Blindness in children - global perspectives

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Overview

- International Centre for Eye Health
- Challenges of research in developing countries
- What we know about how many children are blind, and why
- How research has strengthened programmes for blinding eye diseases of children:
  - Retinopathy of prematurity (ROP) in Brazil
  - Cataract in Bangladesh
The International Centre for Eye Health

Our mission:
- Research and education to improve eye health and eliminate avoidable visual impairment and blindness, with a focus on low income populations

WHO Collaborating Centre for blindness prevention

Activities which focus on major causes of blindness in poor countries:
- research
- education
- information dissemination
Types of research

- Epidemiology
- Operational
- Health systems
- Health economics
- Qualitative
Research: current and recent projects
Education: masters and diploma students
Readers in 2009:
English      20,204
Chinese       6,000
French         3,541
Portuguese  3,000
Spanish       2,500
Total:         35,245
Close collaborative relationships with:

- Major international NGOs involved in blindness prevention, and through them to
- Hospitals providing services, and through them to
- Communities and patients in developing countries
- World Health Organization
- International Agency for the Prevention of Blindness
- ...all contribute to our education and research agenda
- ...provide mechanisms for dissemination of results
Epidemiological research

- How many people in the population have the condition of interest?
  - prevalence (now)
  - incidence (new)
- Who is most affected?
- Why do they have the condition?
- What can be done to prevent or treat it?
Epidemiology of blindness in children
Challenges of research in developing countries

- Weak health systems: data not routinely collected
- More than one service provider
- Lack of subspecialty ophthalmology
- Not a research culture
- Lack of research active institutions / individuals
- Research not a priority when needs are so great
- Impact of other research agendas e.g. HIV/AIDS; TB
Researching blindness in children

- Children do not complain
- They do not like to be examined
- Communication is difficult
- ....standard methods cannot be used
- Blindness is rare so large studies are needed
Other approaches/sources used

- **Prevalence:**
  - population based surveys
    - designed for other conditions
  - key informant method

- **Causes:**
  - schools for the blind
  - rehabilitation programs
  - key informant method
Definitions

- Childhood: 0-15 years
- Blindness: <3/60 in better eye
- Severe impairment: <6/60 in better eye
Visual acuity charts
Visual acuity charts

Blind <3/60: cannot see top letter at 3 ms in the better seeing eye
Visual acuity charts

Age at which children can be tested using standard charts

10+ years

5+ years

5+ years
Testing vision in young children: different tests are needed.....
....and lots of toys
What do we know about the epidemiology of blindness in children?
Available data on the prevalence of blindness, by under 5 mortality rate
Under 5 mortality rates as a proxy for blindness in children: rationale

- Under 5 mortality rates reflect poverty and social determinants of health
  - female education
  - access to services which prevent blindness and mortality e.g.
    - measles immunization
    - vitamin A supplementation
- Being used to predict whether vitamin A deficiency is a public health problem
Prevalence of blindness in children: using under 5 mortality rates 1999 estimate

1.0 - 1.5/1,000
0.7 - 0.9/1,000
0.5 - 0.6/1,000
0.3 - 0.4/1,000
Under 5 mortality rates are declining
Prevalence of blindness in children: using under 5 mortality rates 2010 estimate
Magnitude estimates in 1999 and 2010, by World Bank region

1999: 1,400,000
2010: 1,260,000
Causes of blindness in children

Classification system:
- Developed by ICEH in 1993
- Adopted by WHO
- Anatomical site of abnormality
  - site in visual pathways most affected
- Aetiology
  - time of onset of condition
Parts of the eye

- lens
- iris
- cornea
- pupil
- aqueous
- conjunctiva
- sclera
- retina
- macula
- optic nerve
- vitreous
Cause by time of onset: life-course approach

- Adolescence
- Pregnancy
- Delivery
- Neonate
- Childhood
Cause by time of onset: life-course approach

**Adolescence**
- Genetic conditions

**Pregnancy**
- Infections; genes controlling eye development

**Newborn**
- Brain damage

**Neonate**
- Conjunctivitis of the newborn; if premature, ROP

**Childhood**
- Corneal scarring: VADD / measles / TEM; refractive errors; injury; infections
Complex range of interventions and strategies needed for control: from community through to tertiary level

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Causes of blindness in children

➢ Data on 32,000 children from 43 countries
➢ Marked variation in the major causes
Magnitude and causes: rich communities

- 10 million
  - 20% 0-15 = 2 mill
  - Prev = 0.3/1,000
  - 600 blind

- Scar 0%
- Cat/gl 10%
- ROP 10%
- Others 80%
Magnitude and causes: middle income

- 10 million
- 30% 0-15 = 3 million
- Prev = 0.6/1,000
  - 1,800 blind

Chars: Scar 0%, Cat/gl 20%, ROP 25%, Others 55%
Magnitude and causes: poor communities

10 million

40% 0-15 = 4 mill

Prev = 0.9/1,000

3,600 blind

Scar 20%
Cat/gl 20%
ROP 0%
Others 60%
Magnitude and causes: very poor African countries

10 million

50% 0-15 = 5 mill

Prev = 1.2/1,000

6,000 blind

Scar 50%
Cat/gl 15%
ROP 0%
Others 35%
Number of blind children per 10 million population, by cause and level of development:

- **Preventable**: corneal scarring - measles, ON VADD, HTM
- **Treatable**: cataract and glaucoma
- **Unavoidable causes**: CNS lesions; congenital abnormalities; retinal dystrophies

The graph shows increasing numbers from high income to very low income countries.
Main avoidable causes

Preventable: corneal scarring - measles, ON VADD, HTEM

Treatable: cataract and glaucoma

Unavoidable causes: CNS lesions; congenital abnormalities; retinal dystrophies
Main avoidable causes

Over 40% of blind children are needlessly blind

Preventable: corneal scarring - measles, ONVADD, HTEM

Treatable: cataract and glaucoma

Unavoidable causes: CNS lesions; congenital abnormalities; retinal dystrophies
Impact of blindness in childhood

- Can have profound consequences on the child, their family and community
  - developmental delay
  - no schooling
  - family breakdown
  - loss of income
What is being done about it?
VISION2020: The Right to Sight

- Global initiative for the elimination of avoidable blindness by 2020
- Launched in 1999
- Childhood blindness is a priority...

**Cause:** CHILDHOOD BLINDNESS

**Aim:** To eliminate avoidable causes of childhood blindness
Preventing blindness in children

Report of a WHO/IAPB scientific meeting
How research has strengthened programmes and influenced policy

- Retinopathy of prematurity (ROP) in Brazil and Latin America
- Childhood cataract in Bangladesh
Retinopathy of prematurity (ROP)
Stage 2: ridge
Stage 3: vascular ridge
Stage 4: subtotal detachment
Stage 5: Total detachment
Examining children in Chile...
ROP as a cause of blindness in Latin America (%)

- Argentina: 60%
- Cuba: 38%
- Mexico: 34%
- Paraguay: 33%
- Colombia: 24%
- Chile: 18%
- Peru: 16%
- Brazil: 14%
- Ecuador: 14%
- Colombia: 11%
- Guatemala: 4%

25,000 blind in Latin America
30,000 blind in E Europe and cities in Asia
Risk factors for ROP

- Prematurity, prematurity, prematurity!
- But also:
  - inadequately controlled oxygen
  - infection
  - poor early weight gain
- Inadequate services
  - poor staff numbers
  - poor training and low motivation
  - inadequate equipment
Prevention of blindness from ROP

- Prevent preterm birth (2% in Latin America)
- Antenatal steroids
- Excellent neonatal care
- Screening of premature babies at risk by eye doctors
  - treat those with advanced disease by laser
  - highly effective at preventing blindness
- Which babies should be examined
Characteristics of babies with “severe” ROP in UK, USA and Canada

Gilbert et al. Paediatrics 2005 115  518-525
Characteristics of babies with “severe” ROP in UK, USA and Canada.

UK screening criteria.

Gilbert et al. Paediatrics 2005 115 518-525
Characteristics of babies with “severe” ROP in low/middle income countries
Varying neonatal care in India - variation in exposure to risk factors for ROP
Implications of variability in babies at risk in low / middle income countries

Different screening criteria are needed in different settings.

All these babies would not be examined if UK criteria were used.
Implications of variability in babies at risk in low/middle income countries

Different screening criteria are needed in different settings.

ROP preventable with today’s knowledge
Questions:

- Which criteria should be used in Brazil for eye examination?
- Can ROP be prevented by increasing the knowledge and skills of nurses?
Dr Zin examined preterm babies in the 7 largest units in Rio de Janeiro
Almost 4,000 babies were examined over 30 months

.....some were very small indeed
Characteristics of treated babies

Survival of <1500g babies

2 units high survival

5 units low survival
Characteristics of treated babies

Survival of <1500g babies

2 units high survival

5 units low survival

Criteria: ≤1500g or <32 weeks

Criteria: ≤1500g or <35 weeks
Workload implications of different criteria

- Applying the wide criteria to all units (≤1500g and ≤35 weeks):
  - 20% more babies to be examined but only
  - 12% more examinations
POINTS of Care study (PoC)

Question:
- Does training nurses and providing minimal essential equipment improve neonatal outcomes, including ROP?

Methods:
- 1 year pre-intervention data collection
- POINTS of Care training of nurses and equipment
- 1 year follow up data collection
POINTS of care intervention in 6 units in Rio de Janeiro

Pain
Oxygen
Infection
Nutrition
Temperature
Supportive care
Preliminary results

- No change in ROP or other outcomes
- BUT better nurse practices e.g.
  - monitoring oxygen: 23% correct before training
  - 52% correct after training
- Exploring reasons:
  - internal “brain drain” of neonatologists and nurses due to staff shortages outside urban areas
Programmes for ROP in Latin America

In 1997:

- No awareness that ROP was a major cause of blindness
- Workshop in Chile:
  - only a handful of ophthalmologists screening in 2 countries in the region
Situation now in Latin America

- >30 workshops over last 12 years
- National guidelines and committees in many countries; programmes in virtually all
- NGO support for training, equipment and treatment
- Government policies in Chile, Argentina, Brazil and Peru making examination of preterm babies essential
- PAHO: control of ROP blindness the 2\textsuperscript{nd} Goal in the blindness prevention strategy for the region.....

**Goal 2:** Reduce blindness and visual impairment in children

**Objective 2.1:** Reduce blindness in premature babies due to retinopathy of prematurity (ROP)
....and beyond

- Lithuania 2007 1st World ROP Congress
- India 2009 2nd World ROP Congress
- China 2012 3rd World ROP Congress
- National guidelines in China (2004) and India (2010) and programmes expanding
- Eastern Europe – a big challenge....
Baby treated in India: 12 weeks premature; weighed 1.1 kg
Childhood cataract in Bangladesh
Dr Muhit

50 million children
Questions:
- How many children are blind?
- What are main the causes of avoidable blindness?
- What can be done about it?
Study undertaken by Dr Muhit

Steps:
- Development/refinement of “key informant method”
- Applied to populations of 100,000 in all 64 districts
- Used to estimate prevalence
- Provided data on causes
Training Key Informants: community volunteers
Key informants identify children with eye/visual problems in the community
Children identified by Key Informants examined in the community
Children identified by Key Informants examined in the community
Health education and counselling
Cataract blind children referred for surgery
Summary of findings

- 1,935 blind children examined
- Prevalence estimate:
  - 0.75/1,000 children
  - same as estimate using U5MR as a proxy
- Main causes:
  - unoperated cataract 31%*
  - corneal scarring 27%
  - other causes 42%
  - * beliefs that blind children cannot be treated
Estimates of numbers blind and causes

- 40,000 blind children in Bangladesh
- 12,000 from bilateral cataract

In 2004
- only 1 eye surgeon trained in paediatrics
- only 3 centres could manage children, 2 in Dhaka
- less than 300 child cataract operations/year
Collaborative project: Sightsavers, ORBIS etc

Targets:
- find 40,000 blind children
- operate on 10,000 children with bilateral cataract
- establish 8-10 Child Eye Care Centres

Case finding approaches for whole country
- 1. key informant method
- 2. house to house visits by volunteers
- 3. community based rehabilitation

Bangladesh Childhood Cataract Campaign: 2004-2010
End of project evaluation (2010)

- 16 trained paediatric ophthalmologists
- 8 Child Eye Care Centres established
- 32,641 blind children found - 9,383 from cataract
- 24,500 cataract operations on children
- Awareness raised as many more children presenting for surgery
Back in action!
Further studies using key informants

- Blindness in children:
  - Ghana, Iran and Malawi
- Other disabilities in children:
  - Bangladesh
What next?

- Policy research for ROP in Latin America
- Evaluate the impact of integrating child eye health into government health systems
- Scaling up......
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