possible limitation of this study was the fact that a few patients had opted for surgical care in neighbouring countries. After management, if they were not blind, their names still remained on the register. Thus, the number of people blind due to curable conditions in the register could be overestimated.

The tertiary level ophthalmic services have carried out keratoplasty surgery for the last 4 years, but there are still only around 50 operations per year owing to the non-availability of a local eye bank and the high cost of importing donor corneas. Due to resource constraints and high demand, the cases which need to be operated on are prioritized. Children and young adults with bilateral blindness due to non-trachomatous corneal opacity need to be operated on as soon as possible. The list of such cases was prepared from the register and forwarded to the tertiary eye care unit.

At present, vocational training facilities for the blind adult are not available in Oman. The register identified nearly 80 candidates with such a need. The list was forwarded to the Ministry of Social Affairs for further

action. These people could be guided to attend facilities in nearby countries so that they can be economically independent.

The Ministry of Social Affairs provides financial support to blind people on a monthly basis and is in the process of initiating a nationwide database. The National Register for the Blind identified around 2500 people with non-curable permanent visual disability. The information could be useful to staff of rehabilitative services for strengthening their database and taking further action.

Our study shows how the information on the National Register for the Blind helps the eye health care programme and other institutions in Oman to further strengthen the care of people who are visually disabled.

Acknowledgements

The authors wish to acknowledge the support of the ophthalmologists and regional directorate to maintain the National Register and take action based on the periodic review of this register. The kind patronage of the Ministry of Health authorities facilitated the review of the data and its publication.

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Global estimate of visual impairment, by WHO region (millions), 2002

	African Region	Region of the Americas	Eastern Mediterranean Region	European Region	Region South-East Asia	Region Western Pacific	Total
Population	672.2	852.6	502.8	877.9	1 590.80	1 717.50	6 213.90
No. of blind people	6.8	2.4	4	2.7	11.6	9.3	36.9
% of total blind	18%	7%	11%	7%	32%	25%	100%
No. with low vision	20	13.1	12.4	12.8	33.5	32.5	124.3
No. with visual impairment	26.8	15.5	16.5	15.5	45.1	41.8	161.2

Source: WHO Fact sheet No. 282 November 2004