Available online at www.sciencedirect.com

Public Health

journal homepage: www.elsevier.com/puhe

Original Research

Assessing the impact of a program for late surgical intervention in early-blind children

A. Kalia [a,*,1], T. Gandhi [a,b,1], G. Chatterjee [c,1], P. Swami [d], H. Dhillon [e], S. Bi [e], N. Chauhan [e], S.D. Gupta [e], P. Sharma [f], S. Sood [g], S. Ganesh [f], U. Mathur [h], P. Sinha [a]

[a] Department of Brain and Cognitive Sciences, Massachusetts Institute of Technology, Cambridge, USA
[b] Department of Electrical Engineering, Indian Institute of Technology Delhi, New Delhi, India
[c] Computer Vision and Pattern Recognition Unit, Indian Statistical Institute, Kolkata, India
[d] Center for Biomedical Engineering, Indian Institute of Technology Delhi, New Delhi, India
[e] Community Outreach Department, Dr. Shroff's Charity Eye Hospital, New Delhi, India
[f] Department of Pediatric Ophthalmology, Dr. Shroff's Charity Eye Hospital, New Delhi, India
[g] Lexington High School Lexington, USA
[h] Department of Ophthalmology, Dr. Shroff's Charity Eye Hospital, New Delhi, India

ARTICLE INFO

Article history:
Received 26 August 2016
Received in revised form
12 December 2016
Accepted 20 December 2016
Available online 1 February 2017

Keywords:
Cataracts
Developing countries
Eye health
Outreach
Visual impairment

ABSTRACT

Objective: Many blind children in the developing world are unable to obtain timely treatment due to lack of financial and medical resources. Can public health programs that identify and treat such children several years after the onset of blindness enhance their quality of life? The notion that visual development is subject to an early 'critical period' argues against this possibility. However, there are inadequate empirical data from humans on this issue. To address this need, we examined the quality of life of children living in India and who were treated for early-onset blindness (before one year of age), due to cataracts or corneal opacities.

Study design: Survey study.

Methods: As part of an ongoing scientific effort named Project Prakash, we screened over 40,000 children in rural northern India to identify those suffering from early-onset blindness. They were provided eye surgeries in a tertiary care ophthalmic center in New Delhi. We subsequently surveyed 64 Prakash children, ranging in age from 5 to 22 years and obtained their responses on a multi-dimensional quality of life questionnaire.

Results: Nearly all of the subjects indicated that their quality of life had improved after treatment. Children reported marked enhancement in their mobility, independence, and safety, and also in social integration. Surprisingly, we found no significant correlations between quality of life metrics and factors such as age at treatment, gender, time since treatment, and pre-surgery and post-surgery acuity.

* *Corresponding author*. 46-4077, Department of Brain and Cognitive Sciences, Massachusetts Institute of Technology, 77 Massachusetts Avenue, Cambridge, MA 02139, USA. Tel.: +1 617 252 1815.
E-mail address: akalia@mit.edu (A. Kalia).
[1] These authors contributed equally.
http://dx.doi.org/10.1016/j.puhe.2016.12.036

Conclusions: A key question for public health policy makers is whether a program of surgical intervention for older blind children is likely to be beneficial, or if the resources are better spent on rehabilitation via vocational training and assistive devices. The marked improvements in quality of life we find in our data strongly argue for the provision of surgical care regardless of a child's age.

Introduction

The WHO estimates that there are nearly 39 million blind people worldwide.[1] One and a half million are children below the age of 15 years, and nearly 90% of them live in the developing world.[1] Most of these children live in poverty, which contributes significantly to their poor prospects for receiving treatment.[2] Furthermore, the consequences of living with visual impairment in developing countries are much more severe compared with developed countries. Over 50% of blind children die before they reach the age of 5 years.[3] Given these dire statistics, there is an urgent need to provide appropriate interventions to blind children. From a public health policy perspective, it is crucial to define what form the intervention should take.

For children with conditions like micro-ophthalmos or optic nerve hypoplasia, for which no satisfactory medical procedures currently exist, interventions are constrained to be rehabilitative, with the goal of helping those children best adapt to their blindness. However, for causes like congenital cataracts and corneal opacities, the issue is more complex. Surgical procedures for treating these conditions do exist, but their usefulness for children who have suffered several years of blindness since birth is not certain. Whether they will have a beneficial impact on the lives of the treated children is dependent on the answer to an important, and hitherto open, scientific question: Can the human brain learn to interpret visual information from the eyes even several years after birth?

Past research in visual neuroscience with non-human animal subjects suggests that visual deprivation early in life results in permanent deficits in visual functioning and supporting brain mechanisms, leading to the notion that the visual system has a 'critical period' for acquiring visual proficiencies.[4–8] The implication of this idea for human development is that children who have been blind since early in life due to cataracts or other conditions will not be able to gain functional vision if treated late in childhood. Hence, there is the belief that such treatments will not result in improvements in their quality of life.

Despite the results of previous animal studies, recent work has demonstrated that children treated late in life for blindness can, in fact, develop significant visual proficiencies. Project Prakash is a joint humanitarian and scientific effort to alleviate treatable blindness in the developing world while also studying key questions regarding human brain plasticity and the development of visual functions.[9] Its operations are currently focused on India, which has an estimated 200,000–700,000 blind children, nearly 40% of whom have preventable or treatable conditions.[10–12] Results from Project Prakash show that after treatment for congenital cataracts, patients are able to acquire proficiency on an array of visual dimensions, ranging from basic functions such as acuity and contrast sensitivity[13,14] to more complex abilities such as face localization and classification, spatial imagery, and mapping between visual and haptic senses.[15–17] Although the children do not reach normal levels for basic visual functions, such as acuity and contrast sensitivity, these findings suggest that the visual system and its underlying neural mechanisms do retain enough plasticity to allow for significant improvements, even late in childhood.

This article focuses on the issue of whether the visual improvement exhibited post-treatment in the laboratory translates into an improved quality of life for these children. The Prakash children and their families typically live in impoverished conditions, harsh rural environments with limited access to basic necessities such as electricity, and many of the children do not have access to education. These challenges are compounded by the handicap of blindness. How does the ability to see, even if vision is not perfect, alter the lives of these children? The goal of this study was to address this question by surveying the children and their families after treatment on multiple dimensions related to the quality of life. The results have bearing on the potential effectiveness of large-scale public health programs designed to proactively identify and treat early-blind children.

Methods

Participants

Patients who were surgically treated through Project Prakash for cataracts were eligible for the study. Most patients were treated in both eyes, but a few were only treated in one eye because they had previously received unsuccessful treatment in the other eye, resulting in pseudoaphakia or, in one case, pupillary capture. Patients had been blind since one year of age or earlier as reported by the child's guardian