Community Based Rehabilitation: An Introduction

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Most ‘Community Based Rehabilitation’ (CBR) programmes implemented thus far do not result from the creativity and hard work of the local people themselves. They are products of foreign policy and interest, with the input of foreign manpower and money. At present CBR programmes are largely financed by overseas agencies and plans are made to fit donors’ requirements. This has led to a wide diversity of meanings currently attached to the term ‘CBR’. Most people will however agree with the following ‘definition’:

CBR Programmes
- improve, facilitate, stimulate and/or provide services
- are for people with disabilities (PWDs), their families and carers
- are situated within the locations of these families and communities
- are implemented through local full or part time, paid or volunteer community rehabilitation workers (CRWs)

1. Community Based Rehabilitation: ‘People Taking Care of Themselves’
Services for people with disabilities (PWDs) in most regions in developing countries are still limited to what people can do for themselves. This is the ‘real’ CBR: all the activities that disabled people, their family members and other community members do in their own community for disabled persons, such as general care, accommodating each other’s needs (i.e., family members adapting themselves to the situation of the disabled, and vice-versa), education and health, using whatever they know, whatever they have, in whatever daily circumstances that exist.

2. Community Based Rehabilitation: A Concept and an Ideology
CBR as a concept and an ideology, promotes a de-centralised approach to rehabilitation service-delivery, whereby it is assumed that community members are willing and able to mobilise local resources and to provide appropriate services to disabled people. This concept has been tried out in many CBR programmes in the developing world, by the use of government staff and facilities, but has in most cases proved to be unrealistic.

3. Community Based Rehabilitation: Programmes, Projects, Organisations (mostly Non-Governmental Development Organisations)
Recognising the human and material limitations of disabled people, their family members and other community members, a CBR programme tries to promote and to facilitate CBR (see above: 1), by visiting the disabled persons and their families in their homes, providing appropriate information, therapy and/or training, promoting and facilitating rights and duties of disabled persons, family and community members.

Unfortunately, such CBR programmes often consider ‘local culture’ as an obstacle, rather than as a condition towards progress.

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This issue is generously supported by

Christoffel Blindenmission Germany

National Foundation for the Visually Impaired and Blind The Netherlands
The Main Problems of CBR Programmes

1. Poor families’ priorities may be at the level of survival needs, rather than solving problems of a disabled member. Poor living conditions of most people with disabilities are also poor conditions for rehabilitation. The objectives of individual CBR programmes, therefore, have to be very realistic, focusing on essential needs.

2. The organisation and management of good CBR programmes is complex and difficult in countries where people often have no tradition of formal management and handling funds.

3. Highly educated workers don’t like to go into the field, and may find it hard to communicate well with disabled people who are often uneducated or under-educated. Front-line CBR is a low-profile job, which gives no social status to people who already have higher education. These factors influence the type, level and quality of the services which can be provided by a CBR programme.

4. For several reasons, CBR programmes might often be too much for communities to accommodate. It is precisely the ‘lack of community’, i.e., the breakdown of traditional social structures, that contributes to the many problems facing developing countries. Thus, it is unlikely that these same weakly-constructed communities could organise appropriate services for their PWDs.

Conclusion

Some CBR programmes have had quite good results, by building on the most widespread positive resources, ideas and skills for CBR, which are those already existing in the hearts and minds of mothers and fathers, grandparents, neighbours and disabled persons themselves. If CBR is to have an impact on hundreds of thousands, rather than on merely hundreds, then programmes must study, value and encourage these vital existing community resources. No plan should be approved unless some ‘multiplication factors’ are built in, whereby a small input of knowledge and skills can bring into play a much larger amount of application and energy.

Reference

Community Based Rehabilitation and Prevention of Blindness in South West Uganda

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Introduction

Community Based Rehabilitation is hard work: visiting individuals and their families at home, identifying those with eye problems and those who are blind, encouraging and referring those whose sight can be improved or restored, providing care and guidance for the irretrievably blind and supporting the rehabilitation of those who return to their families and community after hospital and clinic care.

Concepts of prevention of blindness in developing countries have now drastically changed with the introduction of intraocular lenses (IOLs). Now we can consider unilateral cataracts as well as bilateral cataracts. After all, if we operate on unilateral cataract, blindness has been prevented if the second eye should lose sight! What a pity this was not the case when the CBR programme in Mbarara, South West Uganda was initiated in October 1995 – perhaps then results could have been even more convincing – that CBR has a role to play in prevention of blindness. Since many unilateral cataracts were left untreated we are now trying to find them again.

Much of CBR is not easily measurable or quantifiable:

- How will we know if the school lesson given by the Community Rehabilitation Worker (CRW) is the reason why the former schoolgirl will come to the eye clinic when she gets cataract in 50 years time?
- How will we know if the CRW has encouraged the person with red eye to attend the eye centre rather than the Traditional Healer?
- How will we know if the mother has taken her child for measles immunisation because of the CRW or was the mother going to go anyway?

CBR in South West Uganda

The CRWs were trained to conduct the ‘Count Fingers at 3 Metres’ (<CF3M) test during their house-to-house survey. A survey form was completed for all those with bilateral blindness and the CRW had to indicate if the cause of blindness was due to cataract, trachoma or another eye problem. Those with other eye problems were referred directly to the eye clinic using a different form. (Now, I would change the methodology to the <CF6M test in either eye so that early unilateral cataracts would not be missed).

A population of around 120,000 was surveyed. The CRWs identified 456 people with vision <CF3M using both eyes. An eye worker then assessed 81% of the 456 identified, that is 371 patients. Of the 371 assessed, it was confirmed that 308 (81%) had bilateral vision <CF3M (0.3% prevalence). This prevalence rate seems low compared with the 1% prevalence rate that is often quoted. To date, 312 bilateral blind persons have had eye surgery from the CBR working area (70% of those identified). Fifteen other operations were done, for example, trachomatous trichiasis. Some readers may be disappointed that the prevalence rate seems low and would question whether the CRWs really did identify all of the blind people. It has been realised, however, that South West Uganda does seem to have fewer cataracts than other places, for reasons that we do not know. Since completing the survey, a further 71 patients have been identified. We have been especially pleased that 7 babies born with congenital cataracts have been correctly identified and referred by the CRWs via Traditional Birth Attendants and mothers.

The CRWs are now over 90% accurate in identifying cataract. If we consider the number of in-patients and out-patients attend-

Discussion and Recommendations

It should be realised that those blind persons identified in the community are quite different from those who volunteer themselves to eye clinics. Perhaps this is where CBR can now be thought of as Can the Blind Respond? CRWs have an important role to play in motivating these blind persons for surgery. Identification and assessment is useless unless followed through to ensure attendance. This is where CBR has the most significant role to play. Identification and assessment is the easy part! CBR also allows for good follow-up of patients.

Eye clinics also need to appreciate that a lot of work has been involved in bringing just one of these people to their doors since they are unlikely to have made the effort on their own. Good co-operation between a CBR programme and the eye clinic is essential for good results. If the patient is turned away from the eye clinic, for whatever reason, this can prove to be very negative for the CBR Programme.

Radio announcements and information sharing will normally bring those persons forward who are eager to receive assistance. CBR concentrates more on reaching those persons who would never have made an effort on their own. CBR is not, therefore, a way of getting large numbers of patients. It offers a way of reaching a few and is, therefore, an expensive approach. A fully developed CBR programme, involving paid CRWs, is not the way to find quantities but it does encourage good quality service. The other advantage of CBR is that it allows for appropriate home-based rehabilitation programmes for the inoperably blind. A total of 62 received such a service by the CRWs who had undergone a 6 week training course on rehabilitation for the blind.
CBR in Uganda

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(* projected figure)

As previously mentioned, CBR can have many approaches. Personal experience in Tanzania teaching school children proved that they could identify the blind in their community. They easily learned the 

"community-based" or "community involved".

Since the CBR programme is working with all disability groups and not just blind people alone, time does not allow me to try other ways that CBR can work. Radio information programmes (not just announcements for mobilization), working with Traditional Birth Attendants and Traditional Healers, use of successful patients as motivators, motivation of Health Workers, even visiting the graduated tax offices (note that the blind are tax exempt!) are all possible methods to try. There should, however, be no misconceptions that CBR is a cheaper alternative. Definitely, it is not. It is expensive and it requires special people who do not tire of endless days on the road and who do not allow the frustrations of the community approach to disappoint them. There is much work to be done to encourage communities. Perhaps we should be describing these programmes as Village Based Rehabilitation at this stage as there are so many smaller settlements to be visited. If larger communities did exist, the work would not be nearly so hard.

Review Article

Community Based Rehabilitation in India: Who Contributes to CBR Programmes for the Visually Impaired?

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Introduction
Traditionally rehabilitation of the visually impaired used to be institution based and provided by organisations concerned with the welfare of the blind. With the development of the concept of Community Based Rehabilitation (CBR), Sight Savers International (SSI) commenced supporting CBR projects in India. However, the practice of CBR, in quite a few projects:

- had the cultural ‘hangover’ of traditional rehabilitation approaches
- started in geographic areas where organisations o’for the blind were strong leaving the under/unserved areas as they were
- was more ‘community-oriented’ than ‘community-based’ or ‘community involved’.

SSI’s India policy, developed since 1990, stressed the need for development of services to the visually impaired in the deprived parts and States of India – specifically in the central, eastern and northeastern states. Since traditional blind welfare organisations were not available (both in numbers and capacity), in these areas the SSI India programme had to look for alternative agencies for service delivery through CBR. This article attempts to share this experience as well as some suggestions for further expansion of well-developed and networked CBR projects.

Partner Identification and Development
While the blind welfare services were few in number with very limited capacity, the target States had a number of good agencies dealing with one or more community issues such as water management, rural sanitation, adult/female literacy, afforestation, etc. Discussions with these agencies were initiated to motivate them to add rehabilitation of the visually impaired as part of their objectives and activities. Awareness was created of the magnitude of the blindness problem in rural areas and support towards training, materials, funds, resource persons, etc. was offered and assured. Also, agencies with interest were shown running CBR projects to get the feel of the project content and accomplishment. Active networking between blind welfare organisations and the new community based organisations was developed. Thereafter, a memorandum of understanding was developed between...
the partner agency and SSI for a CBR project in the area, to cover a population of 500,000 over a period of five years.

**Training and Development:**

**CBR Coordinators**

From the personnel of identified agencies, one person was selected to be trained as coordinator of CBR projects for the agency. Ten selected persons were given a 3-month training in the Blind Men’s Association at Ahmedabad in two modules, each of 6 weeks.

The first module introduced them to:
- the epidemiological, clinical, sociological and psychological aspects of blindness
- services that could be provided
- exposure to traditional methods and CBR methodology.

These trainees went back to their own area for two months to do a quick survey and study of blindness and develop an understanding of the problem and present level of services.

The second module addressed:
- issues seen by them in their area
- programme management
- record maintenance
- cooperation with other agencies and government assistance.

These persons became the core cadre for actual project developments with the current partner agencies and, as motivators, trainers and resource persons for further partner and project development.

**Methodology of Service Delivery:**

**Clusters and Fieldworkers**

The service area was divided into clusters of about 25,000 population each. Eight clusters were chosen for the initial phase of the project. One fieldworker from each cluster was selected with suitable gender mix. The eight fieldworkers, and two extra persons (to allow for drop outs), were given a six-week training programme of two modules (two weeks and four weeks each).

The training was organised by the partner agencies in their own project area, normally combining two or three projects for each training session (25-30 trainees). The trainers were drawn mostly from local development personnel supplemented by some experts with experience in rehabilitation and CBR.

On completion of the training, the project was initiated.

The identified clients were screened for curable and incurable blindness. The curable were assisted in obtaining services from eye care agencies. The incurably blind were taken for rehabilitation services such as orientation, mobility and daily living skills. Each fieldworker normally dealt with five clients a quarter. The initial 200,000 population is normally covered within a period of two years. Thus the 500,000 population should be served in four to five years.

**Community Participation**

The new partner agencies already had acceptance and credibility in the community for other services given. The community became interested in the additional services and became involved in identification and motivation of the visually impaired in accepting services. The community leaders, who were impressed by the visibly dramatic improvement in mobility, daily living and social skills developed by the visually impaired, actively assisted in obtaining other facilities and concessions from the community, Government and financing organisations, all for the improvement of economic rehabilitation for the visually impaired. The process also involved gifted clients as motivators and facilitators, advising families of the visually impaired, community leaders and other rural service organisations in NGO and occasionally Government sectors.

As part of the project development, refresher courses were organised periodically for one week or two week durations. The participating agencies were encouraged to contribute to the agenda by sharing case studies, special aspects of their areas and specific and common difficulties. The refresher courses were planned to be interactive so that issues and projects were analysed and solutions evolved. The nearby Government officials, blind welfare organisations and eye care institutions were also invited as guest faculty.

In addition, seminars, workshops and social gatherings with blind clients were organised by partner agencies to increase awareness and thereby involvement of the community.

The projects, which were originally handled only by fieldworkers trained in rehabilitation, started involving general community based workers giving them basic training in orientation and mobility. This brought in continuity after the initial prevalent visually impaired population had been serviced. The provision of curative services developed links between eye hospitals and rehabilitation agencies. The case finding and mobilisation of patients for eye care to the hospitals became integrated into the programme, benefiting the community as well as the eye hospital.

There are a number of rural hospitals with eye care facilities that are little used due to lack of awareness, accessibility and affordability. A few eye care partners of SSI were encouraged to take on CBR as an add-on to their programme. At nine locations such linked projects are in place. This gives good outreach programmes from the base hospital and good eye care services to the community.

**Summary**

- The development of CBR projects in India complemented the activities of blind welfare agencies to include other community based service agencies
- Selected core staff of such agencies were trained in methodology as well as management of rehabilitation projects. They became useful in service delivery, training and proliferation of CBR projects
- Networking of CBR project partners geo-graphically further expanded the movement
- Networking of blind welfare agencies and CBR project partners was implemented
- Linking eye care institutions to CBR partners and projects, as part of their outreach activities, became effective
- Motivation of general service providers in rural areas was encouraged to provide further services to blind clients.

**Recommendations**

1. To cover the blind population throughout the country, it is necessary that CBR becomes a part of the national agenda in dealing with disability. The coordination between Government departments of Welfare and Health will be useful in providing comprehensive eye care services.
2. As rural areas are at distances and populations scattered, providing training to general multipurpose workers in rehabilitation services would be useful.
3. It would benefit eye care centres to link with CBR projects. Also they should be
Introduction

The following recommendations are important for all those concerned with restoring sight to cataract patients and thus getting these patients to attend an eye hospital.

Identifying Patients, Raising Awareness and Information

1. Identifying Patients
Do not search for ‘blind people’ in order to find cataract patients but for those who are ‘older with poor vision’. Due to the usually slow process of becoming cataract blind, and adaptation to decreasing vision, cataract patients are often still quite active and so many do not consider them to be blind.

2. Raising Awareness
Most hospitals do not use enough ways of getting patients to the hospital. Patients and their families must be provided with the information required. This information can be passed on in different ways:
(i) Radio (which is often expensive).
(ii) Through churches or other meeting places (ask for 10 minutes of the weekly sermon!).
(iii) Through primary schools (there is virtually no primary school class without a pupil who has a cataract patient in his/her home. Collect names and addresses).
(iv) Through local health units, projects, community activities, etc. During all of these activities, use flyers, brochures and posters to get the required information across (see also 3 below).

3. Information
The information provided by any of your ‘advertisements’ (radio-messages, flyers, brochures, posters) should be comprehensive enough to answer the following questions:
(i) How much will the cataract operation cost?
(ii) How many days in hospital?
(iii) Is a carer required to accompany the patient?
(iv) Is food provided/available at the hospital? What is the cost? Should food be brought to the hospital?
(v) What does a cataract operation involve? Is it a safe procedure?
(vi) What is the expected result?
(vii) Will the patient need to come back

Conclusion

This report gives a brief outline of SSI’s programmes over the last nine years in enhancing services to remote areas in India. The concept of a comprehensive eye care programme arose out of these efforts. All these may need to be modified to suit local conditions, involving the clients, their families, the community and other agencies. Integrating rehabilitation into eye care programmes would be a right step forward in enlarging and enhancing services to the visually impaired in rural areas.

Acknowledgements

The author is grateful to a number of colleagues, experienced partners, rural organisations and rehabilitation professionals in the development and implementation of the above programmes.

CBR in India

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TRAINING COURSE IN PLANNING AND MANAGEMENT OF CBR PROGRAMMES

Dar es Salaam, Tanzania
12–24 April 1999

Once each year the CBR Programme, CCBRT, in Dar es Salaam, Tanzania organises a two-week workshop and training session for planners and managers of CBR. These CBR training sessions offer a practical and theoretical background for planning and management of comprehensive, cross-disability CBR programmes. This approach makes use of all the available human, material and infrastructure resources. The programme does not accept ‘recipes’ or ‘formulae’ for CBR, but requires creative managers with knowledge and vision concerning the real needs of ‘disability’ and of ‘rehabilitation’ in their own country or region.

These training sessions seek to promote this specific approach to CBR, which has very successfully been developed in several areas, and encourage discussion on those key issues that may determine the future of CBR services in the 21st century.

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Fax (++225) 811-604302 or (++255) 51-760266
E-mail: vanneste@twiga.com
later for follow-up? Will there be further costs?

4. Try to find out about the impact of all your cataract detection and ‘sensitization’ methods by asking patients at the hospital how they received the information to come for surgery. This will help you to invest more in cost-effective methods of promotion.

5. ‘Reluctant’ cataract patients, i.e., cataract patients who still fail to present for surgery after having been invited several times, and after having been provided with all the needed information. Try to convince them by introducing them to post-operative patients from their neighbourhood or area. Also, try to discover the (real) reason why he/she has not appeared.

6. Do not spend too much time and money in getting a patient to the hospital within a fullyearafterthefirst contact/information. ‘Money’ is commonly the reason for delays, but this is often available at certain periods of the year, for example, after harvesting. This is the time when a patient is encouraged to come for surgery.

7. For very poor families: offer alternatives in payment (or for reduced payment). There are good examples of family members searching for two other cataract patients (‘people with the same problem in their eyes’). When these patients attend the hospital and they give their names to the local CBR or PHC worker, then their own family member gets free or cheap surgery.

8. Do not forget: it is often the family that needs to be convinced, not the patient! Without the family, the patient cannot get to the hospital (s/he is blind) and also may not have money available (the ‘old person is taken care of’).

**EDITORIAL COMMENT:** In the programme described by Mr Vanneste, in Tanzania, a particular team member has the designation Survey-Detection-Referral Worker. The training and skills of the SDRW and the CRW have some similarity, with community based responsibilities, and so reference to the activities of SDRWs is included in the context of our theme on CBR.

### Survey-Detection-Referral Workers (SDRWs)

**What is a SDRW?**

In the context of detection of cataract patients, it is a person who is attached to an Eye Unit (or a CBR/PHC programme collaborating with an Eye Unit) whose work is to sensitize and inform the community in general, and cataract patients and their families in particular, about cataract, i.e., about the possibility of cure at the Eye Unit. The SDRWs’s job is specifically to get as many patients as possible presenting themselves for surgery.

2. Good SDRWs are extremely cost-effective. They will increase your budget by approximately 1-3%, but they may increase by 100-300% the number of cataract patients coming for surgery, which means that the Eye Unit becomes much more cost-effective.


The communication skills of this person are more important than any academic degree. A trained social worker may not be comfortable in a 95% ‘field job’ with no obvious opportunity of promotion. Employ people who will be able to communicate well with community leaders and hospital staff, as well as with patients and their families.


5. The training of SDRWs should include the following:

   (i) Recording of visual acuity.
   (ii) Identifying a normal, healthy eye.
   (iii) Identifying cataract. Differences compared with corneal scars, etc.
   (iv) Explanations about cataract. Provide information which might be useful when trying to encourage patients (and their families) to come for surgery.
   (v) Understanding and recording findings (e.g., using a Cataract Detection Monitoring Document).
   (vi) The activities and responsibilities of the Eye Unit and its staff.
   (vii) Communication skills. How to meet with a family, i.e., how to introduce him/herself, the Eye Unit, etc. How (not) to explain about cataract.
   (viii) During training, the SDRW should meet with at least 3 cataract patients before their surgery, should witness the operations, and take visual acuities after surgery.

6. Budget items to be considered:

   (i) Salary.
   (ii) Maintenance of a motorbike (petrol, oil, etc.).
   (iii) Insurance for the person + motorbike or money for public transport.
   (iv) Paper + access to a photocopier.

7. SDRWs need not have their own, personal office. They should be 95% of the time in the field.

8. His/her superior should be the ‘manager’ of the Eye Unit, preferably not the ophthalmologist, but the head nurse. The SDRWs should be recognised as members of the Eye Unit staff.


The most fruitful time for the SDRWs to achieve good results is to work during the weekend because that is when most social gatherings take place. These are ideal opportunities to reach many people. Churches, political and other social gatherings, etc. should be addressed.
The Global Initiative: Launch of Vision 2020

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Vision 2020: The Right To Sight is designed to eliminate avoidable blindness by the year 2020. The programme will enable all parties and individuals involved in combating blindness to work in a focused and coordinated way to achieve the common goal of eliminating preventable and treatable blindness. Vision 2020, in conjunction with the World Health Organization, will take on the following responsibilities:

- Increase awareness of blindness as a major public health issue
- Control the major causes of blindness
- Train ophthalmologists and other personnel to provide appropriate eye care
- Create an infrastructure to manage the problem
- Develop appropriate technology.

Vision 2020 involves the active participation of UN agencies, governments, eye care organisations, health professionals, philanthropic institutions and individuals working together in global partnership to accomplish this goal by the year 2020.

In order to communicate effectively the key messages of Vision 2020 to the general public, the programme will be officially announced via an international launch press conference. This launch event is planned for Thursday, February 18, 1999, from the Geneva Press Club in Switzerland, in conjunction with the meeting of the WHO Advisory Group for the Prevention of Blindness. It is envisaged that the WHO Director General, Dr Gro Harlem Brundtland, will lead this event together with staff from the World Health Organization and founding members of the Vision 2020 programme. An international gathering of spokespersons will jointly introduce Vision 2020 at this meeting.

The different speakers will discuss the importance of making blindness a major public health initiative, past programmes designed to help manage the problem and how Vision 2020 programming can help to eliminate avoidable blindness in the world by the year 2020. Following the closure of the WHO meeting by Dr Brundtland, she will participate in a press conference which will be organised at the International Press Platform for the announcement of a Declaration of Support, acknowledging avoidable blindness as a major public health issue. During the months following the press conference, the Avoidable Blindness Declaration of Support will be circulated to every country greatly affected by the impact of blindness. This demonstrates evidence of and builds global support for blindness as a major public health problem.

Other important events in support of the Launch of ‘Vision 2020’ will take place in Cairo (Egypt), Hyderabad (India), New York (USA) and particularly in Beijing (China), on the occasion of the Sixth General Assembly of the International Agency for the Prevention of Blindness in September 1999.

(vi) New vision exercises
- use the restored sight; expect to see and recognise people
- post-operative patients, without social care, may continue to live as a ‘blind’ person.

(vii) Re-integration
- encourage other people to involve the ex-patient
- collect water
- attend the market
- attend meetings, social activities, e.g., women groups.

It is recommended that the CRWs make up to 6 post-operative visits: week 1, week 2, week 3, week 4; month 2 + 1 visit.

CBR in Tanzania

Arriving at the outreach clinic

Photo: Murray McGavin

Post-Operative Community Based Follow-Up of Cataract Patients

Train CRWs (or nurses, SDRWs) to explain the following to patients and family members:

(i) How to use post-operative medicines and the length of treatment.
(ii) How to attach spectacles (as appropriate) to the ears.
(iii) How to clean spectacles.
(iv) How to keep spectacles in order to keep them safe
- a fixed place (otherwise they may be lost)
- where to place them at night.
(v) What to do if spectacles are broken and the cost of replacement.

Global Initiative

- New Delhi, India
- Alexandria, Egypt
- Manila, Philippines

Appropriate spokespersons from each of these regions will be identified by WHO and by founding members of the Vision 2020 programme. These spokespersons will respond to media inquiries generated from each particular region.

The press conference will also serve as a platform for the announcement of a declaration of support, acknowledging avoidable blindness as a major public health issue. During the months following the press conference, the Avoidable Blindness Declaration of Support will be circulated to every country greatly affected by the impact of blindness. This demonstrates evidence of and builds global support for blindness as a major public health problem.

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Epidemiology in Practice: Case-Control Studies

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Introduction

A case-control study is designed to help determine if an exposure is associated with an outcome (i.e., disease or condition of interest). In theory, the case-control study can be described simply. First, identify the cases (a group known to have the outcome) and the controls (a group known to be free of the outcome). Then, look back in time to learn which subjects in each group had the exposure(s), comparing the frequency of the exposure in the case group to the control group. By definition, a case-control study is always retrospective because it starts with an outcome then traces back to investigate exposures. When the subjects are enrolled in their respective groups, the outcome of each subject is already known by the investigator. This, and not the fact that the investigator usually makes use of previously collected data, is what makes case-control studies ‘retrospective’.

Advantages of Case-Control Studies

Case-control studies have specific advantages compared to other study designs. They are comparatively quick, inexpensive, and easy. They are particularly appropriate for (1) investigating outbreaks, and (2) studying rare diseases or outcomes. An example of (1) would be a study of endophthalmitis following cataract surgery. When an outbreak is in progress, answers must be obtained quickly. An example of (2) would be a study of risk factors for uveal melanoma, or corneal ulcers. Since case-control studies start with people known to have the outcome (rather than starting with a population free of disease and waiting to see who develops it) it is possible to enroll a sufficient number of patients with a rare disease. The practical value of producing rapid results or investigating rare outcomes may outweigh the limitations of case-control studies. Because of their efficiency, they may also be ideal for preliminary investigation of a suspected risk factor for a common condition; conclusions may be used to justify a more costly and time-consuming longitudinal study later.

Cases

Consider a situation in which a large number of cases of post-operative endophthalmitis have occurred in a few weeks. The case group would consist of all those patients who underwent elective intraocular surgery. In our example, controls could be defined as patients who underwent elective intraocular surgery during the same period of time.

Matching Cases and Controls

Although controls must be like the cases in many ways, it is possible to over-match. Over-matching can make it difficult to find enough controls. Also, once a matching variable has been selected, it is not possible to analyse it as a risk factor. Matching for type of intraocular surgery (e.g., secondary IOL implantation) would mean including the same percentage of controls.

Epidemiology

- Will endophthalmitis have to be proven microbiologically, or will a clinical diagnosis be acceptable?
- Clinical criteria must be identified in great detail. If microbiologic facilities are available, how will patients who have negative cultures be classified?
- How will sterile inflammation be differentiated from endophthalmitis?

There are not necessarily any ‘right’ answers to these questions but they must be answered before the study begins. At the end of the study, the conclusions will be valid only for patients who have the same sort of ‘endophthalmitis’ as in the case definition.

Controls

Controls should be chosen who are similar in many ways to the cases. The factors (e.g., age, sex, time of hospitalisation) chosen to define how controls are to be similar to the cases are the ’matching criteria’. The selected control group must be at similar risk of developing the outcome; it would not be appropriate to compare a group of controls who had traumatic corneal lacerations with cases who underwent elective intraocular surgery. In our example, controls could be defined as patients who underwent elective intraocular surgery during the same period of time.
Case-Control Studies

as cases who had surgery to implant a secondary IOL; if this were done, it would not be possible to analyse secondary IOL implantation as a potential risk factor for endophthalmitis.

An important technique for adding power to a study is to enroll more than one control for every case. For statistical reasons, however, there is little gained by including more than two controls per case.

Collecting Data

After clearly defining cases and controls, decide on data to be collected; the same data must be collected in the same way from both groups. Care must be taken to be objective in the search for past risk factors, especially since the outcome is already known, or the study may suffer from researcher bias. Although it may not always be possible, it is important to try to mask the outcome from the person who is collecting risk factor information or interviewing patients. Sometimes it will be necessary to interview patients about potential factors (such as history of smoking, diet, use of traditional eye medicines, etc.) in their past. It may be difficult for some people to recall all these details accurately. Furthermore, patients who have the outcome (cases) are likely to scrutinize the past, remembering details of negative exposures more clearly than controls. This is known as recall bias. Anything the researcher can do to minimize this type of bias will strengthen the study.

Analysis: Odds Ratios and Confidence Intervals

In the analysis stage, calculate the frequency of each of the measured variables in each of the two groups. As a measure of the strength of the association between an exposure and the outcome, case-control studies yield the odds ratio. An odds ratio is the ratio of the odds of an exposure in the case group to the odds of an exposure in the control group. It is important to calculate a confidence interval for each odds ratio. A confidence interval that includes 1.0 means that the association between the exposure and outcome could have been found by chance alone and that the association is not statistically significant. An odds ratio without a confidence interval is not very meaningful. These calculations are usually made with computer programmes (e.g., Epi-Info). Case-control studies cannot provide any information about the incidence or prevalence of a disease because no measurements are made in a population based sample.

Risk Factors and Sampling

Another use for case-control studies is investigating risk factors for a rare disease, such as uveal melanoma. In this example, cases might be recruited by using hospital records. Patients who present to hospital, however, may or may not be representative of the population who get melanoma. If, for example, women present less commonly at hospital, bias might occur in the selection of cases. The selection of a proper control group may pose problems. A frequent source of controls is patients from the same hospital who do not have the outcome. However, hospitalised patients often do not represent the general population; they are likely to suffer health problems and they have access to the health care system. An alternative may be to enrol community controls, people from the same neighborhoods as the cases. Care must be taken with sampling to ensure that the controls represent a ‘normal’ risk profile. Sometimes researchers enroll multiple control groups. These could include a set of community controls and a set of hospital controls.

Confounders

Matching controls to cases will mitigate the effects of confounders. A confounding variable is one which is associated with the exposure and is a cause of the outcome. If exposure to toxin ‘X’ is associated with melanoma, but exposure to toxin ‘X’ is also associated with exposure to sunlight (assuming that sunlight is a risk factor for melanoma), then sunlight is a potential confounder of the association between toxin ‘X’ and melanoma.

Comment

Case-control studies may prove an association but they do not demonstrate causation. Consider a case-control study intended to establish an association between the use of traditional eye medicines (TEM) and corneal ulcers. TEM might cause corneal ulcers but it is also possible that the presence of a corneal ulcer leads some people to use TEM. The temporal relationship between the supposed cause and effect cannot be determined by a case-control study.

Be aware that the term ‘case-control study’ is frequently misused. All studies which contain ‘cases’ and ‘controls’ are not case-control studies. One may start with a group of people with a known exposure and a comparison group (‘control group’) without the exposure and follow them through time to see what outcomes result, but this does not constitute a case-control study.

Case-control studies are sometimes less valued for being retrospective. However, they can be a very efficient way of identifying an association between an exposure and an outcome. Sometimes they are the only ethical way to investigate an association. If care is taken with definitions, selection of controls, and reducing the potential for bias, case-control studies can generate valuable information.

Recommended Reading

5. For information about Epi-Info (Version 6), a word processing, database, and statistics program for epidemiology on microcomputers, please contact Centers for Disease Control and Prevention, Atlanta, GA 30333 [contact The Division of Surveillance & Epidemiology, Epidemiology Program Office]

Table: Case-Control Studies: Advantages and Disadvantages

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<th>Advantages</th>
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<td>• can obtain findings quickly</td>
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<td>• can often be undertaken with minimal funding</td>
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<td>• efficient for rare diseases</td>
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<td>• can study multiple exposures</td>
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**In 1993, volume numbers were introduced with Issue 11 (first issue of Vol.6).**

### Subject Index

**COMMUNITY EYE HEALTH**

**SUBJECT INDEX**

**ISSUES 1–24**

Compiled by Sue Stevens

A country index to complement this subject index was published in the last issue (No. 27)

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Community Eye Health Care for Leprosy Patients in West Bengal, India

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Leprosy and Eye Disease in West Bengal

Leprosy is endemic in West Bengal, particularly in the five districts of Burdwan division in the southern part of the State. The endemicity rate of the disease in the districts of Bankura, Midnapore, Purulia, Birbhum and Burdwan under this division varies from 10 to 12 per thousand of the population (the total population of this division is around 30 million). Here most of the patients have paucibacillary (PB) leprosy (75%) and the rest have multibacillary (MB) cases, like other parts of India. Of these patients, 15% had ocular lesions and 1.5% were blind due to the complications of leprosy whether from complicated cataract or uveal affliction. Recently, under the National Leprosy Eradication Programme, the successful implementation of Multi-Drug Therapy according to WHO recommendations declared most of the patients as ‘RFT’ (Released From Treatment). A study on ‘RFT’ patients (with an equal number of PB and MB cases) showed that 52% had eye disease, 70% of which developed as a result of leprosy. Of this group, 28% of after care leprosy sufferers have ‘high risk eyes’, i.e., the aftermath of leprosy, although they are discharged from active systemic anti-leprosy treatment. Leprosalinos with hypoaesthetic corneas (with or without exposure), chronic dacycystitis, recurrent attacks of uveitis, one-eyed individuals, mutilated as well as ulcerated extremities, with maintenance of poor personal ocular hygiene, make these ‘after care leprosy sufferers’ always at risk. They may develop severe ocular inflammation leading to irreversible blindness consequent to the lack of proper supervision and early intervention.

Eye Care for Leprosy Patients

Most of these after care leprosy sufferers live in colonies with their families. Being outcast from healthy society due to the stigma of the disease they have ‘accepted’ this isolated life with an idea of living in a world out of the world. They mainly thrive by cultivating vegetables and fruits, goat rearing, and as cleaning staff of the municipal towns. Until 1990 it was very difficult to perform cataract surgery or other operations on these poor patients in general hospitals, again due to the stigma. So an ‘eye camp approach’ in the leprosy hospital had been adopted to tackle the huge burden of cataract blindness in leprosy. In the 1980s under the National Programme for Control of Blindness the ‘after care leprosy sufferers’ organisation, (namely Pasehimg Banga Kusha Kalyan Parishad and Mahakuma Kusha Nibarani Samiti) used to organise and volunteer their service towards the nursing as well as the paramedical tasks required to conduct these eye camps, solely for leprosy sufferers. The authors, with the help of their mobile eye unit, used to perform intracapsular cataract operations, pterygium surgery, dacrocystectomy, and other operations with a 90–95% successful operative outcome.

Leprosy Patients in the Community

But the concept as well as the certification of these ‘RFT’ patients have revolutionised the total picture of the current day community eye health care programme amongst leprosy sufferers. Today there is no bar to former leprosy patients with the ‘RFT’ certificate being admitted into a general hospital as the doctors, nurses and paramedics are free from fear of the disease. On the other hand, eye camps are still going on in community halls or primary school buildings in the leprosy colonies or in the temporary eye wards of the leprosaria (government leprosy hospitals or the hospitals run by The Leprosy Mission). Amongst these patients attending the camp there are both after care leprosy sufferers of the colonies and healthy individuals from the surrounding villages. These eye camps are being organised jointly by the after care leprosy sufferers organisation, local panchayet (the lowest democratic administrative level of a cluster of villages) and an NGO, like Lions and St John Ambulance Association. It is really community participation beyond all fear, anxiety and stigma when leprosy sufferers and healthy individuals are found side by side on the same floor of the eye camp receiving nursing care as well as the food served and prepared by the after care leprosy sufferers. In 1996, two such eye camps were organised in the district of Bankura – one at The Leprosy Mission Home and Hospital, Bankura with the help of the Lions Club of Bankura and the other at the Peardoba Leprosy Colony, Peardoba, Bankura with the help of the Bankura district centre of St John Ambulance Association. In the first camp 18 mature cataracts and one pterygium, and in the latter 15 cataract and 6 pterygium were operated on, with 97.5% success. (Only one female patient, one-eyed, developed endophthalmitis six months after surgery).

Lastly, another notable feature in the
community ophthalmic picture is the easy acceptance of the after care leprosy sufferers (each with an RFT certificate) in the mass eye camps organised outside the arena of the leprosarium. The leprosy sufferers are not kept in a separate room but receive all the care given to any other healthy individual, staying side by side in the same temporary wards. In the context of the Indian scene of leprosy care, and after care, this unique change of attitude is a positive outcome in our day to day community ophthalmic practice.

References

Abstract

Risk Factors for Noncompliance with Glaucoma Follow-up Visits in a Residents’ Eye Clinic

OmofoLase D Koko MD
Harry A Quigley MD
Susan Vitale PhD
Cheryl Enger PhD
Lisa Kerrigan MS
James M Tielsch PhD

Objective: This study aimed to identify factors associated with compliance with glaucoma follow-up visits.

Design: Computer records of a university residents’ eye clinic were reviewed to identify a random sample of all persons who had an examination with International Classification of Disease (ICD) 9 coding (ICD9) for glaucoma suspect or glaucoma during a 2-year period (1991–1993) to undergo telephone interview.

Participants: Those who were seen at least every 6 months regardless of earlier return instructions were defined as compliant with follow-up (controls n = 362). Those who had any lapse between visits of longer than 6 months were defined as noncompliant (cases, n = 362).

Results: Interviews were completed for 196 cases and 242 controls. Noncompliant persons were significantly more likely to be suspects for glaucoma rather than have definite glaucoma and to be dissatisfied with waiting time in the clinic (29.1% vs. 17.8%, P < 0.005) and to state that they did not take their glaucoma medications as prescribed (25.4% vs. 13.4%, P < 0.004). They also were less likely to have been prescribed eyedrop medication. A high percentage of both patients and controls knew that glaucoma can lead to blindness (85.2% and 88.4%, respectively). The most common reasons patients gave for not keeping follow-up visits were the perception that their eye problem was ‘not serious enough’, the cost of examinations, and that the doctor did not tell them to come back.

Conclusion: Compliance with follow-up visits for glaucoma is associated with markers for early disease. Attempts to improve compliance might focus on improved communication of the seriousness of the disease and improvements in clinic waiting time.


Handbooks from the Community Eye Health Teaching Slides/Text Series:
Now available separately from the slides. The handbooks are for student use, to complement the slide set used by the teacher. They may be ordered as a complete set of 8 (i.e., one of each) or in packs of eight of any one title. Single copies of the handbooks are not available.

No. 1: Examination of the Eyes
No. 2: The Eye in Primary Health Care
No. 3: Cataract
No. 4: Prevention of Childhood Blindness
No. 5: The Glaucomas
No. 6: Onchocerciasis (River Blindness)
No. 7: Trachoma
No. 8: Practical Ophthalmic Procedures (x 6) – Vol 1
Complete set of 8: £20.00/US$36 + post and packing
8 copies of the same title: £20.00/US$36 + post and packing (please specify title)
Post and Packing: Please add £5/$9 (surface) or £9/$16 (air) for each set or pack ordered. Please make payment by bankers’ order or cheque (drawn on US$ or UK£ bank only) made out to University College London.
Please send your order with payment to: Sue Stevens, International Resource Centre, ICEH Institute of Ophthalmology, 11–43 Bath St., London EC1V 9EL, UK.
I found this to be a very interesting and informative teaching aid. It must be highly recommended for anyone who is involved in training health workers in trachoma control and prevention and who has access to a computer which can read compact discs. I particularly like the way the four main tutorials were structured. The first provided some general information. The second gave specific training and teaching for primary health care workers involved in the community and in community action to prevent trachoma. The third and fourth tutorials described the surgical treatment of trichiasis for ophthalmic clinical assistants who may be involved in this type of surgery.

I also liked the self-assessment tests at the end of each small topic. However, I would have been good to include appropriate information and guidance when the student has given the wrong answer.

There is also the opportunity of using this disc to produce teaching materials by printing out copies of the different pages. The colour illustrations and diagrams are both of very high quality.

I did have some difficulty in finding a computer which was compatible with this particular disc. However, the disc comes with a clear user guide and a help line for those who are having difficulties in getting it loaded.

The Wellcome Trust must be congratulated for taking this initiative in using up-to-date technology for health education in prevention of blindness in developing countries. This CD is part of their series on Topics in International Health, and we hope to see similar CDs on other major causes of blindness.

John Sandford-Smith FRCS FRCOphth

For orders please contact:
Tania Fisher, CAB International, Wallingford, Oxon OX10 8DE, UK
Tel: +44 (0)1491 832111
Fax:+44 (0)1491 826090
E-mail: publishing@cabi.org

Note: The minimum requirements for using the TIH discs are:
- PC with Windows 3.11, Windows 95 or Windows NT
- 486 or Pentium processor (Pentium recommended)
- At least 16 MB of free RAM
- Monitor capable of displaying 16,000 colours at 800 x 600 resolution.

Community Eye Health Courses 1999/2000

- MSc in Community Eye Health – 1 year (Sept. 99 – Sept. 2000)
- Diploma in Community Eye Health – 6 months (Sept. 99 – Mar. 2000)
- Certificate Course in Community Eye Health – 3 months (Sept. – Dec. 99)
- Short courses - 1-3 weeks (on-going)

Enquiries: Courses Promotions Officer, International Centre for Eye Health, 11-43 Bath Street, LONDON, EC1V 9EL, United Kingdom.
Fax: +44 171 608 6950; E-mail:clare.scott@ucl.ac.uk

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Email: maezi@iblab.eol.punchdown.org

Nepal: The Fred Hollows IOL Laboratory, Tilganga Eye Centre, PO Box 561, Kathmandu, Nepal.
Fax: 977 1 474937;
Email: tilganga@nco.nos.com.np
Australia: The Fred Hollows Foundation, Locked Bag 100, Rosebery
NSW, 2018 Australia.
Fax: 61 2 9669 5188.
Email: hollows@magnet.com.au
INTERNATIONAL AGENCY FOR THE PREVENTION OF BLINDNESS

President: R Pararajasegaram MD

SIXTH GENERAL ASSEMBLY
SEPTEMBER 5–10 1999

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For further information contact:
International Agency for the Prevention of Blindness (IAPB): Dr Gullapalli Rao
IAPB Secretariat: L. V. Prasad Eye Institute
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Hyderabad - 500 034, India
Tel: 0091-40-215389/248267
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MAYNTEINANCE OF INSTRUMENTS

Authors: Prof Dr J G F Worst and
Danny Haddad

Languages: English and French (advise preference when ordering)

Available from: Dr P Hardus, A van
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Review

This valuable 13 minute videotape covers the following aspects of surgical instrument maintenance:

- cleaning
- removal of rust
- sharpening
- repair of the tips of broken forceps and how to convert these into grooved forceps
- repair of needleholders

The narration, in English, is slightly accented but clear and easy to understand with appropriate emphases. Photography is of excellent definition and sequencing has good and relevant close-ups. A text with drawings is provided to accompany the video.

The subject coverage could be enhanced by inclusion of other important aspects of care of instruments, such as handling, lubrication, storage and transportation.

Sue Stevens